

WHAT ARE THE IMPRESSIONS OF OCCUPATIONAL THERAPISTS WHO USE
THE SHORT SENSORY PROFILE IN ASSESSMENTS FOR DIAGNOSIS OF FETAL
ALCOHOL SPECTRUM DISORDERS?

by

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Submitted in partial fulfilment of the requirements
for the degree of Master of Science

at

Dalhousie University
Halifax, Nova Scotia
November 2010

DALHOUSIE UNIVERSITY
SCHOOL OF OCCUPATIONAL THERAPY

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Dated: November 19, 2010

Supervisor: _____

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DALHOUSIE UNIVERSITY

DATE: November 19, 2010

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SPECTRUM DISORDERS?

DEPARTMENT OR SCHOOL: School of Occupational Therapy

DEGREE: MSc CONVOCATION: May YEAR: 2011

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Abstract

Introduction: The Canadian Medical Association (CMA) released guidelines for Fetal Alcohol Spectrum Diagnosis (FASD) in 2005 that attempted to equalize diagnostic practices across Canada. A multi-disciplinary neurodevelopmental assessment is expected and the occupational therapist must assess soft neurological signs, which includes sensory processing and motor development. In 2007, Northwest Partnership for FASD Research gathered a panel of OTs to consult on assessment tools who chose the Short Sensory Profile (SSP) as the main sensory processing assessment tool. **Methods:** Six qualitative interviews were completed for data collection. The inclusion criterion for the participants were involvement with a FASD diagnostic team and familiarity with the SSP. Qualitative data from the interviews was coded for likeness and analyzed for themes. **Results:** Three main themes developed from this research including: “Uncertainties about the FASD Diagnostic Process”, “Questioning the Validity of the Assessment Tool SSP” and “Strengths of the SSP”. The overarching theme that emerged was that the participants were attempting to find balance in many different ways throughout their assessments. While participants predominantly focused on concerns, they also indicated that the SSP is our best option at this time. **Conclusions:** Participants were not completely satisfied with using the SSP for FASD diagnostic assessments but will continue to use it. It was suggested that the panel of occupational therapists should reconvene and consider further options for assessment of sensory processing for FASD diagnostic assessments. There were also considerations for occupational therapy university education and continuing education.

List of Abbreviations Used

CAOT – Canadian Association of Occupational Therapists

CNS – Central Nervous System

FASD – Fetal Alcohol Spectrum Disorder

OSOT – Ontario Society of Occupational Therapists Perceptual Evaluation

OT – Occupational Therapist

SP – Sensory Profile Caregiver Questionnaire (Long Form)

SPM – Sensory Processing Measure

SSP – Short Sensory Profile

Glossary of Terms

Fetal Alcohol Syndrome (FAS) – Fetal Alcohol Syndrome or full Fetal Alcohol Syndrome is the most visible presentation of the Fetal Alcohol Spectrum Disorders. It is characterized by facial and growth deficits in addition to central nervous system neurodevelopmental abnormalities (Chudley et al., 2005).

Fetal Alcohol Spectrum Disorder (FASD) – This is an umbrella term to encompass all disabilities associated with prenatal alcohol consumption which may include physical, mental, behavioral or learning disabilities. FASD is not the term used for a clinical diagnosis, as diagnosis can be more specific but all diagnoses must have confirmed maternal alcohol consumption (Chudley et al., 2005).

Mental Retardation – The DSM-IV as quoted by Kaplan and Saddock (1998) defines Mental Retardation as significantly below average general intellectual functioning with significant limitations in adaptive functioning that will onset before the age of 18. Factors that are taken account into this medical diagnosis include IQ of around 70 in addition to intellectual and adaptive functioning.

Partial Fetal Alcohol Syndrome (pFAS) – Partial FAS is a specific diagnosis within the umbrella of FASD that is less visible but which includes evidence of some facial anomalies and either growth retardation or neurodevelopmental abnormalities and evidence of cognitive or behavioral abnormalities that are inconsistent with developmental level and cannot be otherwise explained (Chudley et al., 2005).

Sensory Integration – This term was coined by Jean Ayers and refers to the neural organization of sensory information in relation to functional behavior (Case-Smith, Allen & Pratt, 1996).

Sensory Processing – This is a term developed by Winnie Dunn to specifically refer to how auditory processing, visual processing, vestibular processing, touch processing, multi-sensory processing and oral processing function in daily life (Dunn, 1999).

Acknowledgements

I would like to recognize the invaluable contributions of my supervisor Dr. Joan Versnel and committee member Dr. Grace Warner to this thesis. Without their intelligence, dedication and patient teaching, this research and thesis would not have evolved into what it is today. I'd also like to genuinely thank my husband Frank Bojkovsky for the extra time with daddy duty, minimizing household chaos and for providing desperately needed technical support. You are a source of strength for me that I didn't know I needed until I found you. Thank you also to my parents, Kristine and Murray Anderson who taught me the value of education and the importance of perseverance. All of your ongoing positive encouragement has been appreciated more than you know.

Chapter One: Introduction

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a disabling disorder with lifelong effects on individuals who have been exposed to alcohol in-utero. The prevalence in the research varies according to the source, but some research indicates that FASD is the most common cause of mental retardation as individuals suffer from brain structural changes, cognitive impairments and behavioral difficulties (Niccols, 2007).

Approximately 1% of Canadians have been affected by FASD and it is currently the leading non-genetic cause of mental retardation in the Western World (Health Canada, 2004). It is the third leading cause of all birth defects and mental retardation in United States (Case-Smith, Allen & Pratt, 1996), with numbers for FASD reported as 9.1 per 1000 live births in U.S.A. (Chudley et al., 2005). Estimations of lifetime economic impact for the Canadian social and health systems are in the range of \$1.4 million dollars per individual diagnosed with a FASD (Health Canada, 2004). Further study of this debilitating disorder has the potential for significant impact in the lives of hundreds of thousands of affected individuals and Canadian society as a whole.

A diagnosis of FASD not only affects the individual's life, but also that of their caregivers. Individuals with FASD often require greater levels of care as children and throughout the lifespan. Therefore, many caregivers are also affected by this diagnosis. Often these caregivers are extended family members or other members of society, such as foster parents. In many cases, children are not raised by their biological parents due to addictions issues or other social factors, such as an unstable home or being a young parent. Many individuals with FASD also require more guidance and assistance in the

education system than typically developing students and are also known to be heavy users of the healthcare and child welfare systems (Fuchs et al., 2010). They may also require extra guidance with transition to adulthood and establishing work. Preventing secondary disorders related to a FASD is the primary goal of targeting early diagnosis (Chudley et al., 2005). As more information is gathered on FASD through research, hopefully knowledge will help decrease the negative impact of this disorder. More research will help clinicians recognize and more specifically diagnose the disorder, provide intervention and enable caregivers to provide the right kinds of supports.

Description of Fetal Alcohol Spectrum Disorders

Fetal alcohol related diagnoses which together are termed FASD, include full Fetal alcohol syndrome (fFAS, although frequently just written as FAS), partial Fetal alcohol syndrome (pFAS), Alcohol-related birth defects (ARBD) and Alcohol-related neurodevelopmental disorder (ARND) (Chudley et al., 2005). Full FAS refers to individuals who demonstrate facial and growth anomalies in addition to diffuse brain dysfunction. Partial FAS refers to individuals who do not show physical characteristics of the syndrome but do have diffuse brain dysfunction. ARBD is diagnosed when there is a physical anomaly to the musculo-skeletal system that is assumed to result from alcohol exposure in utero. ARND is diagnosed when there is evidence that the fetus has been exposed to high levels of alcohol but the individual demonstrates no physical characteristics and brain dysfunction is less diffuse. There is a group of children who have been exposed to alcohol pre-natally but are too young to be tested or are in an environment that is too unstable. They are referred to as having pre-natal alcohol exposure with a deferred diagnosis. Typically, these children are waiting for standardized

testing due to their young age or because of an unstable home life (Alvin Buckwold Child Development Centre FASD team, personal communication, September 2005). An unstable home life may be described as when the child has had multiple foster placements in the past few years, or has been placed with a new foster family within the past 6-12 months. Diagnosis in these times is generally avoided due to the social influences on the child's behavior.

FASD Diagnostic Guidelines

In 2005, the Canadian Medical Association released Canada's first multi-disciplinary diagnostic guidelines for this disorder (Chudley et al., 2005). Previously, teams across Canada were using a guideline established by the American medical system in Seattle, Washington, known as the "4 point code". Now, in order for a child to be diagnosed with one of the Fetal Alcohol Spectrum Disorders, the child must undergo extensive neurodevelopmental testing by a multi-disciplinary team. Occupational therapy is considered an essential part of the multi-disciplinary team. The diagnostic guidelines indicate that it is within the role of occupational therapy to assess and determine if a child is having a dysfunction that manifests with the presence of soft neurological signs. Soft neurological signs are not well defined but have also been termed as sensory-motor skills. The Canadian Medical Association further explains these soft neurological signs by providing examples such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait or poor eye-hand coordination.

The Role of Occupational Therapy

In September 2007, the Canada Northwest Partnership for FASD formed a panel of informed occupational therapists working with FASD diagnostic clinics across western

and northern Canada. One of the presenting concerns identified by the panel was the poor description of what defines the presence of soft neurological signs. Without having this term well-defined, it is difficult to determine what standardized assessments may assist in the diagnosis of FASD. The panel of occupational therapists suggested renaming soft neurological signs as “Sensory-Motor Skills” as this is specifically being assessed by the occupational therapists. However, the panel of physicians in the group preferred the more general term “Soft Neurological Signs”, particularly for cases where occupational therapists were not part of the multi-disciplinary diagnostic team. The group of physicians felt comfortable with assessing deficits labeled “soft neurological signs” but felt that “sensory-motor skills” was too specific to what OT’s assess and not physicians. In conclusion, the group of physicians and occupational therapists reached consensus to retain the title “Soft Neurological Signs” and defined this as “sensory processing differences or fine motor delay or gross motor delay” (Dr. Sterling Clarren, personal communication, February 2007). The occupational therapists were then asked to reach consensus about what assessment tools would best evaluate sensory processing differences and motor skill delays for the diagnosis of FASD. The panel created a suggested protocol of motor and sensory processing assessments for children with a FASD. The Short Sensory Profile was recommended for all children ages four to ten (Dunn, 1999). It was the only assessment designated to assess sensory processing. There were several assessments designated for motor skills. The Peabody Developmental Motor Scales - Second Edition was the recommended motor assessment for children under age five (Folio and Fewell, 2000). The Bruininks Oseretsky Test of Motor Proficiency – 2 was recommended for children over age five (Bruininks and Bruininks, 2005). The

Movement ABC and Beery-Buktenica Test of Visual Motor Integration – 5th edition were also discussed as a supportive tests for motor skills (Henderson and Sugden, 1992) and (Beery and Beery, 2006). However, the panel, based on information within the diagnostic guidelines, cautioned that assessment tools should be used in addition to clinical judgement when ultimately deciding whether or not a child presented with dysfunction in any of the neurodevelopmental domains. Neurodevelopmental domains include hard or soft neurological signs, brain structure, cognition (IQ), receptive and expressive communication, academic achievement, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity and adaptive behavior/social skills/social communication (Chudley et al., 2005). While occupational therapy predominantly assesses soft neurological signs, often clinical judgement towards other domains is also needed. For an individual to be diagnosed with fFAS or pFAS, (s)he must exhibit deficits in at least three neurodevelopmental domains (Chudley et al., 2005).

Short Sensory Profile

The February 2008 report confirms that the Short Sensory Profile (SSP) is the preferred assessment tool to evaluate sensory processing during the diagnostic process for children between ages 4-10 (Canada Northwest FASD Research Network, 2008). A child's score on the SSP, in addition to the standardized assessment results for motor skills, and clinical judgement, would be used to determine if a child is showing a probable or possible deficit in soft neurological signs or not. Evidence of a sensory processing difference or motor impairment is an indication of the presence of soft neurological signs.

The SSP has been standardized into cut scores of three categories including typical, probable difference and definite difference. The FASD diagnostic criterion uses

the assessment scores to identify the degree of deficit, the terms possible deficit and probable deficit identify areas of concern for the clinician. The definition of possible deficits is when assessment findings are categorized as a probable difference (between one and two standard deviations away from the mean). Probable deficits are assessment findings that are showing a definite difference (more than two standard deviations away from the mean). The child may also score at typical performance level (within one standard deviation of the mean). The mean scores for the SSP were determined by aggregating the results from a study of 1037 children, without disabilities, between the ages of three and ten from across the United States (McIntosh et al., 1999). The original test developers also conducted several small samples studies of children with Attention Deficit Hyperactivity Disorder and Pervasive Developmental Disorder but not FASD. If the results of this research suggest that the SSP is being used effectively with this population, it would warrant further sampling for standardization of the SSP with children who have a FASD.

Table 1.1 SSP Scores as used in FASD Diagnostic Guidelines

<u>Score on SSP</u>	Within 1 SD	1-2 SD away from the mean	More than 2 SD away from the mean
<u>Category on SSP</u>	Typical Performance	Probable Difference	Definite Difference
<u>FASD Guidelines Category</u>	Typical	Possible Deficit	Probable Deficit

Short Sensory Profile and Evidence Based Practice

The Canada Northwest FASD Research Network panel of occupational therapists chose the Short Sensory Profile (SSP) instead of the Full Sensory Profile (SP) for two main reasons. First, the SSP has been standardized for a total score, based on a normal distribution. The longer SP does not allow for a total score and therefore, it is more ambiguous whether the child is demonstrating systemic sensory processing differences from a child who does not have sensory problems. Secondly, the SSP has better discriminative power of identifying atypical sensory processing from the longer version, the Sensory Profile (McIntosh et al., 1999). This is because the 38 questions with the best discriminative power were chosen from the long form (SP) for the short form (SSP). Choices regarding which assessment tool to use could not be based on published evidence as there was not enough literature available within the field of occupational therapy and FASD at that time to support a definitive choice of tools. Therefore, decisions on what tool to use were predominantly based on what clinicians were currently using to guide their practice. This is in accordance with Mary Law's (2002) "E Model" for Evidence Based Practice which establishes experience as one of the five important factors to becoming a reflective practitioner. Law indicates that in addition to experience and evidence, expectations, environment and ethics are also important. The panel of occupational therapists indirectly considered all these factors when deciding to promote use of the Short Sensory Profile. However, choices in assessment tools were also limited by the few options that are currently available. The current study will help to inform future decisions regarding FASD diagnosis by providing some evidence in relation to use of the SSP.

More research in occupational therapy assessment and intervention with individuals with FASD will lead to more effective contributions to the diagnosis and a greater possibility of implementing early intervention. Individuals who are identified in the early years with a FASD can be provided with supports for learning, home life and social development that may prevent some secondary disabilities known to be associated with FASD. Jirikowic (2008) identifies secondary disabilities related to FASD as challenges that could be minimized by early detection, increased understanding and intervention. Examples of secondary disabilities include addictions or mental health difficulties. The profession of occupational therapy needs to take a more active role in contributing to the available research evidence regarding assessment and intervention for children with FASD.

Over the past decade, the need for evidence-based practice has been gaining momentum in occupational therapy. Law (2002) indicates that “professionals within a discipline have collective responsibilities to contribute to evidence based knowledge” (p. 18) and also that “evidence based knowledge must also occur in collaboration with other disciplines that are interested in similar ideas” (p. 19). It is now the responsibility of the profession of occupational therapy to maintain high standards and provide evidence for the role we have in improving the lives of individuals with FASD.

Study Purpose

The purpose of this study is to provide a range of impressions collected from occupational therapists regarding the benefits and disadvantages of using the SSP for diagnostic assessments in FASD. Most occupational therapists on diagnostic FASD teams across Canada are continually evaluating their processes for diagnosing FASD,

particularly because there is such a limited amount of published evidence. The evidence obtained through this study may assist occupational therapists in their processes of choosing diagnostic assessments. This is one piece towards improving FASD diagnosis overall. The intent of this study is to provide introductory evidence for the occupational therapists working with diagnostic teams for children with a potential FASD.

Research Questions

Main research question: What are the perceptions of occupational therapist participants who use the Short Sensory Profile in assessments for diagnosis of Fetal Alcohol Spectrum Disorders?

Additional questions of interest:

1. What implications do these results have for the Canadian Diagnostic Guidelines for FASD and the recommendations of the Canada Northwest FASD Research Network?
2. What strengths and weaknesses exist with using the SSP in the FASD diagnostic battery of assessments?
3. Do SSP results have any influence on the intervention provided by the occupational therapist participants for children with FASD?
4. Are the occupational therapist participants using the SSP in isolation to assess sensory processing? If not, how is this assessment tool being supplemented in FASD assessments?

Chapter Two: Literature Review

The literature review consisted of searching three online databases (CINAHL, Medline and PsycInfo), the Internet, as well as contributions from this author's personal resources. When this literature review was originally started in 2008, the following process was followed. Databases were searched using the terms "sensory processing and fetal alcohol syndrome" and "Short Sensory Profile" (SSP). Medline revealed four articles, CINAHL revealed one publication based on a doctoral dissertation and PsycInfo revealed one article that was also identified by Medline. Databases were searched using the term "Short Sensory Profile". Medline revealed 62 articles (many on other subjects), CINAHL revealed 12 articles and PsycInfo revealed 11 articles. Many of these articles were found in multiple databases but none were focused on the Short Sensory Profile and FASD. All studies available had been done with other client populations. This demonstrated the limited information regarding sensory processing in relation to in-utero alcohol exposure available in 2008. As this thesis has continued into 2010, evidence and journal publications on FASD have increased exponentially. Over time, this literature search was expanded to include certain authors of interest and recommended sources. There is enough evidence available now that not all of it can be captured in this literature review. However, all of the articles that pertain to the field of occupational therapy were included. Other articles were chosen because they had relevancy to sensory processing, were recently published with new information to the field of FASD or they were published by researchers well known in the field. Special consideration was also given to including research published from Canadian universities, as Canada has a different method of diagnosis from the United States of America, since 2005. The growing body of

evidence in FASD speaks to the importance and value of research and providing evidence to guide practice. This was an impressive change in two short years.

The two objectives of this literature review are as below:

1. Describe the Short Sensory Profile and review literature currently available.
2. Provide a background of current literature that identifies concerns regarding sensory processing and other related areas of deficits related to pre-natal alcohol exposure.

SSP Psychometric Properties

The SSP by McIntosh, Miller, Shyu and Dunn (1999) was originally designed to be used both as a research tool and a screening tool for clinicians. It was intended that as a screening tool, clinicians could determine if a more comprehensive assessment would be needed based on the results of the SSP. To develop this caregiver questionnaire, the team that developed the SSP took 38 questions from the full length Sensory Profile that met specific psychometric properties, and construct criteria, that were able to discriminate between children with and without disabilities. In standardization studies, they collected data on four groups of children who had: Sensory Modulation Disorders (SMD), Fragile X, Other Developmental Disorders and typical development. Children with FASD were not part of the initial group of children who participated in the standardization study. The standardization information was taken from the study done originally for the full length Sensory Profile, completed with 1200 children. The internal consistency of the SP = .90, while the discriminant validity is > 95 %. A separate standardization study of the SSP for section scores was completed on a sample of 117 children. The internal reliability (Cronbach's alpha) of seven of the section scores ranged from .82 to .89, as only the

items with $> .80$ were kept. Miller, Coll and Schoen (2007) reported a Cronbach's alpha = 0.96 for the overall score. They also reported that the interclass correlations within the SSP section scores were .25 to .76 with $p < .01$. This indicates that the constructs measured by the different sections are different but do overlap. The researchers used two analyses in deciding which items to keep. First, they kept the questions with highest discrimination for determining a sensory processing difference. Second, they kept items that were highly correlated to other items within each sensory processing section. It was their intention to have the best validity and discrimination for measuring sensory processing differences.

Subsequently, Miller, Coll and Schoen (2007) used the SSP as part of a battery of assessments to identify children with sensory modulation disorders because of its good reliability and discriminant validity. This demonstrates how strong psychometric properties are valuable in all research studies.

Sensory Processing and FASD

There are very few studies examining children with FASD and their sensory processing, but they are beginning to emerge. Jirikowic (2003) published results of an exploratory study regarding sensory processing and children with alcohol-related diagnoses as part of her doctoral dissertation with the University of Washington. This study used a battery of tests to study a subject group of 25 children with alcohol-related diagnoses, matched by controls, who were ages five to eight years six months. Her findings suggest that the children with alcohol-related diagnoses performed significantly different from, and worse than, the control group on 10 of 13 tested items. She suggested that sensory processing, in addition to motor control deficits, were concerns for the test

group that related to poorer performance in math performance, adaptive behavior and problem behavior. Jirikowic (2003) suggests that the implications of sensory processing and alcohol-related diagnoses are very important to occupational therapy clinical practice. This research appears to be the first publication on the specific sensory processing of children with FASD and completed by an occupational therapist.

In 2008, Jirikowic, Carmichael-Olsen and Kartin published another study that provided insight of the sensory processing behaviors of school age children with FASD, as compared to typically developing peers, in relation to their adaptive function at home and school. The SSP was used as part of a battery of assessments to assess sensory processing during this study. They found that children with FASD were three times more likely to be categorized as having significant sensory processing deficit on the SSP than their typically developing peers. Other assessments used included the Developmental Neuropsychological Assessment (NEPSY-SM) sensorimotor core domain and the Quick Neurological Screening Test – II (QNST-II). They report that test-retest reliability for the NEPSY-SM is $r = 0.83$ for the visuospatial processing core and the average stability coefficient for visuospatial processing subtests is $r = 0.70$. They indicate the NEPSY-SM has moderate to high criterion validity and correlates significantly with other neuropsychological measures. The authors report that the inter-rater reliability of the QNST-II is $r = 0.69$ to 0.71 and test-retest reliability is $r = 0.81$. They felt that there was moderate criterion validity with measures of academic achievement, developmental screening, auditory perception and medical/neurological testing. The authors indicate that other assessments were used so that tests of sensory-motor skills could be utilized in addition to caregiver report. Results of the study were adjusted for IQ and still children

with FASD had more significant difficulty with sensory modulation, poorer sensory motor skills and greater presence of soft neurological signs. There were also enough significant correlations between sensory processing and sensory-motor impairment and difficulties with adaptive and academic function to suggest a relationship exists between the two.

Franklin et al. (2008) found that children with FASD between the ages of five to ten who show sensory processing deficits on the SSP also demonstrate problem behaviours as assessed by the Child Behaviour Checklist (CBL). The CBL, which is also a caregiver questionnaire, indicates problem behaviours as socialization, attention, rule breaking and thought problems. They found a statistically significant negative correlation between the SSP and CBL total scores ($r = -.72$, $p < .05$). It is a negative relationship because as the SSP total score lowers (which indicates more difficulties), the CBL scores become higher (which indicates more problems). This research supports the idea that sensory processing deficits do exist co-morbidly with behavioral problems, which are measured by different domains. More specifically, Franklin et al. (2008) found that children with FASD who have auditory processing deficits also show difficulties in modulation with sensory seeking and underresponsiveness to environmental stimuli. These researchers stress the importance of addressing sensory processing differences when providing intervention to a child with FASD, as it may improve the possibility of decreasing problem behaviors.

Canadian studies on sensory processing and FASD are also starting to emerge. Researchers from Winnipeg found a positive correlation between sensory processing and sleep challenges in children with fetal alcohol spectrum disorder (Fjeldsted & Hanlon-Dearman, 2009). These authors compared results of the Infant/Toddler Sensory Profile

with the Brief Infant Sleep Questionnaire (BISQ). They found that daytime sleep correlated to sensation seeking ($p = 0.0103$) and night wakefulness correlated to sensation avoiding ($p = 0.0421$) and oral sensory processing ($p = 0.0494$). This study suggests that the common sleep disruptions of a child with FASD do have a relationship with sensory processing and therefore, are both influencing occupational performance. With more research, this data on sensory processing may have importance diagnostically for FASD.

Carr, Agnihotri and Keightley (2010) from the University of Toronto, completed a study comparing sensory processing and adaptive behavior in children with FASD. To the knowledge of these authors, their study comparing sensory processing within the range of diagnoses within the umbrella of FASD was the first one of its type. They did use the SSP as their tool to measure sensory processing during their research. They found more sensory processing deficits in children with partial FAS (pFAS) and alcohol related neurodevelopmental disorder (ARND) than those who were in pre-natal alcohol exposed but did not meet full criteria for diagnosis. Additionally, these authors determined that sensory processing deficits were not correlated to IQ measures (Wechsler Intelligence Scale - Fourth Edition/Wechsler Preschool and Primary Scale of Intelligence – Third Edition (WISC- IV/WPPSI—III)) but were correlated to adaptive behavior measures (Adaptive Behavior Assessment System—Second Edition (ABAS-II)) that were also completed in the FASD diagnostic battery. They report that the reliability scores for the general adaptive composite score of the ABAS-II is 0.82 to 0.99. They do not report on the psychometric properties of the intelligence tests WISC-IV and WPPSI=III, although these are the test standardly used by psychologists in clinical practice. These researchers encourage practitioners to use a wide range of assessments in the FASD diagnostic

battery; because functional difficulties arise that can not be measured with traditional measures of intelligence.

There are still very few studies published on FASD and sensory processing. However, of the studies that are reviewed here, all of them used the Short Sensory Profile or the Infant/Toddler Sensory Profile within their battery of assessments. This indicates the value of this assessment as it is being used amongst researchers across a geographically diverse area for various types of studies. This suggests that at this time, the SSP is the most commonly used tool for assessing sensory processing in children with FASD.

Animal Studies with In-Utero Alcohol Exposure

Animal studies also suggest there is a neurobiological link between exposure to alcohol and sensory deficits. Medina, Krahe and Ramoa (2005) studied a test group of ferrets that were exposed to alcohol between day 10 and 30 of life and compared them to a control group, which were injected with saline. These researchers found that the test group showed disruptions in cortical processing of sensory information when more mature. Specifically, they found a decrease in contrast of orientation maps and a decrease of neuronal orientation selectivity in the visual system. The authors of this study link these results with clinical characteristics of FASD, including increased incidence of amblyopia and decreased performance on visual perceptual testing. Church et al. (1996) found that in-utero alcohol exposure in a group of rats demonstrated central auditory processing disorders, including some with congenital sensorineural hearing loss. They demonstrated the effects were exhibited in the peripheral nervous system and central nervous system. These researchers also demonstrated that acuity of hearing worsened further with increasing age as compared to a typically developing population. These

animal studies are showing the effects of early alcohol exposure to vision and hearing, which are two of the seven senses considered in the Short Sensory Profile. Emerging animal studies are demonstrating neurobiological sensory deficits which are difficult to test for in human subjects. It is not possible to study the neuroanatomy and neurophysiology to the same degree in humans as it is in animals. As in any animal studies, when introduction of a toxin (alcohol) leads to neural structural and neurobiological changes, a natural consideration is if humans are influenced by a similar neurophysiologic process.

FASD and Magnetic Resonance Imaging

FASD has typically been a diagnosis based upon symptoms and signs of neurobehavioral disorders and growth deficits. While there has been speculation of neurophysiological damage, this was not proven until recently. In 2009, Astley et al. completed research using Magnetic Resonance Imaging (MRI) to study the physical size of children's brains with FASD. They had four groups of participants, based on the American 4 Digit Code for diagnosing FASD and listed from most affected to least affected: 1) Children with full FAS or partial FAS 2) static encephalopathy/alcohol exposed 3) neurobehavioral disorder/alcohol exposed 4) healthy peers with no prenatal exposure. These researchers found that there was a negative correlation between brain size and impairment, a smaller mean size of the brain was associated with a higher level of impairment. Size differences were statistically significant. Additionally, the full FAS and partial FAS group had significantly smaller frontal lobes. This is also the only group to demonstrate alcohol related facial features. This group of researchers suggests that it may be possible to use images from a MRI to someday help diagnose FASD. The main

challenge is that typical age norms for brain size, as measured by MRI, are not currently determined. This group took this research further by analyzing the same four client populations on functional magnetic resonance imaging (fMRI) to study working memory in seven areas of the brain (Astley et al., 2009). They found that all children with FASD demonstrated deficits in brain activation of working memory and different than typical patterns of brain activity for this skill. These studies may have huge implications for the future of FASD diagnosis.

FASD and Executive Functioning Deficits

The occupational therapist's role in FASD diagnosis is to evaluate soft neurological signs. It is within the psychologist's role to assess executive functioning skills, including attention. However, it is important for the occupational therapist to understand the child's executive functioning abilities, particularly so that when attention and sensory processing deficits present co-morbidly, they can be differentiated.

There has been a large body of evidence related to executive functioning and FASD from the University of Alberta in recent years. Green et al. (2009) used the Cambridge Neuropsychological Tests Automated Battery (CANTAB) to compare children with FAS, pFAS and ARND to age matched controls in the executive functioning areas of set shifting, planning and strategy use, attention and spatial working memory. They found the deficits analyzed by this computer test showed all four areas of executive functioning were equally impaired, regardless of facial dysmorphism.

A literature review of animal and human studies confirmed the impact of pre-natal alcohol exposure on visual and verbal memory deficits (Manji et al., 2009). These authors reviewed 63 pieces of evidence in this subject category and determined that despite

certainty that visual and verbal memory is affected, there is not a consistent pattern in type or level of impairment. These authors speculate that one such pattern of deficits does not exist in this population. They speculate that diversity in memory deficits is more the nature of FASD. It is also questionable if other areas of deficit, such as sensory processing, may also have a varying presentation in individuals with FASD.

Research in other areas of executive functioning is showing patterns of strengths and weaknesses for children with FASD. Rasmussen & Bisanz (2009) studied age related differences in executive functioning in children ages eight to sixteen with FASD. They found that executive functioning performance related to verbal skills worsened with age. This is easy to understand, given that the complexity of verbal expectations increases significantly in this age group. However, despite age, there was a pattern of performance consistently shown on the Delis-Kaplan Executive Function System (D-KEFS) with card sorting being the poorest performance test and tasks related to visual-spatial executive functioning being a strength. The authors suggest that the problem solving, concept formation and flexibility of thinking skills, as needed for the card sorting test, are the skills that should be targeted for remedial treatment and that the strength of visual-spatial skills can be used to compensate for other weaknesses.

Short Sensory Profile and Other Populations

Studies have been completed using the Short Sensory Profile to evaluate sensory processing with client populations other than FASD. Tomchek and Dunn (2007) used the SSP to explore differences between children ages three to six with an autism spectrum disorder in comparison to age matched typically developing peers. Their findings indicated that their sample population of 281 children did demonstrate significantly

different outcomes on all sections of the sensory profile as compared to peers. Also, 95% of the sample group demonstrated differences in total score outcomes. They also noted patterns of more extreme score differences in the areas of Underresponsive/Seeks Sensation, Auditory Filtering and Tactile Sensitivity. Tomchek and Dunn (2007) found the SSP worked well for measuring the sensory processing performance of children with autism. This study showed that the SSP was sensitive to sensory processing differences in children with autism. It provides optimism that the same may be possible for children with FASD.

Gal, Dyck and Passmore (2010) used the SSP, in addition to the Stereotyped and Self-Injurious Movements Interview, to determine if there is a correlation between sensory processing and stereotyped movements. The population they studied included children with autism, intellectual disability, visual impairment, hearing impairment and typically developing children. They used the SSP to help determine the presence of a sensory processing disorder (SPD). They found a correlation between the severity of SPD and stereotyped movements. These researchers also felt that the use of single measure, the SSP, to determine presence of SPD was a limitation of the study.

There was an interesting study done by O'Brien et al. (2009) where they adapted the SSP to meet the needs of their study. They used this altered instrument to determine if sensory processing responses to stimuli could discriminate between children with autism and children with learning disabilities. In addition to using the 38 questionnaire items, they added 10 questions from the full form Sensory Profile and 7 questions from their own clinical judgement. They felt that these additional questions allowed them to better identify hyper, versus hypo, sensitivity and stimulus seeking behavior. When they tested

the altered version of the SSP, it was found to have good internal reliability. In conclusion, they found that children with autism had greater impairment in auditory hyper-sensitivity and visual sensory-seeking than controls and children with learning disabilities. They statistically analyzed four factors with 80.9% accuracy that could identify sensory processing in children with autism and feel that this may be relative to diagnostics for autism. It is positive that these researchers were able to manipulate the SSP to meet their needs but without more information, this is not a possibility for clinicians.

The SSP has also been used to analyze four groups of toddlers for their sensory reactivity, including toddlers with autism, fragile X, developmental disabilities of mixed etiology and typically developing children (Rogers, Hepburn & Wehner, 2003). The children in this study were between the ages of 2-4 with the mean chronological age being 31 months. These researchers were able to determine patterns of differences amongst these four groups with the children with autism and fragile X having more significant differences than the other groups, particularly in terms of tactile sensitivity and auditory filtering. The SSP is recommended for children between ages 5-10 but the manual does indicate that it can be used for younger children as well. Unfortunately the authors of the presently described study did not address the differences in using the SSP with this younger population. This would be good information to have as it also applies to FASD diagnostic assessments.

Summary

There is promising research from the field of occupational therapy in regards to sensory processing and FASD. However, currently, most evidence in relation to

neurobehavioral deficits arises from the psychology literature. The review of evidence provided here certainly indicates that sensory processing and soft neurological skills are impaired in children with FASD. Therefore, it is time to add to the body of evidence on FASD from within the occupational therapy profession.

Chapter Three: Methods

This is a qualitative study aimed at researching impressions of occupational therapists who participate in FASD diagnostic assessments. The goal of the study was to determine the perceptions of occupational therapists who use the Short Sensory Profile (SSP) for FASD diagnostic assessments. Methods used to ascertain this information are described within this chapter.

Participants

This thesis was completed through qualitative interviews with six occupational therapists who currently work with FASD diagnostic teams. The Canadian Association of Occupational Therapists (CAOT) has a website entitled “OT Finder” where occupational therapists can choose to have their contact information displayed. The “OT Finder” database is available on the website www.otworks.ca, where the public may search for an OT based on geographical location, area of practice or age of client population. The letter of invitation was sent to the target group of occupational therapists across the country who specified that they work in the area of pediatrics, mixed ages. The occupational therapists in this database have approved release of their contact information through CAOT. The plan was to contact OTs by mail or email, although ultimately, only email was needed as all OTs did have an email address indicated on OT Finder.

Participation in this database is voluntary, as is membership with CAOT. If this method of recruitment with CAOT failed to identify possible participants, others were to be identified via snowball sampling (networking). OT’s who agreed to participate were then to be asked to nominate other OT’s that they felt may qualify for the study.

Participants who were recruited through this method would be approached first by the OT who nominated them before being contacted by the researcher.

More than 400 letters of invitation and consent to participate forms were sent out using the above described methods. Many OT's wrote back to indicate that did not qualify for the inclusion criteria but were interested in the study. Others indicated that while they did not qualify for the study, they would forward the email to colleagues that may have been able to participate. After the first letter of invitation was sent out, some potential participants were identified. Potential participants were sent Appendix One – Letter of Invitation and Appendix Two-Consent to Participate in a Research Program. The occupational therapists themselves had to self-identify as working on a FASD diagnostic team. Once they agreed to participate, they returned a hard copy of Appendix Two: Consent to Participate in a Research Program to the researcher before further contact was made.

Originally, not enough participants were recruited within six weeks of the initial contact with the Letter of Invitation, so a second recruitment attempt was completed. The Letter of Invitation Revised (Appendix One B) was emailed to the same group of occupational therapists identified by OT Finder. At this step, they were sent the Consent to Participate in a Research Study (Appendix Two) only when they replied to the researcher that they were interested in participating. This step was taken because initial recruitment failed to identify sufficient participants. However, this second attempt at recruiting through OT Finder did not result in any more potential participants contacting the researcher. Fortunately, two more participants were located through snowball sampling, or networking. One participant had been forwarded the original Letter of

Invitation as sent to OT's through OT Finder. The other additional participant was informed about the study by a colleague who had already decided to participate. Through the original and secondary invitations and colleague referral, seven participants were identified.

Once interviews were initiated, it surfaced that one participant did not meet inclusion criteria. He had to withdraw from the study. The excluding factor was that while he did provide treatment and intervention services to children with FASD, he did not complete assessments within a FASD diagnostic team.

There were no participants identified for this study that were east of Manitoba or from the Northern Territories. Participants in this study were from British Columbia, Alberta, Saskatchewan and Manitoba.

Process

Semi-structured interviews were used to determine the clinical impressions of the occupational therapists. A general script of this interview is provided in Appendix Three. However, these interviews were not completely structured as flexibility was necessary to enable unanticipated information to surface (Laliberte-Rudman & Moll, 2001). Also, based on the recommendation made by Laliberte-Rudman and Moll (2001), a pilot test was completed prior to conducting the interview. As a result of this pilot interview, several questions and paragraphs to further explain the study were added. During the study, new questions were added over time, as the researcher became more enlightened about potential issues and aware of areas of deficits within the interview structure.

The specific procedures followed are outlined below:

1. Determine all eligible study participants. Contact eligible occupational therapists with a letter of invitation to participate in this study (Appendix One A). Potential participants indicated interest by contacting the researcher and returning a hard copy signed consent form (Appendix Two). The Letter of Invitation-Revised (Appendix One B) was sent six weeks after the initial one to see if more participants could be recruited. Snowball sampling was also initiated to recruit more participants.
2. Interview times were planned with participants and then interviews were completed (Appendix Three).
3. Confidentiality was obtained from transcriptionists (Appendix Four) and interviews were transcribed.
4. Researchers reviewed recorded interviews to code results and identify themes.
5. Written thesis was completed.
6. Defended thesis.

All interviews for this study were completed over the telephone. Interviews were audio recorded so that they could be transcribed for analysis. Information obtained in the recordings of the actual interviews was transcribed to paper by two professionally hired transcriptionists as well as the researcher. Having the transcriptions from multiple sources enabled the process to be completed faster. The transcriptionists were required to sign a confidentiality agreement in regards to the research (see Appendix Four). Transcribed interviews were reviewed for accuracy by the researcher. Results of the interviews were

reviewed to form an analysis of perceptions of occupational therapists who contribute to FAS diagnosis in Canada.

The data analysis was completed using the following step by step approach. This method worked very well to analyze the data in a systematic method.

1. The researcher coded data pieces from each interview in a four step review process.
2. Next, codes were scrutinized to determine if similarities needed to be amalgamated or if large blocks of data required being segmented into smaller components. Matrices were developed as an organizational tool in this step and also used for creating themes. Main themes were determined.
3. Main themes were divided into subthemes.
4. An overarching theme emerged to capture the main perception of the research.

After reviewing the data many times, themes emerged from the interviews that encapsulated the recurring and similar data as presented by the participants. There were some details that differed amongst therapists but the main themes were consistent amongst all participants. There was an indication as to the overall satisfaction with the SSP for FASD diagnostic assessments and concerns or questions that the participants perceived needed to be addressed by the occupational therapy profession.

Trustworthiness

In accordance with Depoy and Gitlin (2005), trustworthiness was enhanced through the following methods. With only six interviews, it is unlikely that data saturation was achieved. However, the research study was exploratory in nature and other methods

were used to enhance rigour. During report writing, reflexivity was used to help reveal personal biases that may have been present within the researcher. Written reporting included an audit trail. Additionally, member checking was completed after the data was summarized. Each participant was sent a summary overview of the analysis of the interviews to ensure that the concepts were analyzed accurately to reflect their perceptions.

Ethics

This study underwent ethics review and approval from the Dalhousie Research Ethics Board. The three principles for protecting human subjects, as outlined by Depoy and Gitlin (2005) were upheld in this study. Firstly, participation in this study was voluntary. Secondly, several steps were taken to maintain confidentiality. Thirdly, dissemination of results was completed after member checking and approval of the accuracy from the participants in this study in order to allow participants to know the information that was gathered from this research.

Participation in this study was entirely voluntary. Consent for participation was clearly obtained from each occupational therapist prior to conducting the interview. After agreeing to participate in this study, participants completed a written consent form, prior to the interview. Additionally, consent was re-confirmed at the start of the interview process. Individuals were given an option to withdraw consent, as outlined both in the letter of invitation and at the end of the interview. All participants chose to maintain consent and proceed with the interview.

Measures of confidentiality, anonymity and security were taken in order to ensure ethical conduct for this study. Confidentiality was upheld so that only the researcher had

access to the data. Transcriptionists were required to sign a confidentiality agreement prior to receiving the data to transcribe. The data in this research was exclusively accessed by the principle researcher, transcriptionists and thesis committee. Meetings, although they were completed on SKYPE, were held in secure locations on both ends so that confidentiality was maintained. In addition, specific information regarding clients was deleted so that it was not possible to link clients with individual participants. This was needed to maintain confidentiality (Depoy & Gitlin, 2005). Fortunately, this did not really become an issue during the analysis of this study as there was very little client specific information provided by the participants. In reported information, anonymity was maintained so that readers will have no way of knowing which participant was responsible for which comments. It was ensured that no identifying features were contained within the reported outcomes. Participants and any client specific information are not identifiable. Limits of confidentiality were communicated to the participants both in the Letter of Invitation and Consent to Participate in a Research Study. They were informed that if unethical practice procedures were reported, this would have been reported to the governing body with which that participant was registered. If illegal processes were reported, such as child abuse, this would have been reported to police or child protection as needed. Any reporting due to limits of confidentiality was to be done with close supervision. Fortunately, none of these conditions arose during the collection of data for this research study.

Measures to maintain security were taken with the data. All information has been stored in a locked filing cabinet within the principle researcher's home. Computer data was password protected when possible and will be erased when the study is completed.

Data will be kept for a period of five years post-publication as per Dalhousie University Policy on Scholarly Integrity.

Occupational therapists who chose to participate in this study were at a small risk of identifying feelings of emotional discomfort or unease. To the knowledge of this researcher, no such circumstances occurred throughout this research. Feedback given by the participants indicated that participation in this research emanated a more positive feeling, as they were happy to share their opinions about a topic deep-rooted in their daily professional practice.

Summary

This study was completed within most of the guidelines set out by the researcher in the original ethics proposal. The only major difference was the delayed timeline of the research, analysis and writing of this thesis. However, this was due to unforeseen circumstances with time needed for the ethics approval. On a positive note, no other unforeseen difficulties were encountered in this research process. The methods, as had been determined, worked well to complete this study and obtain interesting findings regarding the perception of OT's using the SSP in FASD diagnosis. The six completed qualitative interviews revealed a great deal of information to analyze for this research.

Chapter Four: Findings

Introduction

More than 400 occupational therapists, recruited from CAOT's OT Finder website, were sent invitations to participate in this study. OT's were invited if they self-identified as working in pediatrics, with a variety of ages and in a variety of settings. They were not asked to respond unless interested in participating, but 49 occupational therapists did respond. Only six that replied to the invitation qualified to become participants because they were currently working on a FASD diagnostic team. Four participants were recruited by the first Letter of Invitation and two participants were recruited by networking or snowball sampling. A seventh potential participant had also been recruited through the initial invitation but the interview was discontinued before recording began. It was determined that the occupational therapist did not meet inclusion criteria. He did work with children with FASD but only for treatment and intervention, he did not provide assessment for the purpose of diagnosis. The demographic characteristics of the six participants are shown in the Table 4.1 below.

Table 4.1 Participant Demographics

Participant	Years of Practice	Years of Practice with FASD	Frequency of Assessments	Team Type
OT 1	14	4	1-2 per week	Urban Clinic
OT 2	7	7	1 per month	Rural satellite site for Urban Clinic
OT 3	11	5 to 6	3 per year	Rural satellite site for Urban FASD Clinic (Telehealth)
OT 4	35	30	2-4 per week	Urban Clinic
OT 5	10	5	2 per month	Urban Clinic
OT 6	29	6	1 per week	Urban Clinic

Overview of Findings

The above described participants provided an array of data that was analyzed and organized into three main themes. First, the participants expressed uncertainties about the FASD diagnostic process. Second, they discussed concerns with the SSP itself and how it is used with the FASD population. Third, they discussed strengths and positive perceptions of the SSP in the FASD diagnostic process. Within these themes, subthemes also emerged, as depicted in Table 4.2. Additionally, Appendix 6 contains flow charts that provide a visual overview of how sub-themes emerged from the codes and how they fit into the three main themes. The overarching theme that developed was that occupational therapists are seeking to keep balance in the FASD diagnostic process and with the assessment tools that they use. There are many ways participants are attempting to keep balance. They are trying to balance the minimal time they have allotted for the assessment of the child while maintaining quality by using standardized assessments and clinical judgement. They are attempting to obtain information without causing stress and seek this information for diagnostic purposes but also want to be able to use it for treatment. The participants are trying to balance their role as the occupational therapist, while being aware that they are just one part of the multi-disciplinary team. As written below, each theme will be discussed in further detail and it will clarify how participants seek balance.

Table 4.2 Themes and Subthemes

	Uncertainties about the FASD Diagnostic Process	Questioning the Validity of the Assessment Tool SSP	Strengths
Subthemes	<ol style="list-style-type: none"> 1. Contextual Influences 2. Screening and Follow-up 3. Clinical Judgement 4. Overlap with Attention Domain 	<ol style="list-style-type: none"> 1. Lacks Information 2. Caregiver Influences Outcomes 3. Other Assessments 4. Research 	<ol style="list-style-type: none"> 1. Factors 2. Improvement over Sensory Profile 3. Score

Theme One: Uncertainties about the FASD Diagnostic Process

Two main uncertainties were revealed during these interviews. First, participants had many doubts as to how they were individually completing their portion of the FASD assessment. Secondly, when results of this study were analyzed, it was clear that there were many differences across FASD diagnostic clinics that may lead to challenges with maintaining consistency across sites despite use of the same guidelines for diagnosis. The four areas where these uncertainties arise were contextual influences, screening and follow-up, clinical judgement and overlap with attention domain.

A. Contextual Influences

There were similarities and differences in how the participants were completing their assessment for FASD diagnosis. The Canadian Medical Association (CMA) guidelines are intended to standardize the diagnostic processes for FASD diagnosis across the country. Every participant either directly or indirectly indicated that they were using the SSP for the diagnostic process for FASD, because they were following recommendations from the Northwest Partnership for FASD which are based on the 2005

Canadian Medical Association Guidelines for FASD Diagnosis (Chudley et al., 2005). These guidelines for occupational therapists are not a formal part of the CMA Guidelines but are widely accepted by OTs working in FASD diagnostic clinics. This information has dispersed amongst occupational therapists in FASD clinics from the OTs who were originally involved with the decision making panel. A document was released outlining OT recommendations (Canada Northwest FASD Research Network, 2008). Three of the six participants indicated that they had been directly involved with the panel either during the interview or during the pre-interview email communication. Participants who had involvement with the decision making panel were able to speak more specifically about diagnostic procedures during their interview than participants who learned the information second hand. The CMA has not updated their guidelines since the panel met and it is unknown if there will be any changes made in the next revision of the FASD diagnostic guidelines. However, differences were present both in how the clinics run and how each participant is completing the occupational therapy portion of the assessment.

Resource Allocation

Participants reported many differences amongst the clinics that they were working in. All participants contributed to multi-disciplinary assessments, although the composition of the team varied from setting to setting. For example, one team did not have a psychologist, which influenced the role of the occupational therapist. In this situation, the occupational therapist was assessing more domains than just soft neurological signs. Two teams had follow-up workers to provide guidance and consultation after diagnosis. However, one of these individuals was an occupational therapist while the other was a teacher, which also means variations in follow-up.

And then we also have on our team we have a follow-up worker who...meets with the family to go over the report to ensure that the family understands the report and provides information about FAS and sometimes helps brainstorm intervention strategies and she also will go out and meet with schools with regards to the diagnosis and advocating for services within school for the child. And that person on our team happens to have an OT background.

There's a team around the table. So we have a psychologist, a speech language pathologist, a social worker, a nurse usually, the paediatrician, and we'll usually have a mental health worker as well. And the clinic also does follow-up and support. So they'll have a support worker who will follow the client and the family after the diagnosis has been done to help them kind of navigate through the recommendations.

Some teams had all members working under one roof and others were using more of a creative approach to building a team. In some cases, teams were relying on school based assessments to contribute to the diagnosis and in other cases, school based assessments did not play a role. Four of the six participants worked with their core teams in one location in an urban area. One participant consulted via Telehealth from a rural area to an urban based team. The final participant was consulting from a rural satellite site to the main team that traveled from a different urban center.

I know they are trying to shift more in that they get some psychology assessments done in the school previous coming to clinic and then our psychologist will just do a few things that day.

I'm usually involved with it when they do it through the Telehealth.... Yep, the actually assessment team is based out of (city removed) and then we provide information and are involved actually on site with the child and the team is somewhere else.

The amount of time and the process in which the child was assessed also varied frequently. All the participants in the study contributed to the diagnostic process by assessing the soft neurological skills domain but beyond that, the contributions varied considerably. Some occupational therapists were co-assessing with team members and some were doing the assessment alone. The occupational therapist with the least amount

of time had only 30 minutes for an assessment. She did not have time to complete an informal sensory screen and relied more significantly on the SSP results. Two participants indicated that they have 90-120 minutes to complete the occupational therapy portion of the assessment and that the clinic visit was completed over several days. Additionally, the age of the client was another variable factor, although most participants were assessing predominantly elementary school aged children. The age of the child was an influential factor because while the SSP is intended for use with children ages 5 – 10, it can be used for children ages 3 and 4. Also, the motor assessments that are used vary, depending on the age of the child. This will also influence the amount of time dedicated to assessment of sensory processing.

My OT part does. I get a two hour slot to see them. Yeah, ‘cause the clinic day there’s not enough time to see everybody. They come in the week before for the psych testing happens for a day or a day and a half and then they get seen by OT on a separate day and then they come for their clinic day, which they then in the morning get seen by speech and the developmental paediatrician. And then the afternoon is the team and family meetings.

Usually the children that we assess are usually between five and 17 years of age...It’s very rare that we don’t see someone who’s not school age.

Usually we discuss results as a team. Most of the kids that come for preschool screens, some of them are new referrals so it’s the first that they’ve been seen at the Centre but a lot of them have been seen since infancy at our Centre and the FAS diagnosis hadn’t been clear in the first couple years of life so they come for the preschool screens. I’ve been finding that we haven’t been diagnosing a lot of children through the preschool screens. There’s signs that a FAS diagnosis might be clear but a lot of times the diagnosis is deferred until they are in early school age where the psychologist will do a full cognitive screen and look at executive functioning.

Clinician Experience

The amount of experience these participants had with being a part of FASD assessments also varied considerably. The individual with the least amount of experience

in FASD diagnostic assessment completed approximately three assessments per year through Telehealth. However, this participant was also the individual who completed the greatest amount of treatment, as all children she assessed remained on her caseload for treatment, regardless of age or location (school or home) and for an indefinite amount of time. Three of the participants worked exclusively for FASD diagnostic teams but none of them provided treatment beyond initial recommendations through this clinic. The other two individuals provided more regular FASD diagnostic assessments and treatment and also worked frequently with other populations. The follow-up each occupational therapist was expected to provide from the diagnostic process varied.

I don't ever have any kids going through the diagnostic process where I won't be continuing to be involved with them.

I provide assessment, recommendations and selected short term either further assessment or brief intervention, but what we generally do is we are involved in referrals to the community for services that the child needs so I guess I'm not a lot of long term treatment. We do do some parent education sessions or caregiver education sessions.

Clinical Observation

Opportunities for clinical observation and gathering background information also varied amongst participants. One participant had the opportunity to observe the child in multiple environments with unlimited time. Some participants completed part of their assessment process in a sensory gym while others did not have access to such facilities. At least one participant who used the sensory gym environment felt that it was an important part of the assessment where she could make clinical observations not otherwise seen. Some occupational therapists were assessing the child with the parents present and others were assessing the child while the caregivers were being interviewed by other team members. Some participants sat with the caregivers while they completed

the SSP and others gave them the assessment tool to complete on their own time. The participant who had the least amount of time for her assessment had another team member explain the SSP to the parents.

I know when the parents fill out the questionnaire it's their opinions and that sort of thing but sometimes I was kind of wondering if they were stopping to think about the questions because there were so many (questionnaires completed at clinic).

No, we see the child separately while the parents are in the clinical interview.

Deferred Diagnosis

Sometimes despite a team's efforts to determine if a diagnosis is applicable or not, an answer is not determined on the day of the clinic visit. Several participants indicated that if a diagnosis is not given at the time of clinic, the team defers the process to gather more information or wait more time before finishing the assessment. According to the data provided, part of the challenge with being able to accurately determine a diagnosis seems to be with assessing younger children under school age and is at least partly due to limited psychology services.

Most of the kids that come for preschool screens, some of them are new referrals so it's the first that they've been seen at the Centre but a lot of them have been seen since infancy at our Centre and the FAS diagnosis hadn't been clear in the first couple years of life so they come for the preschool screens. I've been finding that we haven't been diagnosing a lot of children through the preschool screens. There's signs that a FAS diagnosis might be clear but a lot of times the diagnosis is deferred until they are in early school age where the psychologist will do a full cognitive screen and look at executive functioning.

Communication of Results

In addition to the process of assessment and diagnosis being different amongst teams, so is the manner in how they communicated results and how they recommended follow-up. Some participants gathered for a multi-disciplinary consultation to compare

performance results and others did not. Four of the six indicated that they completed a multi-disciplinary report and two did not.

We each assess the child individually and then we come together and have a multi-disciplinary meeting, which is almost two hours long where we each discuss what we saw. And sometimes from what another professional will say kind of will change some aspect of how I view the child. So it really is a multi-disciplinary team discussion and we, together as a team, come up with a four digit code.

So then once we've done all our assessments and the questionnaires have been finished with the family we come back to go over the information to see where the score is on the diagnostic code. So we'll talk about growth and face and we'll talk about the brain score and the alcohol and discuss if we have a diagnosis. If there's not a diagnosis then we have to defer and we discuss what we feel is important for recommendations for the family. That usually takes about a half an hour to go through what everybody's results were and to discuss and make sure everybody on the team agrees with the diagnosis. And then usually after our recommendations are done, they will print out a summary sheet that tells them what our diagnosis was, as well as the recommendations and then they get a complete copy of the report at a later date.

B. Screening and Follow-up

Screening Tool

Some data centered on the fact that the SSP is a screening tool, which has both negative and positive influences to the diagnostic process. Typically a screening tool is used to determine if a problem may exist so that further assessment is warranted.

However, in case of these participant's FASD diagnostic assessments, the SSP was being used differently because often it was the only assessment utilized. On a positive note, participants felt that the information from the SSP makes it possible to complete the diagnostic assessment. However, on the negative side, they felt it was not the best option for occupational therapists wanting to provide intervention or treatment. Additionally, they felt that because it is a screening tool, deficits noted on the SSP should be further assessed by a more comprehensive tool. Participants expressed their discomfort with

completing treatment planning while using only the results of a screening tool. The data suggests that using a screening tool in the FASD diagnostic process influenced the follow-up that the OT provided after the diagnosis was determined.

Participants agreed that the SSP is an effective screening tool. It is short, collects basic information and indicates if a child has a sensory processing dysfunction or not. Essentially, participants felt that the information obtained by the SSP does give the occupational therapist enough information to work with to contribute to the diagnostic process. However, several participants questioned whether it is appropriate to use a screening tool for this diagnostic process.

And when I first rotated onto the team actually we weren't able to do pre-clinic assessments because we have a such a small amount of time donated to the OT part of the assessment, because we weren't doing pre-clinic assessments so I moved to using the Short Sensory Profile and when I looked in the manual it said that it was basically for a screen so I thought well it's a good tool to use for a screen. However I have, in my experience, I've had some difficulties with the Short Sensory Profile...

It gives some basic information that we need for the assessment process, realizing, need to realize that it is a screening tool and not a comprehensive assessment. So, as long as we have that understanding, it certainly serves, serves the purpose for the diagnostic procedure that we follow at facility (name removed).

You know, it's excellent for a screening tool. You know, at a basic level, it's great for a screening tool, not for a comprehensive assessment...I would prefer to have a more comprehensive one for our purposes...'cause there's not always an OT that we can refer the child to, to do more assessment.

Intervention and Consultation

While the SSP was deemed useful, although not excellent, to use in the diagnostic process, the problems seem to arise more when some participants use the SSP for follow-up intervention or consultation. Participants did feel that the SSP was useful to determine if a child needed more occupational therapy assessment or intervention. However, details

of how to proceed were difficult to determine from the results of the SSP. Three of the six participants provided ongoing intervention for the children being assessed in FASD clinic. Of these three participants, two indicated that they would follow-up SSP results with another sensory assessment if challenges were present in this area of function. The other three participants all indicated that SSP results allow them to provide basic consultative suggestions but that they would recommend further OT services. The recommendation of further occupational therapy assessment suggests that there is either a lack of trust in the results of the SSP or the information provided is not sufficiently comprehensive.

Well I think it can be a starting point for reframing what might be seen as the child's behaviour from a sensory view point, because the caregivers may not have ever considered that. And I think it helps to guide a beginning for environmental adaptations that can be made.

Yep it's a beginning point; it's a starting point and certainly opens up that door. To know whether or not we need to look at that area in more detail, and whether or not they're having issues in that area... Yep, at a basic level... Well, it gives us a starting point. It gives us basic information that we know up front. But, but it's only a starting point for intervention.

And I don't know if that's more because of the clinic, because when I go to clinic we don't have as much time and we're trying to get a picture of how the child's functioning so it just gives me a quick screen of what's going. I use the longer one with the other kids on my caseload.

C. Clinical Judgement

A theme that recurred throughout participant's interviews was the importance of clinical judgement. This idea supports the intentions indicated by the Canadian Medical Association in the diagnostic guidelines that a FASD assessment is to be done with standardized assessment tools in addition to professional clinical judgement (Chudley et al., 2005). Participants felt that it was very important for an OT to interpret the SSP using

clinical judgement and that the score alone was not a sufficient assessment of sensory processing.

I do think that ethically as OT's we need to not just rely on the scores from the sensory profile, but we need to rely on like our observations and information from others involved with the child, so I think we need to be more global in our gathering of information.

So I think the Short Sensory Profile is a really nice screening tool but it can't replace clinical observations or you know they complement each other. But neither one can replace the other.

I do think it gives you a snapshot of the sensory processing. I guess this might not be strength, but I think its best used if in conjunction with an occupational therapist interpreting the results and knowing the child not just relying on the score that you get on the form.

Generally, the SSP was felt to supplement clinical judgement. Several participants indicated that while many of the sensory systems evaluated by the SSP could be observed, there are certain skills that are difficult to observe in a clinical setting. Specifically, participants were appreciative to have an assessment tool to further investigate functional difficulties and taste/smell sensory processing.

Well, just to see, because in our gym I think we can observe a lot of the sensory motor issues whereas it's more difficult in our set-up environment to screen for auditory sensitivity as well as taste/smell sensitivity and tactile sensitive, well tactile, we can observe a chunk of that but not some of the functional areas of difficulty that a child might have.

And then we'll just get additional information from them...How it impacts, how it, how it impacts their everyday life.

Trusting Clinical Judgement

Participants indicated struggling with how much to trust their own clinical judgement versus the results of the SSP, particularly when the results differed. One participant referred to the results of this standardized quantitative assessment tool as "qualitative" input that she used to support her clinical judgement. One participant used

clinical observations and judgement to decide whether or not to have a caregiver complete a SSP. As one other participant indicated, an OT does not need the SSP to prove when a child does not have sensory processing challenges; this can be confirmed through clinical observation. Also, there was discussion that balancing the clinical judgement and the standardized assessment tool results is a skill that is particularly difficult for a new occupational therapist, or one that is new to FASD diagnostic assessments. As there are no standards set for clinical judgement, the manner in which clinical judgement is used for FASD diagnostic assessment could vary considerably, as it did amongst the participants.

I struggle with if it is useful for the diagnosis or if it's more useful clinically, if that makes sense, more of a qualitative approach. So I struggle with like we had talked about before about you know are you taking the sensory profile and considering using that towards your brain score and also using a diagnosis that something that behaviour wise has some sensory issues already associated with it, such as the ADHD. So I struggle with whether it should be more qualitative in helping to guide what our recommendations are going to be or whether it's useful for the diagnosis.

I rely on sort of my clinical observations of the child within my assessment...

I think it (SSP) helps to reinforce that what they're saying in the interview and what the score is of the questionnaire. It helps in, sometimes what a guardian says or a parent says and then when they start to fill out a form it just helps to reinforce it if the Short Sensory Profile is matching what's being said in the clinic interview.

Caregiver Influence on SSP

They also had concerns with caregivers completing the SSP incorrectly or from a biased point of view, which would then influence the process of the assessment and diagnosis. One example given was that a caregiver who really wants services and support may answer questions more negatively than would be truthful. Another participant commented that in her experience if she has two parents of a child complete the SSP, results can be contradictory. Generally, participants were hesitant to fully trust the results

of the SSP because it is a caregiver questionnaire and parents may not really understand sensory processing. It seemed that participants felt that clinical judgement needed to be weighted heavier than the assessment tool outcomes because the SSP is a caregiver questionnaire.

I have a lot of kids that have vestibular processing issues and you notice this in how they position their body, they're really uncertain on swings and movement apparatus and that sort of thing and somehow the fear of falling, being anxious, distressed when feet leave the ground...we see kids that you know have some gravitational insecurity but you know they might not flip out. Like I think just that become anxious or distressed makes it more severe than a lot of our kids demonstrate so parents would score that as never when they actually are showing some signs of gravitational insecurity.

The one main weakness? It would be nice if it had a way to measure like a negativity or inconsistency in the responsive. ... I don't know whether the inconsistency could be addressed by having more questions that perhaps ask the same or try to obtain the same information and then having a system to compare whether or not the person filling out the profile has answered that question consistently.

Environmental Influence

Contributing to the FASD assessment through clinical observation of the child's environment was also thoroughly discussed by participants. Several participants indicated that different environments create different outcomes in sensory processing and the child's ability to cope. Some participants felt that coping skills were not well assessed by the SSP and that clinical observation must be done for this reason. Additionally, they suggested that parents may not always be aware how their child functions in other environments, especially school. As participants indicated, the environment a child comes from may influence performance as much as the environment that the child is currently in. Participants discussed the value of sensitivity to cultural backgrounds and family dynamics and how this may influence SSP results. This sensitivity must be accounted for

through clinical judgement as there are not any questions on the SSP to account for it.

Generally, it was thought that clinical observation in multiple environments is the best tool to see how the child's sensory processing truly functions.

I don't know if this would go along with cultural sensitivity, but I think sometimes we need to be aware of the environment that the child is coming from. ...For example if there's a child coming from say a rural area or a Reserve sometimes they haven't been exposed to as much noise and things like that as some of the other children, so I don't know if that's something.

I find the clinical observations are good for giving you a better idea of what in the environment might be over stimulating for them or might be causing some issues for them....And I like seeing them in the classroom too because if I can see some of the ways they're dealing with if they're overwhelmed by the environmental stimulus in the classroom. Are they covering their ears, are they wearing a hoodie all the time to help filter some of the noise, are they the child that's under the teacher's desk to kind of get away from everything.

Most of the questions that are asked on the Short Sensory Profile are things that I can actually see while watching the child for half an hour or an hour.

D. Overlap with Attention Domain

Participants also discussed the importance of balancing how occupational therapy assessment results are used within the FASD diagnostic process, specifically in terms of which neurological domains have occupational therapy contributions. Four out of six participants discussed concerns with the soft neurological skills domain overlapping with the attention domain. Their concern with this was that if the psychologist assesses impaired attention and the occupational therapist assesses impaired sensory processing, the child may have two out of three indications of neurological dysfunction. However, the sensory processing difficulties may be resulting in the attention difficulties and they often present co-morbidly. Therefore, participants expressed a very real concern that a child's level of dysfunction may be artificially inflated. Sensory processing differences and attention issues present too similarly. These four participants were unsure that the SSP is

truly assessing sensory processing and that the psychologist is truly assessing attention when these issues present co-morbidly.

It would be nice to filter out attention issues versus sensory. I know there, that's hard to do and they're so closely linked but there's such an overlap with those two things.

...if you're new to diagnosing or not overly familiar with the sensory processing then some of the ADHD characteristics and sensory processing characteristics could be confused or you could be counting them twice, allowing them to contribute twice towards the brain score when maybe they shouldn't be.

I do have some concern is when a child doesn't get an overall definite different score, but gets definite different scores particularly in the under responsive seek sensation and auditory filtering sections and then they have the attention domain is positive as well, so and I struggle a bit with whether we should count that as sensory for the sensory motor domain or whether it's actually more a function of their attention difficulties.

One participant felt that the auditory filtering section helps determine if the dysfunction is more attention related or sensory. Other participants did not make any indication of this thought.

Clinical observation and clinical judgement are an integral part of this diagnostic process, as outlined by the diagnostic guidelines. The challenge for occupational therapists is in balancing the results of standardized assessments and their own clinical judgement and then knowing how to use this information within the context of the diagnostic guidelines. The participants in this study suggested that if they had an assessment tool that they could more implicitly trust, they could rely less on clinical judgement. Unfortunately, none of the participants had solutions of how to separate assessment of sensory processing from attention.

Theme Two: Questioning the Validity of the Assessment Tool SSP

Participants conveyed ideas that suggest there was a general distrust in using the SSP specifically for FASD diagnostic assessment, although it was still effective for screening sensory processing. The two main reasons for distrusting the tool in the diagnostic process was that there is a lack of information gathered by the SSP and that caregivers had too much influence on the outcomes. To address this distrust, participants were using several other sensory assessment tools to complement their assessment process. They felt it is time for sensory processing assessment tools in FASD to be further researched.

A. Lacks Information

Participants struggled with whether the brevity of the SSP was a positive point or a negative point. They were glad to have a short assessment that did not take up much of the limited available time. However, the stronger message delivered was that participants found that the information they obtained from the SSP was too minimal. They felt that there were some sections missing or inadequately measured on the SSP. There was some concern that the information obtained by the SSP is superficial and easily observed. Participants expressed preference to have an assessment tool that would delve more deeply into sensory differences.

...it's pretty good but it's just missing some big areas like motor planning and body awareness motor coordination stuff. But...but, overall, you know I like it because it's short and gives us a starting point. So, if they have a lot of problems, then when we can, we refer on for more assessment.

It isn't that we didn't like the Short Sensory Profile, and I think we might start using that more again, but we sometimes felt that it wasn't giving quite enough information for some of the kids that were more involved or that were showing more sensory issues.

Most of the questions that are asked on the Short Sensory Profile are things that I can actually see while watching the child for half an hour or an hour.

...if I see a child for a short period of time and I talk to their parent or their teacher I can find out a lot of these answers to a lot of these questions very quickly, but because they're the most obvious ones which I guess is why they're in the short profile.

I think it (one main weakness) would be that there could've been a mix of questions that were harder to observe if you didn't know the child well as a therapist. More questions that only the parents could really know the answers to, so some of the ones that are present in the longer form.

The four areas of sensory development that seem to be repeatedly frustrating for the participants were 1) sense of vestibular and movement, 2) olfactory/gustatory senses, 3) tactile processing and 4) coping with sensory challenges through behaviour and social development. Participants felt that the SSP did not provide enough information about these areas. The auditory processing area was also discussed frequently but the concerns with this area were different. Participants felt that the auditory processing area led to confusion when caregivers answer the SSP.

...if you think of how complex the vestibular processing is, that's the category with the least amount of questions. It's kind of interesting, it's fairly interesting that it is weak, it makes that sort of the weakest because it has the least amount of questions.

The movement sensitivity category I find is weak and that's the one that consistently doesn't line up with my observations.

...in the oral sensory processing, just because I can't observe that I need to be told more about that.

They could possibly add a couple more questions in the taste/smell sensitivity.

I would also like to know are they localizing touch in their hands because I'm also looking at fine motor skills and you know, do they have poor pencils grasp because they don't feel it, they don't localize it well in their hand, you know.

Those behaviours are often present in the kids with FASD and there isn't enough questions about them in the Short Sensory Profile.

The radio is on and a lot people take that quite literally...And the radio is not on that often and they're fine, but they can't do anything when the TV's on and the TV's on all the time.

B. Caregiver Influences Outcomes

Concerns with the caregiver influencing outcomes have already been discussed in terms of how it influences the diagnostic process. But, it was also one of the main reasons why participants were reluctant to rely exclusively on the SSP as their assessment tool of choice. Participants did not seem to trust that caregivers are always able to complete the SSP accurately and without bias. Participants indicated many reasons why they had concerns in this area. Five out of six participants felt that answering the SSP may be different for foster, adoptive and biological parents. One participant felt that the type of caregiver did not influence outcomes. The length of time and experience a foster parent has may influence how they answer the questions.

It all depends on how long the child has been in foster care. One thing that has come up a couple times is what is normal. Like you know, if you have, if you have a child that's in a foster home with 8, sorry, with you know 8 children in the foster home, what's normal for even tactile and auditory, especially auditory filtering because often these homes with 8 foster kids are quite loud... And there might be other children that have more sensory processing issues than the child that you're assessing so their standard of what is normal is a little skewed.

Also, the length of involvement a biological parent has with the child may also influence outcomes of the SSP.

...it depends on when they (biological parents) were involved with the child, you know, so if the biological parent wasn't around for certain years of the child's life then their answers are different.

Regardless of what type of caregiver, some participants felt that different caregivers can be more or less sensitive to the child's needs and perspectives. Participants felt that this ability to understand the child's sensory processing varies and also impacts SSP

results. Also, there was data provided that sometimes caregivers may have their own bias when completing the SSP. This is evidenced by different caregivers completing it for the same child and getting different results. Also, as previously mentioned, one participant was concerned that caregivers may complete the SSP more negatively than is true in attempt to obtain services for their child.

I think there's definitely a difference between caregivers, whether they're adoptive or foster or biological. Some parents, some caregivers are a lot more in tune with their, with how the child is functioning in different areas than others. But the differences aren't specific to whether they're biological or foster.

I guess I have had some caregivers say to me I've filled everything out negatively, because I want services for my child.

Literacy and SSP Language

The overwhelmingly greatest concern from participants was the challenge some caregivers have with the level of literacy that is needed to complete the SSP. Some participants felt that completing the SSP has been stressful for parents, as evidenced by difficulties in having it returned to them. Decreased reading abilities, lower cognitive functioning and English as a second language were all identified as reasons why caregivers may experience stress with the SSP. These situations also caused stress for the occupational therapist as they needed to obtain the information for diagnosis but did not have an alternative assessment that does not rely on caregiver input. Seeking a balance of obtaining information but not causing stress is evident here.

If the caregiver has, is functioning at a lower cognitive level then of course we need to explain more of the questions to them and fill it out together with them rather than they, them filling it out independently....I think it probably makes it more reliable if they understand the questions more fully.

I think the clinician needs to be aware of the literacy of the parent or caregiver. It's a good idea to sort of check that out before you give it to the parent or caregiver to fill out. I have had some circumstances where if the parent/caregiver doesn't seem

to understand or has reading difficulties I will sit with them and go through the questions and help them fill it out.

I think with our FAS population you know we have a lot of families where English reading isn't a strength we have some, if it's birth parents. Sorry, like a lot of them might not have graduated from high school, English might not be their first language and that makes the language level of the Short Sensory Profile a little higher. Recently it's been, seems like I've been seeing a lot of children with foster parents and haven't had to deal with that issue as much but...

Regardless of literacy levels there was also some frustration with the language level of the SSP. Participants felt that the SSP can be difficult to understand, even for an average reader, because of the occupational therapy jargon and the negative approach to questions. Participants often found themselves providing examples to further explain questions. As every occupational therapist is likely to provide different examples and explanations, they felt this may also influence outcomes.

I think when you're summarizing it's tough, it is quite "jargony", even terms like "underresponsive" and "auditory filtering". Some of the titles are very "jargony", even "probable difference", "definite difference" and that sort of thing... it's sometimes difficult to know how much leeway we can have to make it a little more reader-friendly.... But I find sometimes in OT we forget that our jargon isn't common language.

I think if the questions could not be worded... some of them can be worded in a negative way, like an exclusion way. I don't know how to explain that, but it's like, "Your child doesn't do this." ... Whereas if they could be worded in a, "Your child does this."

...a lot of the questions were tricky for caregivers to, I don't know, to get their head around I guess or understand. It's almost like there's a lot of double negatives in there and it's long to fill out, umm, some of the caregivers just found it really difficult and they thought some of the questions weren't that relevant or difficult to understand. So they were having a hard time....

Often these difficulties with literacy and language led to occupational therapists reviewing the SSP verbally with the client. Interestingly, some participants believed that this makes the assessment more standardized and accurate while others felt that it changes

results somewhat and created a less standardized assessment. The problem may also be that several participants were already pressured by time in the assessment and verbal reviewing of the assessment required even more time, thus creating more stress for both the therapist and the caregiver.

They fill it out and then we sit down and go through the answers... Usually we have to make changes.

...if there are one or two things that they're not sure what the question is they have an opportunity to ask me and we discuss it and I might paraphrase so they'll understand or give them an example.

Participants are clearly frustrated by the amount of influence a caregiver can have on the sensory processing portion of a FASD assessment. This problem originates because the SSP, a caregiver questionnaire, is that the only recommended standardized assessment from the occupational therapy panel in association with the Northwest Partnership for FASD and participants wanted to follow this protocol.

C. Other Assessments

It is easily understood why participants attempted to use other assessment tools, given their high level of frustration with the SSP not providing the information they seek. All participants indicated that they were not fully satisfied with using the SSP for the diagnostic process. Another concern was that the SSP seemingly does not generate all the data that they felt that they needed for their assessment. There were suggestions of other assessment tools or components of those tools that participants were using to supplement the SSP results.

Sensory processing...I think we're using just about everything there is (laughs)...Well, a lot of what there is, kind of the more commonly used measures.

Participants had a desire for a more hands-on assessment to accompany the SSP. Five out of six participants completed an informal sensory hands-on assessment based on clinical judgement. Participants in the urban centers were all using a sensory gym to assist with clinical observations. The sixth participant likely did not have time for a hands-on assessment in the 30 minute session she had with each child. Participants have taken sensory tools on handling from a variety of sources but they did not really identify how they learned to do this skill.

Well yeah I also do like a sensory motor screen, so I would also look at proprioception, kinaesthetic sense, tactile localization, like things like that and then each clinician on my team also talks to me about what the child did during their assessment, were they leaning over their hands on their chair, were they wiggling, were they... you know so each clinician talks about what they saw, what they observed in their assessment. And sometimes I take them to a little sensory motor gym to see how they do in that and I also talk to the parents about sort of their sensory motor history. So you know, "As a baby or as an infant, you know, what was it like?"

There were four main assessments that were spoken about by the participants. The first one, the Ontario Society of Occupational Therapists Perceptual Evaluation (OSOT), was mentioned by one participant for its hands-on perceptual screen and how this helps her develop her own informal sensory screen. Several participants mentioned the Sensory Profile Caregiver Questionnaire (SP) School Companion and the Sensory Processing Measure (SPM). These four assessment tools for sensory processing were being used relatively frequently to supplement the SSP.

Do you know the OSOT?...Well you know, you get them to close their eyes and you hold their extremity on certain points and you move their shoulder up or down and you ask them to tell you which direction did it move for proprioception. And you just go through all the joints and you do that.

Sensory Profile Caregiver Questionnaire and School Companion

Participants had mixed opinions on whether the SSP was preferred over the SP or vice versa. All participants determined positive and negative features of both assessments. Participants liked that the SP delved more in depth into the child's sensory processing. With the full version Caregiver Questionnaire, they felt that they were able to obtain more useful information, particularly for making recommendations or providing intervention. While they liked the increased comprehensiveness, they disliked the length of the assessment for other reasons. They felt that it was more difficult for caregivers to complete. Also, they felt that it was more difficult to score and communicate the results to team. Essentially, they felt that the one total final score is a feature that makes the SSP more user friendly than the SP. The Sensory Profile School Companion seemed to be quite appreciated by the participants who had experience with it. They liked that it was less stressful for teachers to complete than the SSP is for parents and that it provided information from a different environment. Participants found that the information provided by the School Companion enhanced information otherwise just gathered by using the SSP.

I think the main weakness for it is that, and you can correct me if I'm wrong, it was more created by Winnie Dunn to be more of screen to see if further assessment needed to happen, right?...I would say it's a weakness because you're not getting into as much detail as you get into with the sensory profile.

Well and also too we're using it very much for diagnostic purposes. Whereas when I had a different type of a caseload I used the Short Sensory Profile as a screen for my own OT assessment. I used it as a screen and if I had a positive result on the Short Sensory Profile then I would have the parent fill out the Long Sensory Profile.

The reason that I don't use the Short Sensory Profile... I'm going to be involved with them ongoing and most of the questions in the Short Sensory Profile I usually have the answers to. I realize it's not standardized, that I have a hard time, it's hard for a lot of the families to fill out the Short Sensory Profile, so to ask them to do it

and to make sure that it's done properly and then get it back and I actually know most of the information. The Long Sensory Profile and the School Companion give me information that I can't gather on my own.

That's why the School Companion is helpful, because the teachers actually really like the School Companion...And they find that it's not too hard to fill out and as a team we're getting good information.

So with the FASD population I guess I'm using the Short Sensory Profile as part of the diagnostic process, so that would be different...I feel that I need to use it with something else as well...Which is why I use the School Companion.

Sensory Processing Measure

The SPM was also mentioned by a few participants who had only positive reviews for it. The main factor that they preferred about the SPM than the SSP is the section on movement, including body awareness and motor planning. It was also indicated that scoring system on the SPM is easier than the SSP.

Either we will use the Short Sensory Profile, we use the, my colleague and I were using the Short Sensory Profile for the majority of the kids that came through the clinic for a while. But, we have also used the Caregiver Questionnaire and the Sensory Processing Measure for some of the kids more recently.

Anyway, we became aware of the Sensory Processing Measure and we started using that for some of the kids out of curiosity, just to see how it compares...when I look at the Sensory Processing Measure I really like some of the areas that they have on there. They have more information about body awareness and motor planning. Which, we certainly see issues in the FASD population with that. So, I like the addition of those questions and also the socialization section, I find really helpful to give a better picture with how the child is managing with sensory stuff.

The data from the interviews in this section suggests that participants were not fully satisfied with using the SSP. Participants were seeking to balance parental input with their own assessment skills and relying on the SSP as the only source of standardized information makes this challenging.

D. Research

There was not a lot of data provided by the participants regarding research. However, there were two important messages communicated. Participants would like to see more research completed regarding assessment tools for children being assessed for FASD. Also, several participants indicated that they would like the panel of occupational therapists gathered by the Canada Northwest Partnership for FASD to reconvene and evaluate how decisions made at the first meeting are being upheld.

Yeah, and I would actually say for the most part for the Short Sensory Profile at this point in time because there isn't as much research out there, that we end up using it more for qualitative...

Well I think that, I think that the whole assessment of the brain domains I really think that it would almost be nice to regroup with the group of OTs who were at the meetings where it was decided to use the Short Sensory Profile. To regroup and actually clearly look at the assessments that were chosen and what we're finding and I think that would guide us in terms of having some evidence based practice in terms of what's the best tool or what are we finding or what are the qualifiers for using it.

Theme Three: Strengths

Information provided by these participants was not all negative about the SSP. Within the theme strengths, the participants identified three main strengths of the SSP. First, the participants identified factors that contributed to them using the SSP. Second, participants discussed their preference for the SSP over using the lengthier similar assessment tool, SP. And third, all participants expressed appreciation for the scoring system of the SSP.

A. Factors

As previously discussed, use of the SSP has been recommended by occupational therapists working with the Canada Northwest Partnership for FASD. Beyond this initial

apparent reason for using the SSP, there was also a fairly unified voice in six other reasons why participants chose to use the SSP.

The most abundant answer given by the participants was that they liked how quick the SSP is to use, score, communicate and report. Time seemed to have a sense of urgency for these occupational therapists in FASD diagnostic assessments. Therefore, the quickness of the SSP is an important feature.

...we don't have as much time and we're trying to get a picture of how the child's functioning so it just gives me a quick screen of what's going.

It's helpful, because it's quick.

I like the fact that it's short to do.quick, it doesn't take very long.

And with being brief at the same time because I think it's a Short Sensory Profile and you know, you could go on, you know you could go on and on about the results but at the same time I like to keep things summarized.

All of the participants also expressed several times that they found the SSP easy to use for themselves and even more importantly, also for caregivers. This was an important factor because within the current diagnostic process, the caregiver is expected to complete many questionnaires. Several participants did contradict themselves with this data as they also indicated that completing the SSP can be stressful due to literacy issues. When participants indicated that the SSP was easy for caregivers to complete, they were comparing it to other caregiver questionnaires in the FASD diagnostic process and likely considering caregivers that did not have literacy issues.

I like that it's not too long. I know I'm contradicting, kind of going back on what I said before about its weakness, but I like that the... I mean the questionnaires that they have to fill out from the psychologist and they have so many to fill out on that day, I like that it's a little bit more short because, like there's less questions that the adults have to answer because I just find sometimes by the time they get to the Short Sensory Profile they're a little overwhelmed with the other questionnaires that they've been given.

The parents and guardians are a little bit more willing to answer it 'cause it's a little bit shorter.

The third strongly communicated idea as to why participants chose to use the SSP was that they appreciated having an overall score for sensory processing. An overall score was important because it influenced whether an individual received a FASD diagnosis or not.

I like that it's a quick questionnaire for the parents to fill out and I like that you get an overall score that you can use...

In addition to the top three factors collectively voiced and mentioned above, there were three other factors that recurred many times. While the top three factors were identified by all participants, the following three factors were abundant but not collective. Another factor why participants choose to use the SSP was that they found that it was a good assessment tool to use for FASD diagnosis and its questions were relevant for the FASD client population.

I think they're (questions in SSP) relevant for that population as for any population, when we're looking at kids who might be struggling with sensory processing difficulties.

I think at this time I think it's (SSP) almost the best tool that we have.

One participant had even completed her own retrospective chart analysis of her past clients because she felt that she was observing similar results on the SSP of many children diagnosed with a FASD.

I analyzed the results of Eighty-two Short Sensory Profiles. Twenty of the children had a diagnosis of partial FAS and sixty-two had a diagnosis of ARND and the one thing that came out that was statistically significant, and this was kind of a surprise to me, that the children with the partial FAS diagnosis had significantly more difficulties with taste/smell sensitivity.... And that was that there was a pattern of definitely differences in the areas of the tactile sensitivity under responsive sensation seeking and auditory filtering. So that was a pattern in my eighty-two

children that was quite consistent.... And another thing was that the children diagnosed with ARND had more difficulty with auditory filtering than the partial FAS.

Participants specifically mentioned that the sections on auditory processing, tactile processing and taste/smell or oral processing were the most helpful parts of the assessment tool. Several participants indicated that they appreciated how the SSP can attain information regarding sensory processing that can be difficult to observe clinically.

I know that kids with FASD usually have sensitivities in tactile and auditory processing. So I do think that it does pick that up.

...the oral sensory processing that you don't observe in a short amount of time.

The final factor expressed repeatedly by participants in why they chose to use the SSP was that it helped screen for the need to have further involvement from an occupational therapist for that client.

You know good, good, it is a good way to screen whether the child needs occupational therapy treatment or not.

Well, just to see, because in our gym I think we can observe a lot of the sensory motor issues whereas it's more difficult in our set-up environment to screen for auditory sensitivity as well as taste/smell sensitivity and tactile sensitive, well tactile, we can observe a chunk of that but not some of the functional areas of difficulty that a child might have. So, you know it might come out that child always is fighting or crying during haircuts or during face washing. So, if it's all, if that's a huge need for the child and for the family then tactile processing might become more of a priority during treatment.

Individually, participants revealed over 20 factors that helped explain why they chose to use the SSP. However, it was the above six factors that clarified and summarized why this group of participants continued to use the SSP, despite concerns they may have had about it.

B. Improvement over Sensory Profile (SP)

Participants were asked to describe their experiences with using the SSP in comparison to the longer form SP. The vast majority of data in this area indicated that the SSP was preferred over the SP. The reasons why participants preferred the SSP over the SP varied but commonalities were found amongst answers. Reasons why participants prefer the SSP over the SP were because it is more precise, it has one final score which makes it easier to use in the process and communicate the results to team, it is short enough to be done concurrent to the assessment with the child, less stressful for families, results seem more consistent with clinical judgement than SP and the scoring is easier and quicker.

And so then I can use that one final score when I'm considering what number to put for sensory motor as one of the brain domains. So we're asked to give a score between one and three and so if they score in significant to a more [unintelligible] deviations from the norm on the Short Sensory Profile then I'm more likely to give them a three in that sensory domain. And versus the other full format one, I have to kind of look at how many areas were in the two standard deviation away from the norm range versus the ones that in the typical score and I have to give more of a subjective... like I have to figure it out myself.

...we found that it took a really long time to score the full format.

I found that I felt I needed something that was easier for parents to complete.

Better (using SSP instead of SP). I had started off using the long Sensory Profile and I got really discouraged with the results that I was getting so I stopped using the Sensory Profile all together. I think it was a long a process for the families to go through and then more typically than not I was finding that the results of the long Sensory Profile were not consistent with my observations.

Four of the six participants preferred the SSP over the SP. One participant preferred the SP over the SSP because it provided more information. The other participant preferred the SP over the SSP in all other situations but for FASD assessments preferred the SSP because she was pressured for time and because of the final score. Even the participants

who preferred the SP over the SSP felt that there were several strengths of the SSP that were improvements over the SP. Participants were likely to prefer the SSP because they were seeking to balance decreased time with having a quality assessment as well as balance what the therapist needs to find out with what stressors the assessment places on the parent.

C. Score

Participants identified three main strengths of the scoring system of the SSP. First, participants felt that it was very important to have one final score. This was a factor in why the participants chose to continue using the SSP but this advantage of the SSP reached deeper than that. The final score is important because it allowed occupational therapists to have more concrete input on whether a client had soft neurological signs or not. The participants interviewed here seemed more comfortable with having quantitative evidence to support this judgement call over just clinical observation.

...it was nice to get a total score at the end of it that we could use to substantiate the score that we would give them for that particular category of their assessment. So then we could indicate...we could indicate then whether their ability in that area was within the typical range or between the first and second standard deviation or below the standard deviat...second standard deviation. So, it was pretty handy to do that.

I also like it because it gives me an overall score for everything, like there's a total score for sensory at the bottom.

Secondly, participants identified that the scoring system of the SSP is easy and quick. This makes the assessment user friendly. This was especially important because in many cases the assessment was being scored while the child was with another team member and results were needed quickly.

It's easy to be scored. It doesn't take very long to be scored. So I would say those are the things that I like about it.

Thirdly, participants appreciated having specific standardized scores in the different sections of the SSP that represent each sensory system. This provided them with more detail for which areas of sensory processing therapists should focus on when communicating the results to the team and family and also when providing intervention. Participants liked to have these definitive scores to support their clinical observations and provide some quantitative evidence towards dysfunction in sensory processing.

And because it's standardized I can use those scores to point out to family members or other team members the areas of difficulty that may be affecting behaviour and kind of explain some things that we may be seeing with the child.

Summary of Findings

The participants were interviewed about their perceptions of the SSP. Data analysis of these interviews indicated that participants were feeling uncertain about using the SSP as the exclusive assessment tool for sensory processing. Participants had doubts about the assessment itself and how it fit into the FASD diagnostic process. However, they were also able to identify strengths of the SSP and reasons why they chose this assessment tool. Overall, participants were seeking to find balance. They sought balance between using an assessment tool and clinical judgement, between caregiver and therapist input, and also between time and stress of using the SSP and the information that it obtains. Given the numerous negative perspectives shared, it is possible to assume that the participants have not yet found balance in all these areas.

Chapter Five: Discussion

Introduction

In this research, three main themes developed from the six interviews that were completed regarding occupational therapists perceptions of using the SSP with FASD diagnostic assessments. Theme one was that participants expressed uncertainties about the FASD diagnostic process. Subthemes as discussed in chapter four have been subdivided into more specific discussions in this chapter. In theme one, discussion includes contextual influences (the FASD diagnostic guidelines, resource allocation and child and therapist experience), screening and follow-up (screening tool, communication of results), clinical judgement and domain overlap. Theme two was that participants were questioning the validity of the assessment tool SSP. Subthemes within theme two included lacks information (deficit areas of the SSP, challenges with measuring validity and validity of the SSP versus attention measures), caregiver influences outcomes, use of other assessment tools and more research needed. Despite the uncertainties and the questions, the third main theme that emerged addressed the strengths of using the SSP in the FASD assessment battery. Three subthemes that participants expressed for theme three were with the factors of the assessment tool, preferences for the SSP over the SP and the scoring process. The analysis of these themes and subthemes has been reported in the previous chapter. In this chapter, these results will be discussed more in depth.

In the interest of full disclosure, it is important to provide some background information regarding the author's experience and beliefs with FASD diagnosis. The primary researcher of this study was an occupational therapist within a couple FASD multi-disciplinary diagnostic teams for about nine years prior to completion of this

research. Additionally, she also took part in the 2007 Northwest Partnership for FASD Research panel discussion. In the past, the researcher has used the Sensory Profile for FASD assessments but since the meeting in 2007, has used the SSP. Completion of this research did not change any process methods in terms of diagnostic tools but did result in the researcher being more sensitive to barriers of completing a caregiver questionnaire and differences that may present culturally. Given the tools that are available at the current time and the published evidence that is available, the researcher feels that it is appropriate to continue to using the SSP but to investigate other options. The researcher also believes that maintaining practice procedures within the diagnostic guidelines continues to be of importance but that it would be ideal to specify these procedures further. It is the intention of the researcher that these beliefs did not lead to bias within the interviews, findings or discussion. However, this possibility does exist given the clinical involvement of the researcher in the practice area of FASD but attempts were made to minimize potential bias.

Theme One: Uncertainties about the FASD Diagnostic Process

The make-up and structure of each team and in the clinic that each participant practices varies in a way that influences how the assessment is completed. This leads to discrepancies in how the FASD diagnostic guidelines are being interpreted and may ultimately result in differences amongst diagnoses. It is valuable to consider differences amongst teams and clinics to determine if changes need to be made to improve uniformity of FASD diagnostic teams across Canada. These uncertainties in the diagnostic process led to participants expressing doubts about their approach to assessment within FASD diagnosis.

FASD Diagnostic Guidelines

The Canadian Medical Association (Chudley et al., 2005) released the FASD Diagnostic Guidelines, which made it much clearer and easier for FASD assessments to be completed thoroughly. This was the first time such a document was released in Canada and was received very favourably by FASD teams across the country. These guidelines stressed the importance of using a multi-disciplinary team to evaluate physical and neurobehavioral features of a FASD. However, the guidelines are not very descriptive or detailed in how to proceed with the team development or steps to assessment.

Occupational therapists find themselves in a position of interpreting how assessment of soft neurological skills should be done, because a concrete definition of soft neurological signs was not provided in the guidelines. It would be helpful if a more specific definition of soft neurologic signs was provided within the guidelines document. This would help decrease the uncertainty of what exact skills one should be assessing to determine the presence of soft neurological signs. Additionally, there is a great possibility for personal interpretation within the diagnostic guidelines. If all the domains were better defined and clarified with what type of assessment is expected, the overall diagnostic process would be easier to equalize across the country.

In order to begin addressing the above mentioned problem, the Northwest Partnership for FASD collected a panel of occupational therapists (in addition to physicians, psychologists and speech language pathologists) to help provide more clarity in how to approach assessment of the neurobehavioral domains. While some of the participants had the supplementary information from the Northwest Partnership for FASD first hand as they had been involved with the panel, others learned the information from

the documents released or by word of mouth from colleagues who had attended. There was a noticeable difference in participant's confidence of their own knowledge in the diagnostic process between those who received the information first hand and those who received it second hand. If all occupational therapists working with FASD diagnostic teams had the opportunity to participate in a review of the CMA's guidelines, there may be better adherence to the recommended process. This may in turn improve the similarity of assessments at different clinics, quality of assessment completed and confidence of the clinicians working on FASD teams.

Resource Allocation

The resources available to teams were quite variable. The multi-disciplinary make-up of the teams was not consistent for participants and would likely lead to differences in work load for the OTs. If there was a psychologist available, the occupational therapist would have less responsibility, or if there was a follow-up worker would likely result in caregivers having a better understanding of this complex subject, and decrease the stress for the occupational therapist and other team members on the day of the diagnosis and afterwards. This would be particularly helpful for the occupational therapist who worked on a team where the follow-up worker was also an OT. Sensory processing is a very complex subject to explain briefly, and it would be helpful to have a knowledgeable follow-up worker who could review sensory processing with the caregivers. Many of the participants expressed difficulties with communicating this subject to the caregivers in a short time, and knowing that a follow-up worker could further explain it would be very helpful. The participants who reported having a follow-up worker on the team spoke positively about this experience. It may be a consideration

for other FASD teams to also add a follow-up worker to improve the caregiver's and clinicians experience with the clinic. It can be very stressful and emotional on the day that a child is diagnosed and caregivers may have difficulties absorbing all the information provided during team feedback. A follow-up worker can ensure that the caregiver has the opportunity to learn what he or she needs to know in a manner that works for them. In turn, this will also reduce the stress on the team, who worry about only having one opportunity to tell the caregivers what their assessment findings were. The CMA Guidelines do encourage a team approach and perhaps it would be better to have all teams with the same range of professionals. However, the challenge with this equality is that fiscal resources and availability of trained professionals vary amongst teams in different regions.

In addition to the individuals on the team being different, the location of the clinic varied. Some teams had all team members working in one building who completed assessments together with regular frequency. Others consisted of satellite sites with local occupational therapists consulting to a core team or joining via Telehealth a few times per year. It is likely that teams who are practicing together more frequently will have better cohesiveness, understanding of each other's roles and fluidity of assessment. However, at this time, there is no evidence to suggest that the other types of multi-disciplinary teams are anything less than successful also. Additionally, input from a school based team would likely improve the understanding of a child's occupational performance, but it may not allow for a thorough assessment of sensory processing that an OT can attain in a sensory gym environment. However, it is possible that participants with access to clinical observations in multiple environments may see a more realistic view of occupational

performance with sensory processing deficits than those who do have access to clinical observations in a gym environment. The system that the OTs are working within would influence their role and how they are able to assess the child.

Timing, and the amount of time available, have also had bearing on a child's performance on assessments. There may be performance differences in children who attend assessments over the course of one day versus multiple days because a child may fatigue in a team assessment that is completed entirely over one day. Also, performance differences for the child may also exist when the amount of assessment time ranges, as participants indicated everything from 30 minutes to 120 minutes available. These differences in time must lead to inequity in the thoroughness of OT assessments amongst different teams. It is also likely that the timing and the time available would impact the nature of the OT assessment.

CMA must be credited for their attempt to equalize services across Canada with the diagnostic guidelines. However, as long as resources are inequitable this will not be completely successful. Creating resource equity is a difficult challenge but it is possible to make improvements. Novita Children's Services in South Australia mapped services using an International Classification of Function framework and focus groups to determine how to allocate their resources (Murchland & Wyke-Dyster, 2006). These researchers found that type of service delivery, practice model, client issues and family well-being issues influences needs for resources. These researchers demonstrated that it is possible to objectively allocate services between disciplines and with different populations. Theoretically, this type of service review could be done within contexts of FASD teams to determine what the best balance of discipline allocation would be.

Determining the best possible discipline distribution would be a solid starting point to re-organizing resources to further enhance equity amongst teams.

Child and Therapist Experience

The age of the client also influences the OT portion of the assessment. Most of the participants are assessing elementary school age children. Some participants are also assessing preschoolers and teens. Some participants indicated that diagnosis was being deferred after the first set of assessments were completed, because the team was unable to gather enough information needed for the guidelines but there were indications that the child did have FASD. So, either more information is gathered through more assessment or the child is seen again when (s)he is older and more domains can be assessed. Use of the SSP with the preschool age population is approved in the SSP manual. However, there is some question as to the validity of this process. Some questions on the SSP are not very applicable to this age group. Perhaps a different assessment would be better used to target preschoolers and give OT's more confidence with standardized assessment of sensory processing for preschoolers. It is also possible that more confidence in the assessment tools used with preschoolers would result in fewer deferred diagnoses.

Each occupational therapist's experience outside of the diagnostic clinic will impact how she practices. Some participants worked exclusively on the assessment for these children with FASD, while others also provided treatment. Occupational therapists who provide ongoing treatment may have a slightly different approach in what information they wish to gather during the assessment process than occupational therapists who only provide the diagnostic assessment. It is also likely that those occupational therapists who have more frequent experience with FASD diagnostic assessments would also have more

effective clinical judgement than those who are less frequently involved. The satisfaction with the SSP seemed higher for the OT's who did not provide treatment after the child was seen for a clinic team assessment. Participants who also provided treatment to the children being assessed had more dissatisfaction with the SSP. They felt that they needed to complete a more comprehensive assessment to obtain the information they need for providing treatment and intervention.

Screening Tool

There was also doubt raised as to the appropriateness of using a screening tool, such as the SSP, for this diagnostic procedure. A diagnosis of FASD has lifelong implications and should not be given lightly. Rasmussen et al. (2006) indicate that better assessment techniques and diagnosis of FASD could lead to a reliable, sensitive and valid screening tool for the whole neurodevelopmental component. It is doubtful that use of a screening tool for one small part of the FASD diagnosis meets these criteria. Typically screening tools are a suggestion to do more assessment and are followed up with a more comprehensive assessment. Unfortunately, there is no follow-up assessment recommended after the SSP shows sensory differences during this diagnostic process. However, the fact that the SSP is a screening tool also leads to some positive characteristics. While the general thought was that this tool is not ideal, it does make it possible to complete an assessment. The participants do trust the information they receive from this tool but not without reservation. There was a sense that participants would be more comfortable with a more comprehensive assessment tool to provide input on this very important diagnosis.

Communication of Results

Differences and reservations were also noted in communicating results of the SSP to the team and caregivers. Explaining sensory processing can be quite complicated depending on the knowledge of the caregiver and other team members. Some participants participate in a multi-disciplinary case conference and complete a team report whereas others do not. A lone OT presenting results may have the time and attention of the caregiver to more fully explain sensory processing as compared to when results are communicated in a multi-disciplinary manner. This is a rationale for having OTs provide follow-up consultation or intervention, or for having them work closely with a team follow-up worker.

Clinical Judgement

The CMA guidelines for diagnosis recommend using a standardized assessment tool only in partnership with clinical judgement. Participants recognized the importance of clinical judgement but expressed difficulty with knowing how to balance input from the standardized tool versus their own clinical judgement. Essentially the feeling was that the SSP results were being used to supplement clinical judgement. Clinical judgement would outweigh the SSP results in situations of disagreement. The basic reason for this is because the SSP is a caregiver questionnaire and there are concerns with outcomes being biased by the caregiver. A study on why pediatric OT's choose the assessment tools they do was completed by Kramer et al. (2009). Kramer et al. (2009) indicated that even if OT's need to rely on standardized assessment to determine the need for intervention, the informal methods provide the guidance for goal planning and addressing specific needs. As the OT's in this study have suggested, intervention is very difficult to plan from the

SSP results, perhaps this is one reason why there is so much reliance on informal assessment also. However, it is also possible that the occupational therapist doing the assessment may also have some bias in clinical judgement. Each occupational therapist is likely to be influenced by their own background and experience. Additionally, it is likely that occupational therapists assessing for FASD have very different clinical skills that they are relying on to supplement the SSP results. It may be more beneficial to have a standardized assessment that includes some direct therapist-client assessment so that the process can be more uniform across sites. It is very important that occupational therapists involved with FASD diagnostic teams be well informed and educated regarding sensory processing with a child with FASD as well as aware of their own personal bias.

Several participants also valued the knowledge gained by clinical observations, particularly when it could be done in multiple environments. Clinical observation in several environments may result in opportunities for improved clinical judgement. Occupational therapists could see how a child is coping with differences in sensory processing and if there are functional differences amongst varied environments. There is not a current recommendation to include clinical observation outside of the clinic environment but based on the data, this seems to be a good addition to information collected within the clinic.

Several participants also indicated that they based clinical judgement on their observations of the child in a sensory gym environment. Not all participants had access to such a space. However, the participants who did indicated that the clinical observations in the sensory gym really helped them agree to, or negate, the results of the SSP. This

suggests that occupational therapists completing FASD assessments should have access to a sensory gym to complete clinical observations as part of this assessment process.

Domain Overlap

One of the most significant concerns voiced by several of the participants in the FASD diagnostic process was the possibility that there may be an overlap between domains. Participants expressed trepidation that often sensory processing (soft neurological skills) and attention domains both show positive results and then are counted twice but actually represent one area of neurobehavioral dysfunction. As there only needs to be three positive areas of dysfunction to lead to diagnosis, this is a significant concern. The difficulty is that sensory processing differences and attention difficulties very frequently present co-morbidly and can be challenging to separate. There is some thought that if the sensory dysregulation is improved, the attention will also improve. Based on this concept, it raises the question as to whether it is fair to count attention and sensory processing deficits as two separate areas of dysfunction. This is particularly of concern when participants are feeling that assessment tools do not distinguish well between these areas of function. For several of the participants, this potential overlap was the greatest concern leading to doubts about the diagnostic process for FASD. Research from Dunn and Bennett (2002) may help provide insight on how to differentiate between sensory processing and attention related problems. In their research, they showed that the Sensory Profile can contribute to the diagnostics and program planning for Attention Hyperactivity Deficit Disorder (ADHD), which also present co-morbid with FASD in reasonable frequency. These researchers found that patterns of sensory processing were present in children with ADHD. It is possible that this information may help lead to

differentiating between sensory and attention issues in children with FASD. Solving this concern with the diagnostic process would strengthen the diagnosis each child with attention issues receives.

Franklin et al. (2008) found that children with FASD who show sensory processing deficits on the SSP also demonstrate problem behaviours, such as socialization, attention, rule breaking and thought problems. This research supports the idea similar signs can be interpreted into different domains due to co-morbidity. In reviewing this literature, it suggests that clinicians should be careful that their assessments are sensitive to measure the domains they are intended to. It is also important that clinicians assessing sensory processing are knowledgeable in this area and able to identify the differences between sensory processing and attention with clinical judgement. Given the multiple areas of overlap, this should be further researched.

One participant in the present study felt that auditory processing, specifically auditory sensitivity, may be the factor that differentiates sensory differences from attention. This idea was not expressed by other participants and warranted investigation into the literature. Coles et al. (2002) completed a study evaluating sustained visual and auditory attention. Their results indicate that adolescents who had been exposed to alcohol and drugs prenatally processed visual information more effectively than auditory information. Although, they also suggest that research in this topic is limited and contradictory. Further into the article by Franklin et al. (2008), it finds that children with FASD who have problem behaviours (including attention) have difficulty processing auditory stimuli. They suggest that deficits in auditory processing, which may include auditory sensitivity as measured by the SSP, in addition to modulation, present with a higher prevalence of

behavioural impairments because of poor adaptive behavioural responses. Essentially, the research by Franklin et al. (2008) disproves the participant's theory about auditory processing being the sensory system that differentiates between sensory deficits and attention. However, Franklin et al. (2008) were surprised to find that children with FASD and behavioural impairments did not show differences on the SSP in the areas of tactile, visual/auditory (a different category on the SSP) and movement sensitivity. With more research, outcomes of these areas on the SSP may be more helpful in separating sensory processing deficits from attention impairments.

Theme One Summary

Overall, participants were content working within the CMA FASD diagnostic guidelines. They were pleased that occupational therapists were able to collectively make some recommendations on how to improve the process for this profession in partnership with the Canada Northwest FASD Network. However, the current status of the guidelines and OT processes within them are not without problems. These problems are what are leading to uncertainties of these participants with the diagnostic process as a whole. As a couple participants indicated, it would be very worthwhile to have the panel of occupational therapists reconvene to review and update the OT recommendations for the FASD guidelines. Additionally, it would be very beneficial to have research completed on the potential overlap of the domains that include sensory processing and attention. Creating more similarity amongst teams and having team members well trained in FASD assessment will lead to improved diagnostic practices for FASD in Canada.

Theme Two: Questioning the Validity of the Assessment Tool SSP

The SSP is a measure used to assess whether a child has sensory processing differences or not. As the results of this research indicate, OT's in various FASD clinics are using it to assess for sensory processing differences in children who are being assessed for FASD. However, as the analysis also shows, there is some discontent with exclusively using this assessment tool to determine if a child undergoing a FASD assessment actually has sensory processing differences. The uncertainties raised by participants were due to decreased confidence in this instrument, specifically in terms of the validity of using the SSP for this diagnostic process.

The SSP by McIntosh, Miller, Shyu and Dunn (1999) was originally designed as a short screening tool for clinicians and a sensory processing evaluation tool for researchers. The researchers used two analyses in deciding which items from the SP to keep on this shorter assessment tool. To test construct validity, they used a skin conductance or electrodermal response test to compare results to the SSP. In this electrodermal response test, they found that hyperresponsivity, hyporesponsivity and typical function of children with Sensory Modulation Disorder and typically developing children correlated to similar results on the SSP. This is the only assessment of validity that is reported by the researchers in their manual. This testing group did not include children with FASD and was not done on any other sensory processing areas. Further literature review in several databases did not reveal any subsequent studies of the validity of the SSP.

The validity of an assessment tool seeks to determine if it really measures the underlying concept it proposes to address (DePoy & Gitlin, 2005). There are two types of

validity that are in question by these participants. The participants in this study question content validity as there are concerns that the SSP does not encapsulate all the information needed to determine if a child with a FASD does have differences in sensory processing. They also question criterion validity. Concerns are expressed that the SSP might not be effective in discriminating between problems in attention and sensory processing. Also, participants attempt to enhance validity by using other assessments to supplement the results of the SSP, in attempts to support results already obtained. In addition to concerns with validity, the SSP may be limited by reliability, because it is a caregiver questionnaire. Ultimately, there are likely to be differences in how caregivers interpret the questions. The data from this research does not strongly indicate that there are definite problems with the validity of the SSP for use in FASD assessments or that the reliability is a definite concern. Rather, the data collected here suggests that more research is needed to determine what components of the SSP are valid for diagnosing FASD and what components are better assessed by other assessments or clinical observation.

Deficit Areas of the SSP

Participants felt that many areas of the SSP could be improved. To have more confidence in the ability of the SSP to comprehensively assess sensory processing in FASD, participants felt the assessment tool needed to improve its evaluation of 1) sense of vestibular and movement, 2) olfactory/gustatory senses, 3) tactile processing and 4) coping with sensory challenges through behaviour and social development. If these areas were better represented, the participants would likely feel that the SSP is more fully assessing sensory processing.

Challenges with Measuring Validity

DePoy and Gitlin (2005) indicate that there are two major flaws with measuring content validity. First of all, there is no way to determine if the full range of a concept is being assessed by a tool or not. This flaw is revealed in the data collected for this research. Participants had different ideas as to what areas of sensory processing were missing or under-represented on the SSP. Certainly there was some overlap between participant's answers but they were not equal in their concerns. Some of this confusion may be due to the broad definition of soft neurological skills in the FASD diagnosis. It may also be related to decreased evidence as to which areas of sensory processing are most important for a FASD diagnosis. According to the information from DePoy and Gitlin (2005), it may be very difficult to ever prove error in content validity. In terms of content validity for the SSP, more specific definitions would be needed and much more research regarding which areas of sensory processing deficits are specific to FASD. The second reason why DePoy and Gitlin (2005) suggest content validity is difficult to evaluate is because there is no objective measure available for assessing the complete construct, which in this case, does apply to FASD.

Validity of SSP versus Attention Measures

Another concern regarding validity that participants raised was that the SSP and attention measures used by the psychologist in the FASD diagnostic process were both leading to deficit areas based on similar presentation. There is concern that the two different assessments reveal problems in two different functional areas, sensory processing and attention, but they are based on the same reported behaviours. This is not meant to suggest that sensory processing deficits and attention related problems are the

same thing. Rather, the problem is that the assessment tools used are not sensitive enough to determine the differences between these two areas of function when they overlap. One assessment tool that could evaluate and discriminate between sensory processing and attention would be very helpful in the FASD diagnostic process as opposed to the current process where different tools are used to analyze these areas separately by different clinicians. The SSP does not have the capability to do this.

There is research currently being done to demonstrate that attention and sensory processing are related but are not the same deficit. If research can discriminate between these two functional areas, it is hopeful that perhaps some day there may be an assessment tool that can also show the differences. Weissman, Warner and Woldorff (2009) completed a study showing that adults who have momentary lapses in attention have difficulty suppressing irrelevant sensory processing and engaging relevant sensory processing. They used a fMRI to measure brain activity when individuals were asked to focus on visual stimuli, while being distracted by auditory stimuli. They found increased response times and changes in the brain mapping of sensory processing when attention was altered. These authors suggest that these findings may be linked to attention problems in Attention Deficit Hyperactivity Disorder, Alzheimer's disease and drug addictions. Given what the participants have indicated, it is also possible that these results have relevancy in the field of FASD.

Caregiver Influences Outcomes

One of the main reasons why participants question the validity of the SSP in FASD diagnostic assessments is because of the heavy influence that caregiver's have on the results. Caregiver questionnaires have been used successfully as assessment tools in

various ways. However, for the field of FASD, there are some confounding factors that complicate use of a caregiver questionnaire. Participants questioned the ability to gather reliable information from a caregiver questionnaire for this population, for a wide variety of reasons. Biological parents can be transient and often have their own social or physiological challenges that led to maternal alcohol consumption in the first place. Foster parents can have a skewed sense of normalcy as they often have large family units leading to loud homes and can have many children with sensory processing disorders in the home. Culture and environment (such as rural versus urban) can influence perceptions of sensory processing. Many concerns with literacy may exist including low levels of intelligence, low reading ability or reading English as a second language. Also, there is no consensus as to whether verbally reviewing this assessment leads to more accurate collection of information or if the OT is more likely to introduce her own bias. The SSP does have certain language that one participant coined as “OT jargon” and this may also be difficult for caregivers. It seems to be a fair analysis of the participants to have reservations in using this assessment when there are so many potential confounding factors that may affect the validity of the SSP when being used for FASD assessment.

Use of Other Assessment Tools

Participants also seek to enhance validity when they access additional assessment tools to support results they obtain from the SSP (DePoy & Gitlin, 2005). Five out of the six participants have developed an informal hands-on assessment based on clinical observations to assist with enhancing validity. As Depoy and Gitlin (2005) indicate, the challenge with this is that the concurrent validity is only as good as the assessment it is being compared to. As this informal hands-on assessment is not standardized and depends

on each OT's clinical knowledge, there is room for error with enhancing validity through this means. However, participants are also using other assessment tools to enhance validity. They are using the Ontario Society of Occupational Therapists Perceptual Evaluation (OSOT), Sensory Profile Caregiver Questionnaire (SP) and School Companion, and the Sensory Processing Measure (SPM).

The OSOT is a perceptual evaluation and not a measure of sensory processing. This may not be the best assessment tool to enhance validity. However, use of its hands-on clinical observations demonstrates how the participants are seeking some guidance in how to approach this part of the assessment.

The SP is the full form from which the questions of the SSP have been taken. As discussed above, the SSP was developed to better discriminate if sensory processing deficits exist or not. However, many of the participants felt that the SP gave them more information and thus, more confidence in knowing whether a child truly does have a sensory processing difference or not. Although, they weren't entirely pleased with the SP as they found it too long and stressful for the caregivers to complete.

The Sensory Profile School Companion assessment is a questionnaire that teacher's complete regarding a student's sensory processing skills in the classroom. Several of the participants in this study spoke highly of using the results of this assessment to supplement the SSP results. It was especially appreciated that with this assessment tool, the results were not exclusively based on caregiver input. Brown & Dunn (2010) have shown that the Sensory Profile School Companion assessment tool is helpful in showing how context can influence sensory processing for children with Autism Spectrum Disorder. Showing that sensory processing differences exist in multiple environments, as

measured by different individuals will enhance the validity of the assessment. If this assessment tool has been shown useful in the assessment of children with autism, the same may also be true for children with FASD.

The SPM was spoken highly of by a few participants but not mentioned by everyone. Presumably, not all of the participants have trialed use of this assessment as it is newer on the market of sensory processing assessments. According to Henry et al. (2009), the SPM has been designed with the key features of being quick, easy to use and easy scoring which are some the features the participants like about the SSP. Henry et al. (2009) also indicate that the SPM was standardized in home and school environments and has strong psychometric properties. The supporting information provided by the SPM knowledgeable participants in this research suggests that the OT's completing FASD assessments should consider use of the SPM as an alternative to or in support of the SSP.

Until more research is completed or informed evidence is gathered from experienced OT's, regarding FASD and sensory processing, it will be difficult to know what assessment tool is a better choice. The panel of OT's that originally met within the organization the Northwest Partnership for FASD may also be able to provide some input on this if given the opportunity to compare and contrast the SSP and SPM.

Theme Two Summary

Having a valid assessment tool of sensory processing for the FASD diagnostic assessments is very important. If the tool is not valid, the team will have doubts about the results and less confidence in this very important diagnosis. The research gathered here does not suggest that the SSP lacks validity; rather it puts forward questions to consider. The only way these questions can be addressed is with more research.

Theme Three: Strengths of the SSP

As has been discussed, there is much dissatisfaction with using the SSP to assess sensory processing in the FASD diagnostic process. However, the data is not all negative. Participants expressed reasons as to why they continue to use the SSP, despite it not being ideal. They also communicated that they prefer using the SSP more than the full Sensory Profile (SP). Also, they find the scoring system of the SSP terrific and user-friendly.

Factors of the Assessment Tool (SSP)

The participants all chose to initially use the SSP for the FASD diagnostic assessments based on the recommendations of the Northwest Partnership for FASD. It is interesting that all participants continue to use this assessment tool, despite dissatisfaction with it. There are no regulations or rules that firmly indicate use of the SSP as protocol for FASD assessments, rather it has been a suggestion made by colleagues. It is also interesting and important to note that in all of the studies that could be found on sensory processing and FASD for the literature review used the SSP or the Infant/Toddler Sensory Profile in their research (Carr, Agnihotri & Keightley (2010), Fjeldsted & Hanlon-Dearman, 2009) Franklin et al. (2008), Jirikowic (2003) and Jirikowic, Carmichael-Olsen and Kartin (2008)). Regardless of the reasons, all the participants chose to continue using the SSP. Therefore, despite some the negative opinions as discussed previously in this chapter, participants also had many positive reviews of the SSP for use in FASD assessments. The positive factors of the SSP that result in continued usage include: 1) quick to score, communicate and report, 2) easy to use for OTs and caregivers (who do not have literacy issues), 3) obtain an overall score, 4) most questions are relevant to

FASD, 5) some information gathered by SSP is difficult to assess in the clinic setting and 6) the SSP screens for whether the child needs OT follow-up.

Quickness and ease of use are important features in this assessment process. The caregivers must complete several questionnaires from different disciplines in the diagnostic process. This can be tiresome and difficult for many caregivers, particularly when literacy issues do exist. Therefore, in terms of a caregiver questionnaire, the SSP is a reasonable option. Timeliness seems to be an important factor as many of the participants indicated that they very much felt under time pressure to complete their assessment. This is the nature of it for two reasons. This multi-disciplinary assessment means that the children and their parents are subjected to many assessment tools. Also, fatigue is common both for young children and children with FASD, particularly when they are required to concentrate on assessments. A short assessment tool that is easy to use is necessary in this FASD diagnostic process.

Participants generally felt that most questions on the SSP are relevant to children with FASD. When asked if they would remove any questions, a few participants said they would not and others gave only one answer, which differed amongst them. This indicates that the participants do feel that the questions on the SSP are useful in the assessment of children who may have a FASD. In addition to this, there are certain questions on the SSP that are very helpful to have because they are difficult to determine in a clinical setting. In particular the participants appreciate learning more about the child's sensory processing at home and in the areas of auditory filtering, tactile sensitivity and taste/smell sensitivity. This is information that the OTs would have to obtain from the caregivers in some way, so use of the SSP makes this task easier. This would be especially important for OTs

completing this assessment without the use of a sensory gym. Participants mostly agreed that information gathered by the SSP was useful, just not comprehensive enough.

Scoring

The reasons why they like the scoring system of the SSP are as follows: 1) they appreciate having a final score, 2) the scoring system is easy and quick which makes the assessment user friendly and 3) each different sensory area of function has a standardized score. Because the scoring system is clear and concise, participants also found it easy to communicate to team and within a report.

A study done by Donaldson et al. (2004) found that parents have two main expectations of reports written by OTs and speech language pathologists. They hope that the report will give them some information about their child's performance on the assessment and provide consultation for home programming suggestions. The findings of Donaldson et al.'s (2004) study supports what the participants indicated in the current study. The participants felt it was important to communicate sensory processing results clearly and the SSP does make this an easier task. However, participants were not pleased with how the SSP informed the development of home programming and consultation for intervention strategies. Participants appreciated that the SSP assists an OT to determine if further OT involvement is necessary, but felt that it did not provide enough information to give really useful home programming. According to Donaldson et al., for effective family centered intervention, the parent's expectations of reports should be considered. Essentially, use of the SSP provides only part of a strategy to enhance family centeredness.

Preference of SSP over SP

In the interview for this study, participants were asked to compare their experiences with using the SSP and the SP for FASD assessments. One of the main complaints from participants was that the SSP does not gather enough information, so one would think that they would prefer the longer and more comprehensive SP. However, this is not true. Five out of six participants preferred the SSP over the SP for FASD assessments. One of the participants prudently accepts it only because of time factors but the other four participants preferred it for other reasons. They felt that the SSP is more precise, which is certainly what it was intended to be by the creators of the assessment tool (McIntosh et al., 1999). Some participants felt that they results of the SSP were more congruent with their clinical observations than the SP. This may be a result of how McIntosh et al. (1999) standardized this assessment as they attempted to enhance validity of the SSP by choosing the best questions from the full caregiver questionnaire. Participants also appreciate that it has one final score, which is very important for the diagnostic process. The one final score also makes it easier to communicate the results and determine if sensory processing is a deficit area for a FASD. The longer SP, without its one final score, means that the OT must use more clinical judgement in determining if sensory processing is a deficit area in the diagnostic process. In some cases, children with a FASD can have very good motor skills but very impaired sensory processing. Without a total score on a sensory assessment, therapists are forced to make a judgement call based entirely on clinical observation as to whether there is indications of soft neurological dysfunction or not. The one final score and preciseness of the measure provides the OT with more quantitative evidence and confidence in what exactly is the concern with the

child's sensory processing system. They also like that the SSP is shorter and less stressful for caregivers than the SP. Overall, the SSP is favored more than the SP for a variety of reasons. However, several participants did indicate that if they were planning on providing intervention to the child with FASD, they would use the SP in follow-up to gather more information for intervention and home programming. Therefore, the preference for the SSP is very specific to the way in which the FASD diagnosis is organized and not necessarily the best option for intervention or consultation.

Theme Three Summary

Each participant had their own thoughts as to why the SSP is a preferred tool over the other options. However, when data was compared amongst participants, many of the reasons were similar. Interestingly, positive attributes were often identified in a manner that seemed to be compensatory for answers that frequently focused on weaknesses of the SSP. In that sense, participants were seeking to balance their input during the interview with positive remarks in attempt to offset the more numerous negative responses.

Summary of Discussion

The results of this study indicate that the SSP is being used in FASD clinics across western Canada as a result of recommendations from the Northwest Canada FASD Partnership panel of occupational therapists. To summarize findings, it is generally thought that the SSP is the best tool amongst what is available. Despite this, it is still not ideal for FASD diagnostic assessment. There are too many questions surrounding how it is used within the diagnostic process and with the validity of the assessment tool for this diagnostic population. A more hands-on assessment that is less dependent on caregiver input would be preferred. Positive aspects such as time, the scoring system and ease of

use create some favour for using the SSP. Intervention and consultation with SSP results are challenging. This challenge should be considered when choosing which assessment tool to use in the FASD diagnostic process, as many of the children do not receive ongoing follow-up after the diagnosis. The Sensory Processing Measure is a tool that also received positive review in this data and should be evaluated for use in the FASD diagnostic process. Ideally, a group of occupational therapists associated with the Northwest Partnership for FASD could continue dialogue about which assessment tools are most effective. It is excellent that the information originally determined by this group disseminated so widespread and suggests that continued dialogue may be useful in ongoing equality and improvements amongst practitioners in FASD clinics. Margo Holm (2000) in The 2000 Eleanor Clarke Slagle Lecture challenged occupational therapists to be able to provide the evidence needed for practice by 2010. Based on the research completed here, the field of occupational therapy has failed to do so in the area of FASD. It is only with more evidence both in terms of research and practice that occupational therapists can be more confident with the assessment tool they choose to use in the FASD diagnostic process.

Chapter Six: Conclusion

Introduction

Alcohol exposure on infants in-utero is widely known to result in adverse effects on the development of that child, with specific concern related to vulnerability in the brain (Streissguth, 2007). Streissguth (2007) reported on a longitudinal study that looked at 500 babies born in 1974 to mothers who consumed alcohol, before this was well known to be a problem. In this study, they found long term deficits of pre-natal alcohol exposure in individuals that were revealed in early infancy and expanded into adulthood. Deficits and problems appear to range over the lifespan. In early childhood, deficits present with behavioural concerns such as decreased attention and learning problems, such as decreased intelligence quotient (IQ) and slow processing speed. In adulthood, secondary challenges such as increased abuse of alcohol and drugs, as well as double the chance of six psychiatric illnesses are concerns. Studies such as this one give merit to the value of proper assessment and diagnosis of FASD. With accurate identification, individuals with FASD may be given the supports they need to succeed into adulthood.

Findings

This exploratory qualitative study looked at the use of the Short Sensory Profile (SSP) by Canadian occupational therapists in FASD diagnostic assessments. The participants of this study brought forth many relevant and valid questions regarding the assessment tool SSP and the process of diagnosing FASD. Participants expressed concerns with neurodevelopmental domains overlapping (attention and soft neurological skills) and struggles with discrepancies between clinical judgement and standardized measurement tool results. Concerns regarding the validity of using the SSP with FASD diagnostic

assessments were also brought to the forefront. Ultimately, the participants expressed satisfaction with using the SSP for assessment of sensory processing in FASD diagnosis, but this is at least partly due to the limited options of tools available. Main frustrations with this tool are in regards to having to rely on caregiver input and the challenges it brings with providing follow-up and intervention. Within current practice, all the participants will continue to use the SSP for FASD diagnostic assessments.

Limitations

There were three main limitations of this study. The first limitation is that only six occupational therapists were able to participate in this study. A greater number of participants would have enhanced the validity of the results. The second limitation of the study is that all participants were located in British Columbia through Manitoba. The Canadian Medical Association has released the FASD diagnostic guidelines across the country and there is evidence of FASD clinics in eastern Canada (Chudley et al., 2005). Team members of FASD clinics in Ontario and Newfoundland have been introduced to this researcher at conferences in the past. Also, new research emerging from the University of Toronto suggests that FASD diagnoses are occurring in that geographical region. However, in northern and western Canada, the awareness for FASD and need for FASD clinics has been enhanced by the Northwest Partnership for FASD Research and the education and training that they spearhead. Given the responses to the letter of invitation, it is very possible that the prevalence of occupational therapists working in FASD clinics is higher in northern and western Canada than in the eastern part of the country.

Intentions were to originally have representation from across the country but this did not occur. The method of recruitment did influence this to some degree. There was opportunity for OT's across the country to respond to the initial letter of recruitment, but only western Canadian OT's were recruited. Therefore, with the secondary recruitment method of snowball sampling or networking, more western Canadian participants were located. On the positive side, all participants were familiar with the same process and recommendations for assessing for FASD. The third limitation of the study is that the researcher, who was also the interviewer, has been actively involved with a FASD team and meetings held by the Canada Northwest Partnership for FASD Research (from which participants were following procedure). The potential for researcher bias does exist, although steps were taken to maintain objectivity and provide reflexivity. While the limitations of this study have affected the outcomes, the value in the findings is not altered.

Outcomes for Early Intervention

Obviously the goal of a thorough assessment for FASD should be to provide appropriate intervention and consultation to hopefully minimize the impact of alcohol exposure on a child's developing brain. Better and more specific testing procedures will lead to increased accuracy with diagnosis. Occupational therapy is just one part of the team process but it may be increasingly important in identifying the children with need earlier in their lifespan. Carmichael-Olson et al. (2007) state "Unfortunately, it is often difficult to gather clear evidence of CNS dysfunction at a young age. Early developmental deficits of alcohol-exposed children may be subtle and yet important precursors of later problems." (p. 174). Additionally, they suggest that many children miss the opportunity

for early intervention because their deficits do not become obvious until they are school age. This is especially concerning because the plasticity of the central nervous system is more easily influenced at younger ages (Carmichael-Olson et al., 2007). Using evidence of sensory processing challenges and motor skill deficits of young children, under age five, Carmichael-Olson et al. (2007) suggest that these are some of the signs that indicate need for early intervention. Skilled occupational therapists with the proper tools can be invaluable in helping to identify these children at a younger age and provide some of the supports that are needed.

Outcomes for Cultural Awareness

There is very little research regarding the influence of ethnicity on deficits created by pre-natal alcohol exposure. Some participants in this study identified concerns with their own ability to meet specific needs of children who have cultural differences. This concern has recently been highlighted in the research. A group of American researchers determined that occupational therapists confront issues of cultural diversity more now than ever before (Suarez-Balcazar, 2009). They also indicate that occupational therapists may not desire to or have the ability to adapt their practice to specific cultural values. Participants in this study suggested the opposite to what these researchers suggested, as they were interested in adapting their practice but were not really sure how to do this. While the needs in the U.S.A. are likely slightly different, the principles of cultural competence are the same in Canada.

One study done at the University of Alberta that evaluated fifty children with FASD found that ethnicity does influence neurobehavioral strengths and weaknesses (Rasmussen, C., Horne, K. & Witol, A., 2006). Specifically, they found that Aboriginal

and Caucasian children performed differently on various neurobehavioral tests. The Aboriginal children had better visual memory than verbal memory and the Caucasian children had better verbal memory than visual memory. Although in both cases, performance was below average means. The authors of this study suggest that visual strategies for memory, such as pictures, are even more important for Aboriginal children. Whereas, the Caucasian children may need to develop strengths in verbal memory with tasks such as recalling lists and verbal coding. The results of this study may also have implications for occupational therapists assessing sensory processing. It is possible that differences in memory may also be related to differences in sensory processing of the visual and auditory systems.

In 2009, the Public Health Agency of Canada funded a study that evaluated the need for developing culturally sensitive diagnostic tools for FASD. Focus groups of Aboriginal representatives, occupational therapists, speech language pathologists, psychologists and physicians gave feedback about this issue. Clinical groups in this study expressed concern with current assessment tools not being standardized to specifically meet needs of the Aboriginal population. To further complicate the issue, the Aboriginal representatives indicated that community norms have great variability within the Aboriginal culture. One Aboriginal representative suggested that it is not the norms of the tools that need to change, rather there should just be a culturally sensitive component included as part of the criteria for assessment of FASD. Issues of cultural competence are important to occupational therapists working in the field of FASD.

Implications for Occupational Therapy Practice, Education and Future Research

Most of the participants of this study were quite invested in the area of practice with FASD and subsequently expressed significant interest in this research. All participants in this research study were following the procedures outlined by the Canadian Medical Association's 2005 Guidelines for Diagnosing FASD (Chudley et al., 2005). Additionally, they had all either been in attendance of meetings or received information from the meetings of the Canada Northwest Partnership for FASD Research where specific assessment tools for FASD assessment were recommended (February, 2008). Participants who had attended those meetings expressed desire to reconvene to further analyze the occupational therapy portion of FASD diagnostic teams. Based on the results of this research, it would be useful for experienced occupational therapists working on FASD teams to trial the use of the Sensory Processing Measure and the Sensory Profile School Companion prior to meeting once again. These assessments were spoken highly of from participants of this study and may provide some alternative or supplementary assessment for the SSP. If occupational therapists are given the opportunity to reconvene, better outcomes will be dependent on the OT's bringing forth as much experience and knowledge as possible.

Methods in which practice information is disseminated to occupational therapists practicing on FASD teams is not organized or efficient. Several of the participants in this study were organizing their practice process based on what they had learned by word of mouth. Students of occupational therapy faculties in Canada should be learning about the CMA Guidelines for diagnosis in addition to the recommended battery of assessments for occupational therapists (Chudley et al., 2005). From this researcher's experience with

occupational therapy students from two different Canadian universities, this information is either not taught in their curriculums or just not all the students are truly learning it. Additionally, occupational therapists who are currently practicing need the opportunity to learn about this, particularly when they are new to a FASD assessment team. The Northwest Partnership for FASD does host a large international conference every two years in Victoria, B.C., where issues like practice protocol and using the CMA guidelines are discussed. This is a good opportunity for clinicians who need more education regarding FASD.

Some of the uncertainties that the participants of this study raised also reveals important findings that may impact clinical practice and student education. Despite being experienced occupational therapists, each of the participants expressed some challenge with using clinical judgement to evaluate sensory processing. This suggests that it is important that student occupational therapists are taught the skill of using clinical observation to informally assess sensory processing issues. This is a skill that is expected in this diagnostic process. To create more complexity, the clinician working on a FASD team also has to be able to not only identify sensory processing issues but have some understanding how this may be influenced by but is separate from attention deficits. This skill is challenging but very important for the OT working with a FASD diagnostic team. It is likely that a more experienced pediatric occupational therapist would find clinical judgement for sensory processing differences in the FASD population easier than a new OT to this area of practice.

Like any healthcare settings in Canada, FASD teams are often functioning with fiscal restraints. In the ideal situation, the fiscal capabilities of FASD teams would be

more similarly distributed across the country so that services could be more equal. All OTs should have equal time to dedicate to their assessment in order to achieve the desired outcomes. Additionally, the expected outcomes should be the same. If the team composition was the same everywhere, this would be more possible. Based on the information given by these participants, FASD teams across Canada should also consider including a follow-up worker. Realistically, fiscal constraints will always vary amongst centers in our current healthcare system. However, perhaps the possibility exists that if research could indicate how much time is needed for each team member to do their job well, some equality may prevail.

Many interesting ideas for further research developed out of the findings of this study. Suggestions for future research that evolved from the data in the findings are as follows:

1. Are there particular patterns of sensory processing present in a child with FASD that can be evaluated by the SSP?
2. Are the attention measures and sensory processing measures sensitive to the differences in these deficit areas?
3. How can cultural sensitivity be best maintained throughout the diagnostic process?
4. Is there any way to provide some protocol for clinical judgement that may assist OT's working on FASD to quantify their observations?
5. Is the language level of the SSP resulting in decreased validity or reliability for FASD assessments?

6. What is the appropriateness of a caregiver assessment as the only standardized assessment used for sensory processing when providing a diagnosis of FASD?

The ideas for further research that arose from the information provided by these participants were diverse and very applicable to education and daily practice.

Conclusion

This exploratory study on occupational therapist's perceptions of the SSP in FASD diagnostic assessments may have actually produced more questions than answers. This is indicative of the uncertainties that the participants are feeling and facing in their assessment of children who have been exposed to alcohol prenatally. More research, clinical evidence and consensus amongst informed professionals with process and procedure will help occupational therapists maintain the confidence they should have when proceeding with assessment for FASD diagnosis.

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Appendix One – Letter of Invitation

School of Occupational Therapy, Dalhousie University

Dear (Name of occupational therapist),

You have been identified as a possible candidate to take part in a research study regarding the assessment of children with possible Fetal Alcohol Syndrome by occupational therapists. This research is a thesis project being conducted as part of a master's degree in occupational therapy from Dalhousie University. You were identified either through CAOTs OT Finder on the website www.otworks.ca, or your name was brought to my attention by a member of this CAOT directory. OT Finder identifies a group of occupational therapists who work in pediatrics, but for the research project I need to find a group of occupational therapists who not only work in pediatrics but also work with Fetal Alcohol Spectrum Disorder (FASD) diagnostic teams and have had some experience using the *Short Sensory Profile* in this capacity.

If you are a registered occupational therapist who works or have worked with a Fetal Alcohol Spectrum diagnostic clinic or assessment team and uses the Short Sensory Profile tool, we invite you to participate in an interview in person, or over the phone, (depending on distance) that will take approximately 20-30 minutes. We hope to interview five occupational therapists for this research study. These interviews will provide important information on occupational therapists' impressions of the *Short Sensory Profile*. This information will increase the research evidence regarding the use of this tool for this client population. It is through more evidence based research that occupational therapists can contribute to the diagnosis of FASD.

A description of the study is provided below, including risks and potential benefits. There is not likely to be any direct benefit to you, but your participation may help benefit the profession of occupational therapy and individuals involved in the diagnosis of fetal alcohol spectrum disorders. You are welcome to ask me, Cynthia Bojkovsky, any questions you may have about the study at (306) 655-1108 or cy889928@dal.ca or you may contact my supervisor Joan Versnel (902) 494-2601 or jversnel@dal.ca.

Purpose: The purpose of the study is to explore occupational therapists' perceptions of the use of the *Short Sensory Profile* for diagnosing FASD. This assessment tool has been chosen by a panel of occupational therapists involved with the Canadian Northwest FASD Partnership as the best assessment to evaluate sensory processing in children who may have a FASD. However, more research evidence is needed to support the use of this assessment

tool for this client population. This research will contribute to and help support evidence based approach to the inclusion of occupational therapists on FASD teams.

How Does it Work: You are free to choose whether you would like to participate in this research. If you would like to participate, please sign the included consent form. If you have received this invitation by email and would prefer to be sent a hard copy and self-addressed envelope, contact me and this can be arranged. Please fill out the consent form, keep one copy for yourself and return one copy to me in the included envelope by **November 10, 2009**.

If you choose to participate, I will contact you after I receive the consent form to set up a qualitative interview regarding this topic. The interview will take approximately 45-60 minutes. It may be completed in person, when possible or over the telephone if we cannot meet in person. Your interview will be audio-recorded for data collection purposes. All information will be kept confidential. Once I have analyzed your interview, summary data will be sent back to you for review of accuracy. Upon your approval of the analysis, the process will continue. There will not be any information used in the written thesis that will enable one to determine your identity or the identity of any clients that may be discussed.

This information will be used to complete my master's thesis and may be presented at a conference or published for use within the profession of occupational therapy or the field of FASD research. Any information that is shared with the public will not contain any individual information or names.

Consent to Participate: If you choose to participate, please read and sign the enclosed consent forms. Keep one copy for your records and return the second consent form to me in the enclosed addressed and stamped envelope by **November 10, 2009**. When I receive the consent form I will contact you to set up a time for an interview.

If you have any questions, please feel free to contact me, Cynthia Bojkovsky at (306) 668-1917 or cy889928@dal.ca or my supervisor Dr. Joan Versnel at (902) 494-2601 or jversnel@dal.ca. Thank you in advance for your time.

Sincerely,

Cynthia Bojkovsky BSc.O.T. (c) Reg SK; MSc OT (post-professional) candidate

Appendix One B – Letter of Invitation Revised

School of Occupational Therapy, Dalhousie University

Dear (Name of occupational therapist),

You have been identified as a possible candidate to take part in a research study regarding the assessment of children with possible Fetal Alcohol Syndrome by occupational therapists. This research is a thesis project being conducted as part of a master's degree in occupational therapy from Dalhousie University. You were identified either through CAOTs OT Finder on the website www.otworks.ca, or your name was brought to my attention by a member of this CAOT directory. OT Finder identifies a group of occupational therapists who work in pediatrics, but for the research project I need to find a group of occupational therapists who not only work in pediatrics but also work with Fetal Alcohol Spectrum Disorder (FASD) diagnostic teams and have had some experience using the *Short Sensory Profile* in this capacity.

Several weeks ago you were sent an initial invitation to join this study. This second invitation is being sent out because unfortunately five participants have not yet been recruited. If you are interested in participating in this study, please contact the researcher Cynthia Bojkovsky at (306) 668-1917 or cy889928@dal.ca. Thank you for reconsidering this research study.

If you are a registered occupational therapist who works or have worked with a Fetal Alcohol Spectrum diagnostic clinic or assessment team and uses the Short Sensory Profile tool, we invite you to participate in an interview in person, or over the phone, (depending on distance) that will take approximately 45-60 minutes. We hope to interview five occupational therapists for this research study. These interviews will provide important information on occupational therapists' impressions of the *Short Sensory Profile*. This information will increase the research evidence regarding the use of this tool for this client population. It is through more evidence based research that occupational therapists can contribute to the diagnosis of FASD.

A description of the study is provided below, including risks and potential benefits. There is not likely to be any direct benefit to you, but your participation may help benefit the profession of occupational therapy and individuals involved in the diagnosis of fetal alcohol spectrum disorders. You are welcome to ask me, Cynthia Bojkovsky, any questions you may have about the study at (306) 655-1108 or cy889928@dal.ca or you may contact my supervisor Joan Versnel (902) 494-2601 or jversnel@dal.ca.

Purpose: The purpose of the study is to explore occupational therapists' perceptions of the use of the *Short Sensory Profile* for diagnosing FASD. This assessment tool has been chosen by a panel of occupational therapists involved with the Canadian Northwest FASD Partnership as the best assessment to evaluate sensory processing in children who may have a FASD. However, more research evidence is needed to support the use of this assessment tool for this client population. This research will contribute to and help support evidence based approach to the inclusion of occupational therapists on FASD teams.

How Does it Work: You are free to choose whether you would like to participate in this research. If you would like to participate, please sign the included consent form. If you have received this invitation by email and would prefer to be sent a hard copy and self-addressed envelope, please contact me and this can be arranged. Please fill out the consent form, keep one copy for yourself and return one copy to me in the included envelope by **November 30, 2009**.

If you choose to participate, I will contact you after I receive the consent form to set up a qualitative interview regarding this topic. The interview will take approximately 45-60 minutes. It may be completed in person, when possible or over the telephone if we cannot meet in person. Your interview will be audio-recorded for data collection purposes. All information will be kept confidential. Once I have analyzed your interview, summary data will be sent back to you for review of accuracy. Upon your approval of the analysis, the process will continue. There will not be any information used in the written thesis that will enable one to determine your identity or the identity of any clients that may be discussed.

This information will be used to complete my master's thesis and may be presented at a conference or published for use within the profession of occupational therapy or the field of FASD research. Any information that is shared with the public will not contain any individual information or names.

Consent to Participate: If you choose to participate, please read and sign the enclosed consent forms. Keep one copy for your records and return the second consent form to me in the enclosed addressed and stamped envelope by **November 30, 2009**. When I receive the consent form I will contact you to set up a time for an interview.

If you have any questions, please feel free to contact me, Cynthia Bojkovsky at (306) 668-1917 or cy889928@dal.ca or my supervisor Dr. Joan Versnel at (902) 494-2601 or jversnel@dal.ca. Thank you in advance for your time.

Sincerely,

Cynthia Bojkovsky BSc.O.T. (c) Reg SK; MSc OT (post-professional) candidate

Appendix Two

Consent to Participate in a Research Program
School of Occupational Therapy; Dalhousie University

Introduction: You are invited to participate in a study being conducting entitled Occupational Therapy Assessment of Children with Fetal Alcohol Spectrum Disorder (FASD). Your participation is voluntary. Please read this form carefully, and feel free to ask questions you might have. The researcher of this study is Cynthia Bojkovsky who is an occupational therapist graduate student with the Faculty of Occupational Therapy at Dalhousie University. Please contact Cynthia Bojkovsky at (306) 668-1917 if you have any questions regarding this research study.

Purpose: The purpose of the study is to find out more about occupational therapist's perceptions of using the Short Sensory Profile for assessments with children who have FASD. This will help us better understand the impact of prenatal alcohol exposure on children's sensory processing skills and our assessment of this skill area. It will help us better understand the use of the *Short Sensory Profile* and increase research evidence for this client population.

Study Design and Participants: We hope to interview five registered occupational therapists who have experience with pediatric FASD diagnostic assessments will be interviewed for their perceptions of the Short Sensory Profile. This interview will occur in person or by telephone, (depending on distance) and will take 45-60 minutes. Information will be compiled and reviewed for themes and global perceptions. Once the information has been analyzed, it will be sent back to you for review. Occupational therapists who do not have experience with FASD diagnostic assessments with children will not be included in this study.

Potential Risks: There is very little risk of emotional distress in this study. However, if you are feeling uncomfortable, you are welcome to choose not to answer any question or discontinue the interview. The data collected will be kept confidential and secure. Any names used in the reported format will be pseudonyms in order to uphold confidentiality. Your participation is completely voluntary.

Potential Benefits: Although there are no direct benefits to you for participating in this study, there are potential for benefits to the wider healthcare community by increasing the understanding of FASD and impact of FASD-related disabilities. In addition, the research

may help contribute to future development of clinical guidelines for assessments for children with FASD.

Storage of Data: The data for this study will be based on the information you provide during a recorded interview. Written work will be stored securely and confidentially at Dalhousie University for 5 years after the Master's Thesis is completed and post-publication, at which time it will be destroyed. Electronic data will be erased after use is complete.

Duty to Disclose: The researcher of this study is under duty to disclose professional misconduct to regulatory bodies. Additionally, if there is any suggestion of child abuse or neglect, this will be reported to the proper agency.

Confidentiality: Although the data from this study may be published and presented at conferences, the data will be reported in a way so that it will not be possible to identify individuals. Pseudonyms will be used to identify direct quotable information. If you have any questions, please feel free to contact me, Cynthia Bojkovsky at (306) 668-1917 or cy889928@dal.ca or my supervisor Dr. Joan Versnel at (902) 494-2601 or jversnel@dal.ca.

Consent to Participate in a Research Program Faculty of Occupational Therapy; Dalhousie University

Right to Withdraw: Your participation is voluntary, and you may withdraw from the study for any reason. The right to withdraw is open until the data analysis is completed. After this step, it will no longer be possible to withdraw from this study.

Ethics: This study has been ethically reviewed by the Dalhousie Research Ethics Board. Please feel free to contact the Dalhousie Office of Research Ethics Administration if any concerns arise. Their contact information is 5248 Morris Street, Halifax NS, B3J 1B4 or (902) 494-1595.

Outcomes: Please indicate if you wish to be contacted with the study results.

- Yes
- No

Questions: If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researcher at the number provided.

Consent to Participate: I have read and understood the above. I have been provided with an opportunity to ask questions and my questions have been answered. I consent to participating in the study described above, understanding that I may withdraw this consent at any time. Please retain a copy of this consent form for your records.

(Name of Occupational Therapist)

(Date)

(Signature of Occupational Therapist)

(Signature of Witness)

(Date)

Please sign the consent below if you agree to allow audio-recording of this interview.

(Signature of Occupational Therapist)

(Signature of Witness)

(Date)

Consent to Participate in a Research Program
Faculty of Occupational Therapy; Dalhousie University

Please sign the consent below if you agree to allow direct quotes from your interview to be used in the written results for this research.

(Signature of Occupational Therapist)

(Signature of Witness)

(Date)

Appendix Three: Interview Script

Researcher's Introduction: Hello. I'm Cynthia Bojkovsky. As you know, I've set up this interview as part of a research program examining occupational therapist's perceptions of using the Short Sensory Profile in FASD assessment and diagnosis. I am doing this research as part of my Master's thesis at Dalhousie University. I have been working as an occupational therapist for about eight years. I have been providing assessment and treatment for children with a FASD during my whole career, although I don't work exclusively with this population. I am interested in this research because I think occupational therapy needs more evidence to guide practice, particularly for FASD. I will be asking you a series of questions. Please feel free to add information at any time during this interview, even if it does not directly answer the specific question I have asked. You can refuse to answer any questions and can stop the interview at any time if you change your mind and decide not to participate. Do you have any questions? Do you still consent to participate in this interview?

First I will be asking you questions about yourself.

1. What is your full name?
2. Where do you work?
3. Which professional associations are you currently registered with?
4. How long have you been an occupational therapist?
5. How long have you been working with children with fetal alcohol spectrum disorder?
6. How frequently do you participate in FASD diagnostic assessments?
7. What percentage of your caseload is working with children with FASD?
8. What diagnostic method does your team use for FASD assessments?
9. Do you provide both assessment and treatment for children with FASD?

Next I will be asking you questions about your experiences using the Short Sensory Profile with FASD assessments.

10. Tell me about the assessment process for FASD that you are involved with.
Probe: Which professions are represented on the team? What age of child do you usually assess? What assessments do you routinely use?
11. How often do you use the Short Sensory Profile in your assessment of a child with FASD?
12. What is your experience with using the Short Sensory Profile versus the longer version of the Sensory Profile?

13. Why have you chosen (not) to use the SSP?
14. What do you like about using the Short Sensory Profile?
15. What do you dislike about using the Short Sensory Profile?
16. What do you think is the one main strength of the Short Sensory Profile?
17. What do you think is the one main weakness of the Short Sensory Profile?
18. Tell me how you find using the Short Sensory Profile specifically in FASD assessments.
19. Do you find any differences in using the Short Sensory Profile for FASD assessments compared to other populations (if applicable to your caseload)?
20. Do you find the Short Sensory Profile easy to use for the parent or caregiver answering the questionnaire?
Probe: Do you feel that you often need to explain certain questions?
21. Do you have any ideas that would make using the Short Sensory Profile better?
22. How do you find the quality of questions on the SSP?
23. What do you think of the amount of time it takes to complete a SSP?
24. Have you found it necessary to review the SSP verbally with parents/caregivers?
How do you do that?
25. How do you find the scoring process of the Short Sensory Profile? Probe: Time, Ease of Use
26. Do you feel that the information you obtain from this assessment is useful for diagnosis?
27. In what way is the information you obtain from this assessment is useful for intervention?
28. When assessing sensory processing, do you use any other techniques besides the Short Sensory Profile?
29. What information do you get from these other techniques that you can't obtain through the Short Sensory Profile?
30. Do you have any ethical concerns with using the SSP for FASD diagnostic assessments?
31. Is there anything else you would like to mention about using the Short Sensory Profile with children who have a FASD?

Researcher's Conclusion: Do you have any questions that have not already come up during the interview? (Answer questions) Thank you very much for your time and participation in this study. If at any time, you wish to withdraw consent, please contact me or my supervisor at Dalhousie University, Joan Versnel, to initiate this process. I would also like to confirm your address for when the results of this study are available. Thanks once again and have a great day.

Appendix Four - Transcriptionist Confidentiality Agreement

Study Title: What are the perceptions of occupational therapists who use the Short Sensory Profile (SSP) in assessments for diagnosis of Fetal Alcohol Spectrum Disorders (FASD)?

1. Confidential Information

The ‘Perceptions of OTs who use the SSP in ax and dx of FASD’ study hereby confirms that it will disclose certain of its confidential and proprietary information to interview transcriptionist, _____.

Confidential information shall include all data, materials, products, technology, computer programs, specifications, manuals, software and other information disclosed or submitted, orally, in writing, or by any other media.

2. Obligations of Transcriptionist

I, _____, hereby agree that the confidential ‘Perceptions of OTs who use the SSP in ax and dx of FASD’ study and is to be used solely for the purposes of said study.

I, _____, hereby agree not to disclose, publish or otherwise reveal any of the confidential information received from Cynthia Bojkovsky, the Principal Investigator of the project.

Materials containing confidential information must be stored in a safe location so as to avoid third persons unrelated to the project to access said materials. Confidential Information shall not be duplicated except for the purposes of this Agreement.

3. Completion of the Work

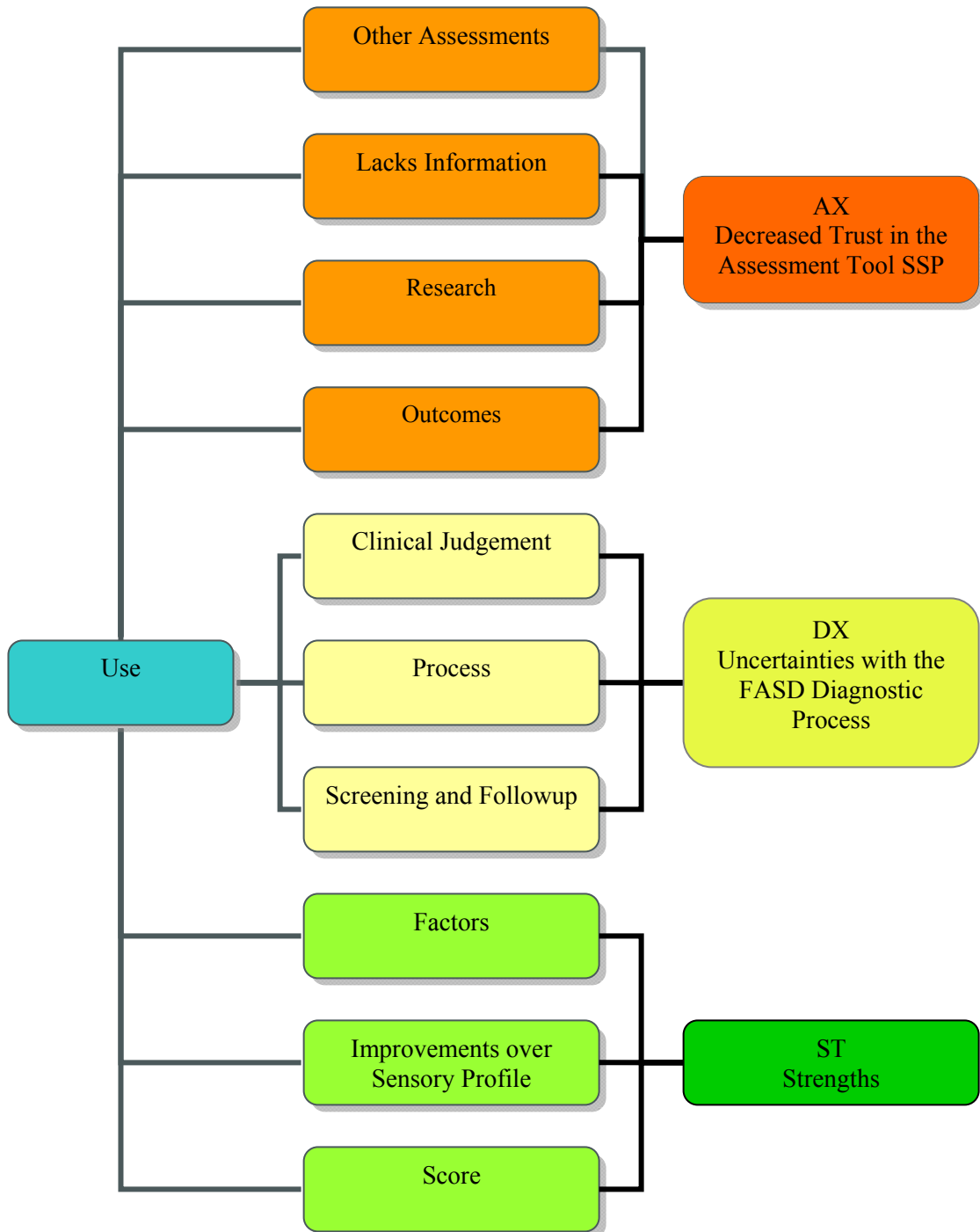
Upon the completion of the work and at the request of Cynthia Bojkovsky, Principal Investigator, I, _____, shall return all confidential information received in written or tangible form, including copies, or reproductions or other media containing such confidential information, within ten (10) days of such request.

Signature

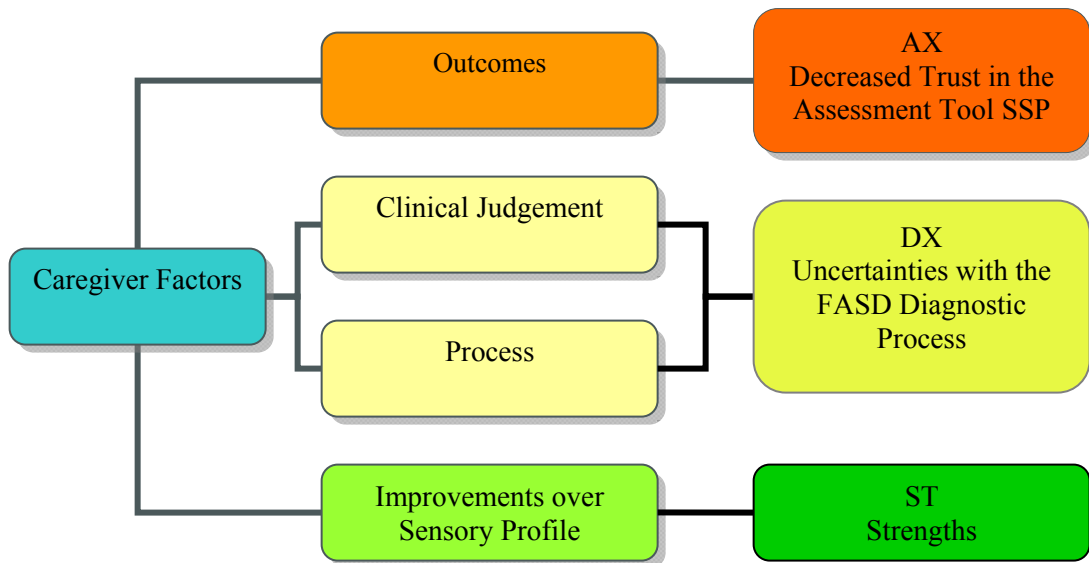
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Appendix Five: Flow Chart of Data Analysis: Codes – Subthemes - Themes

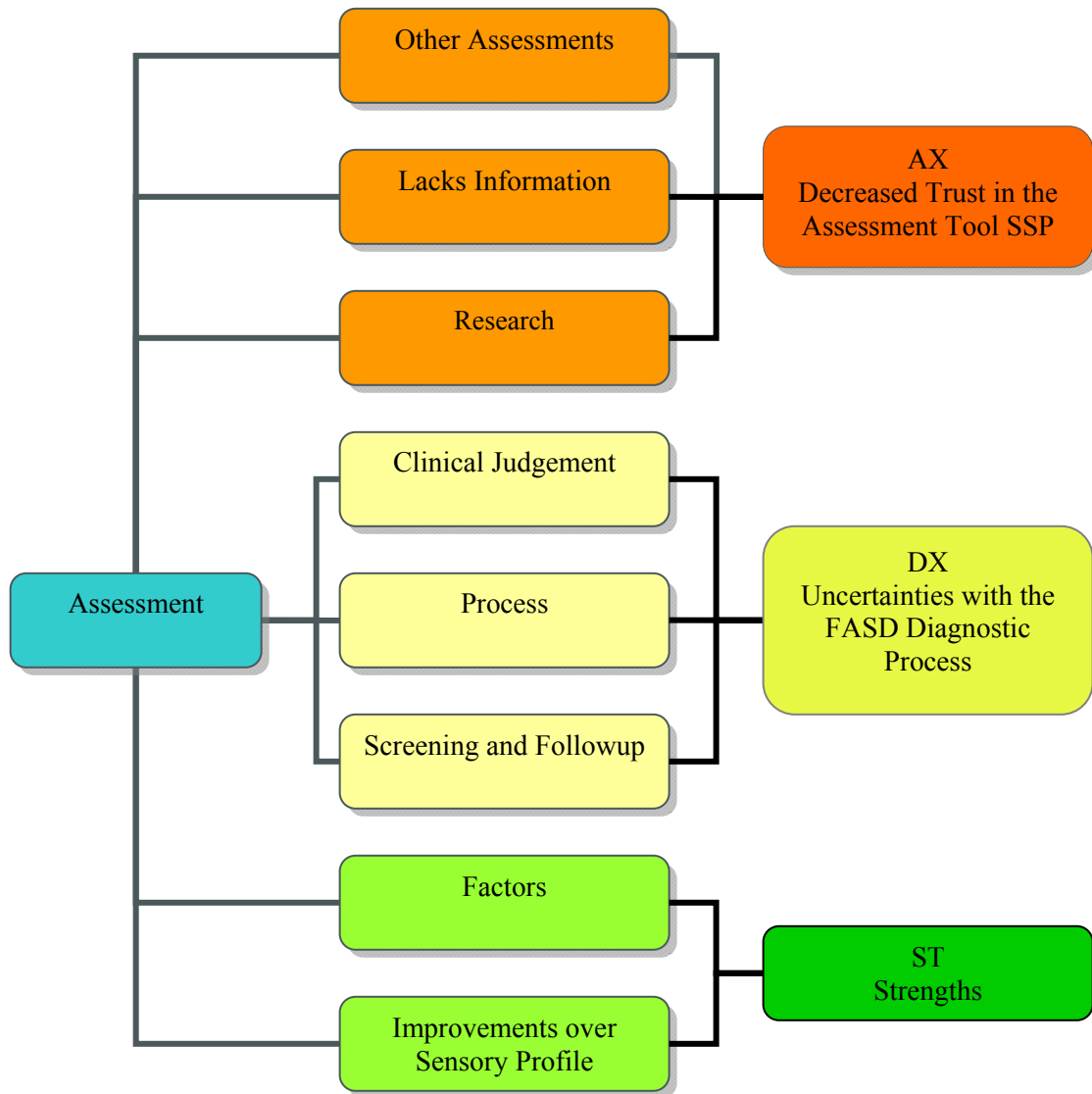
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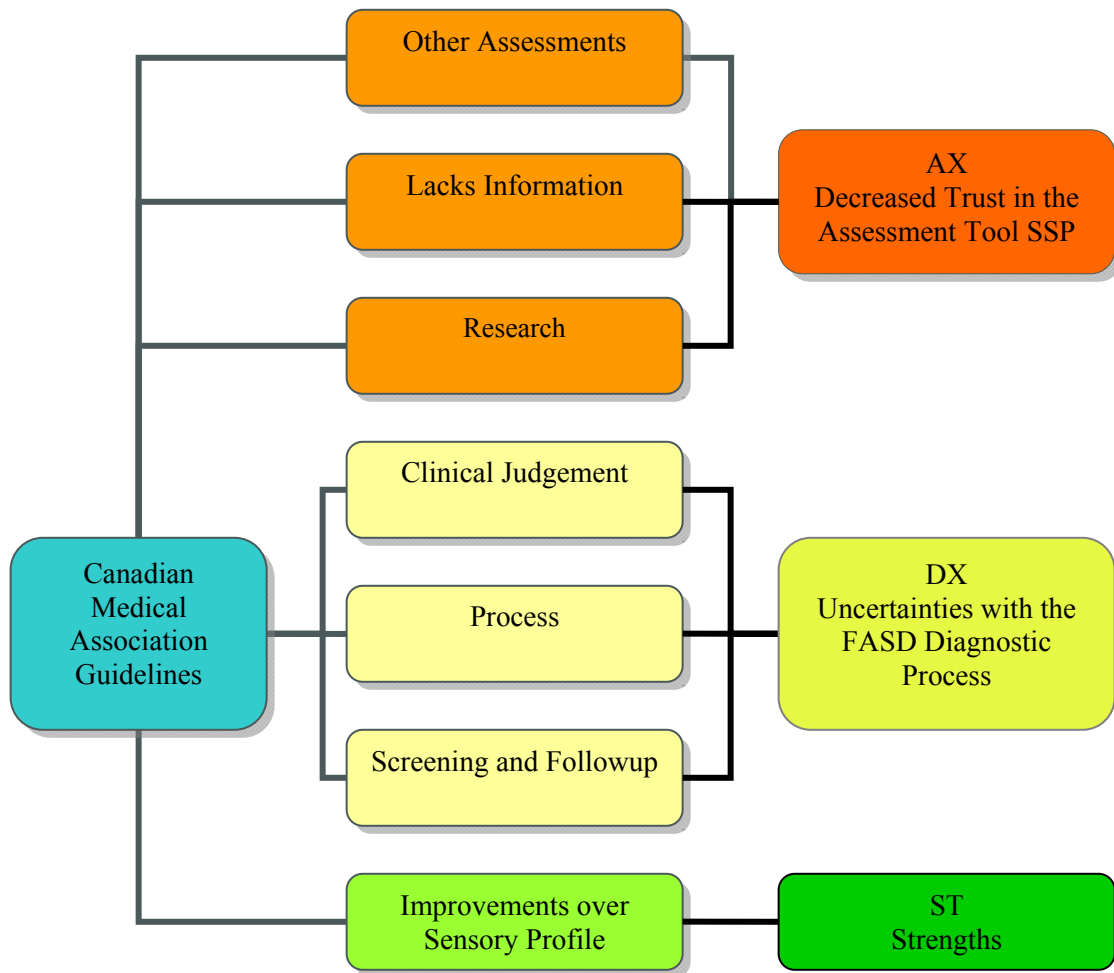
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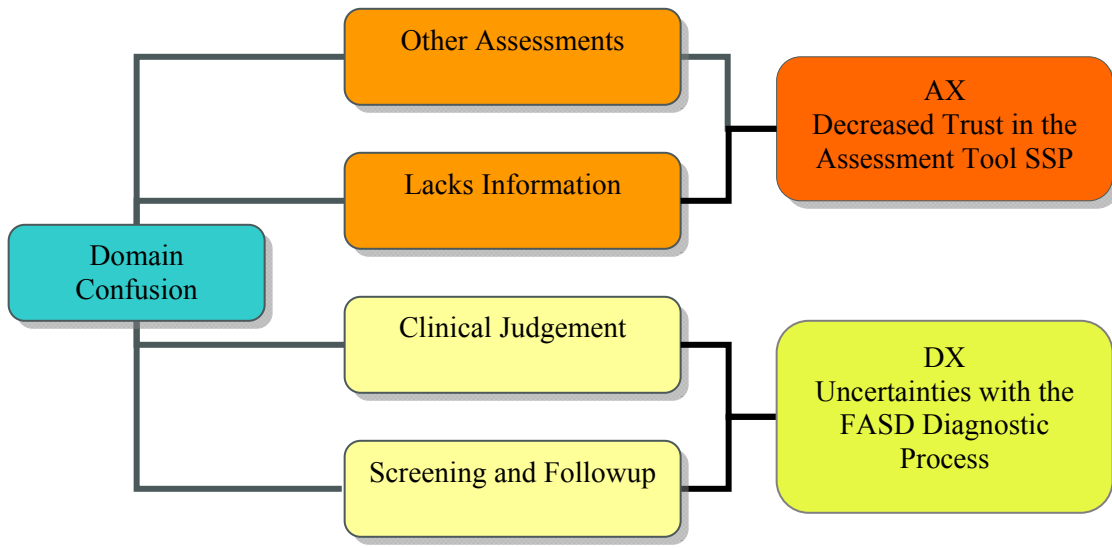
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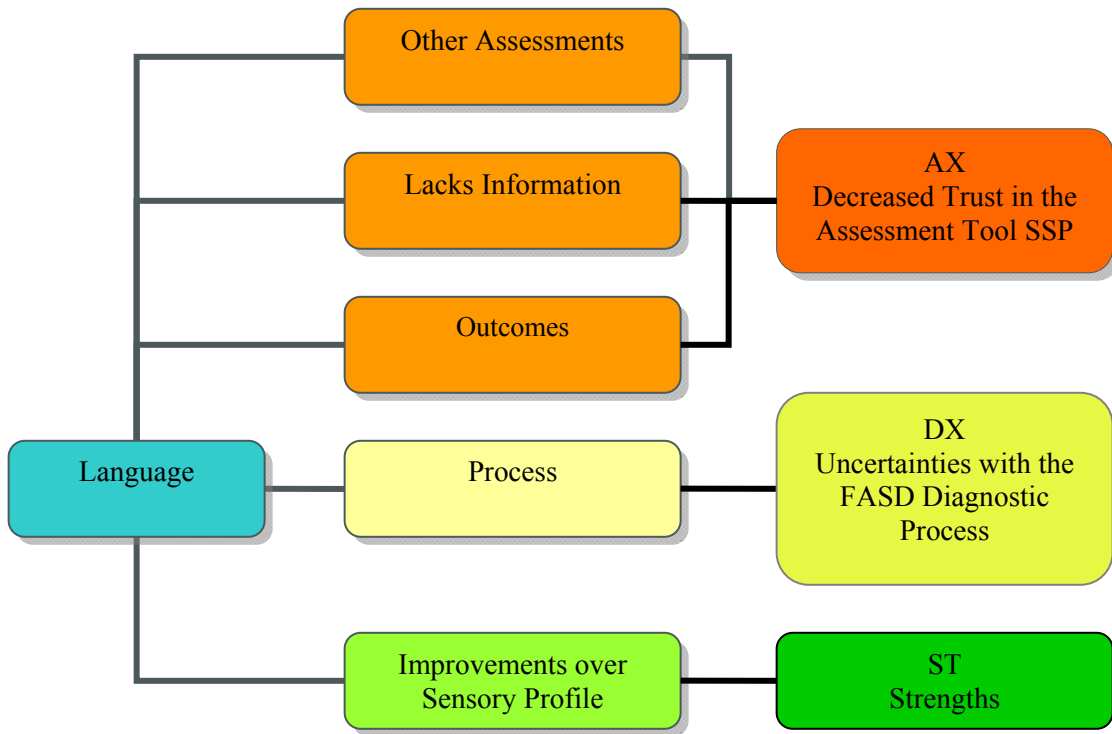
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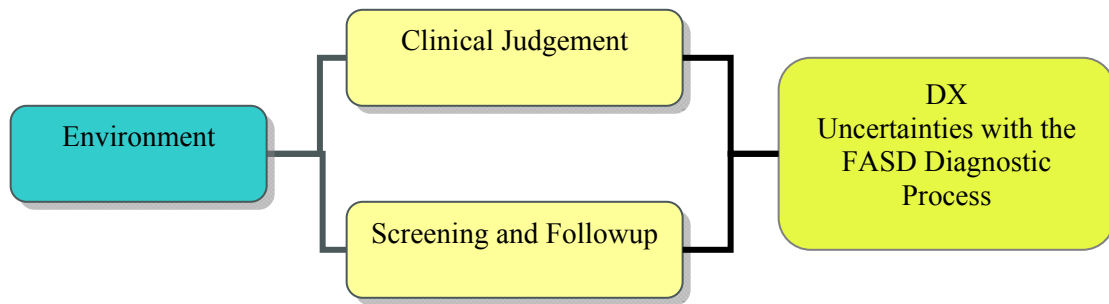
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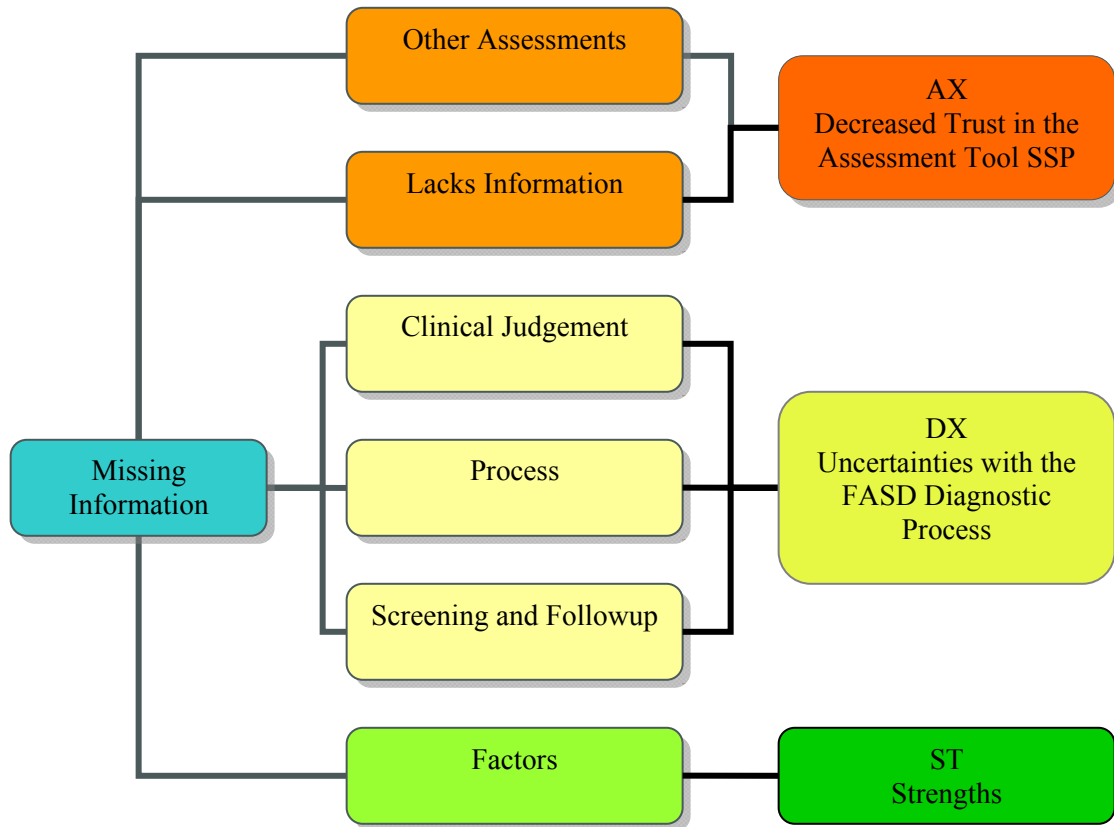
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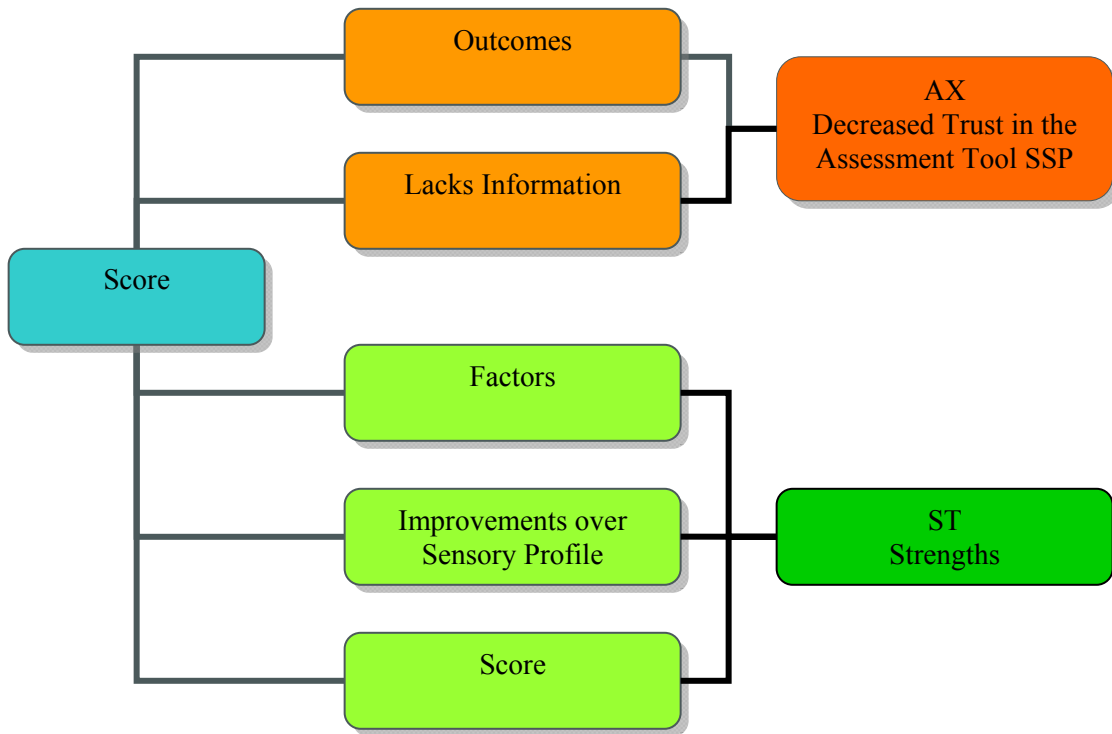
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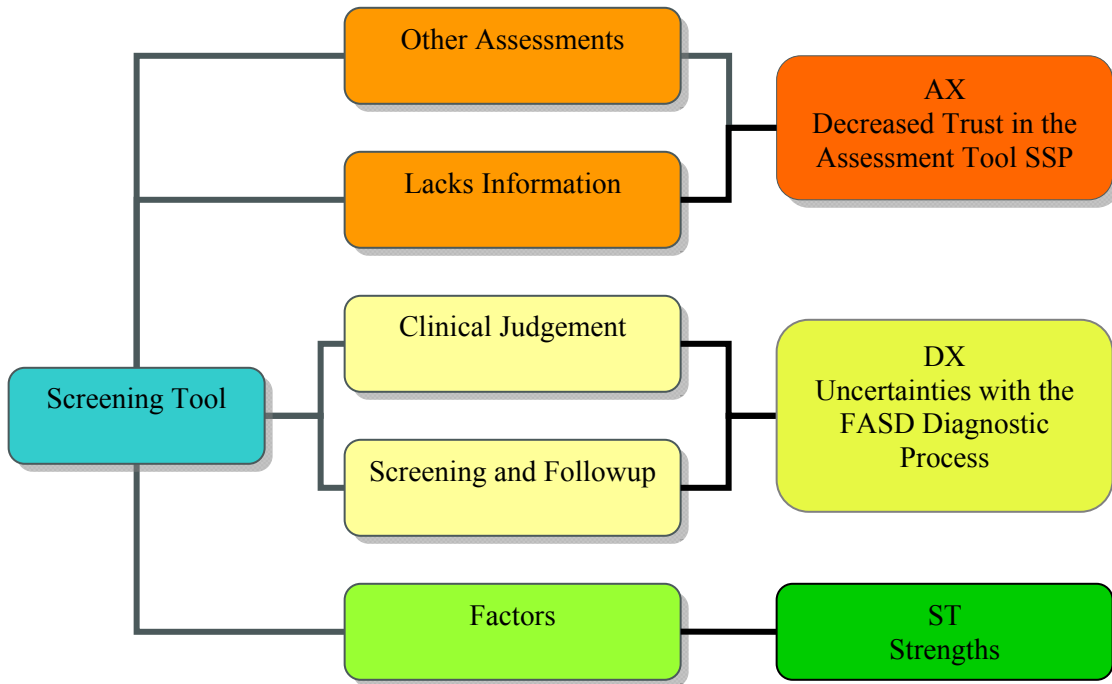
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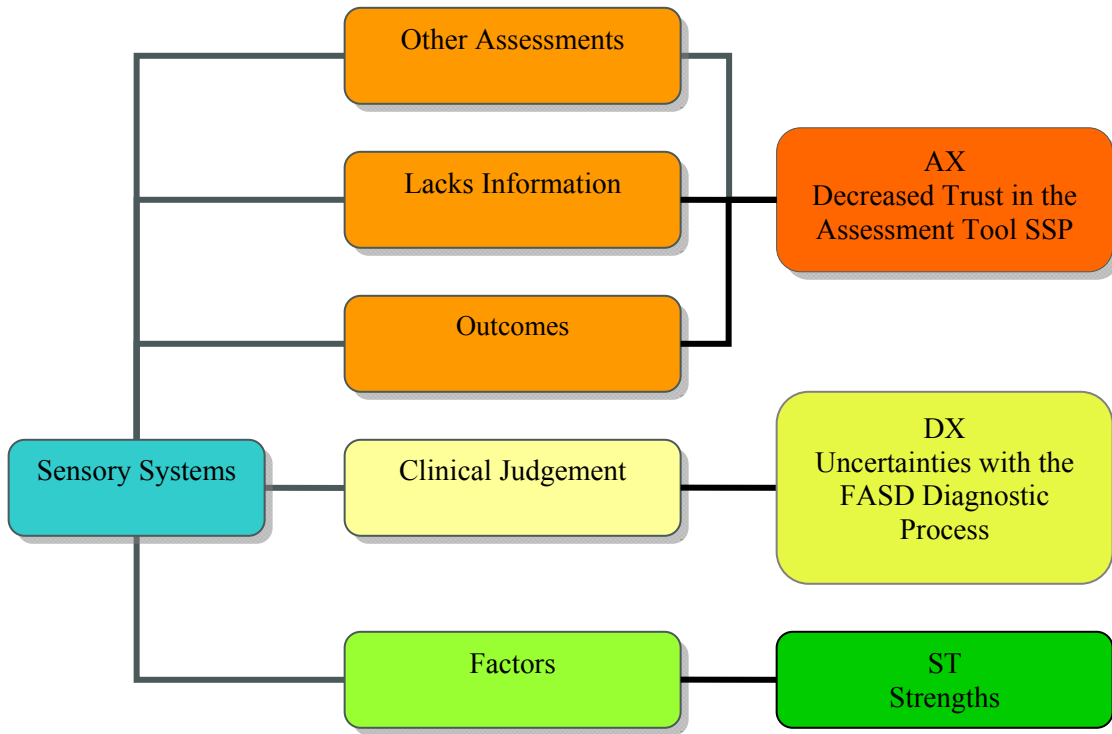
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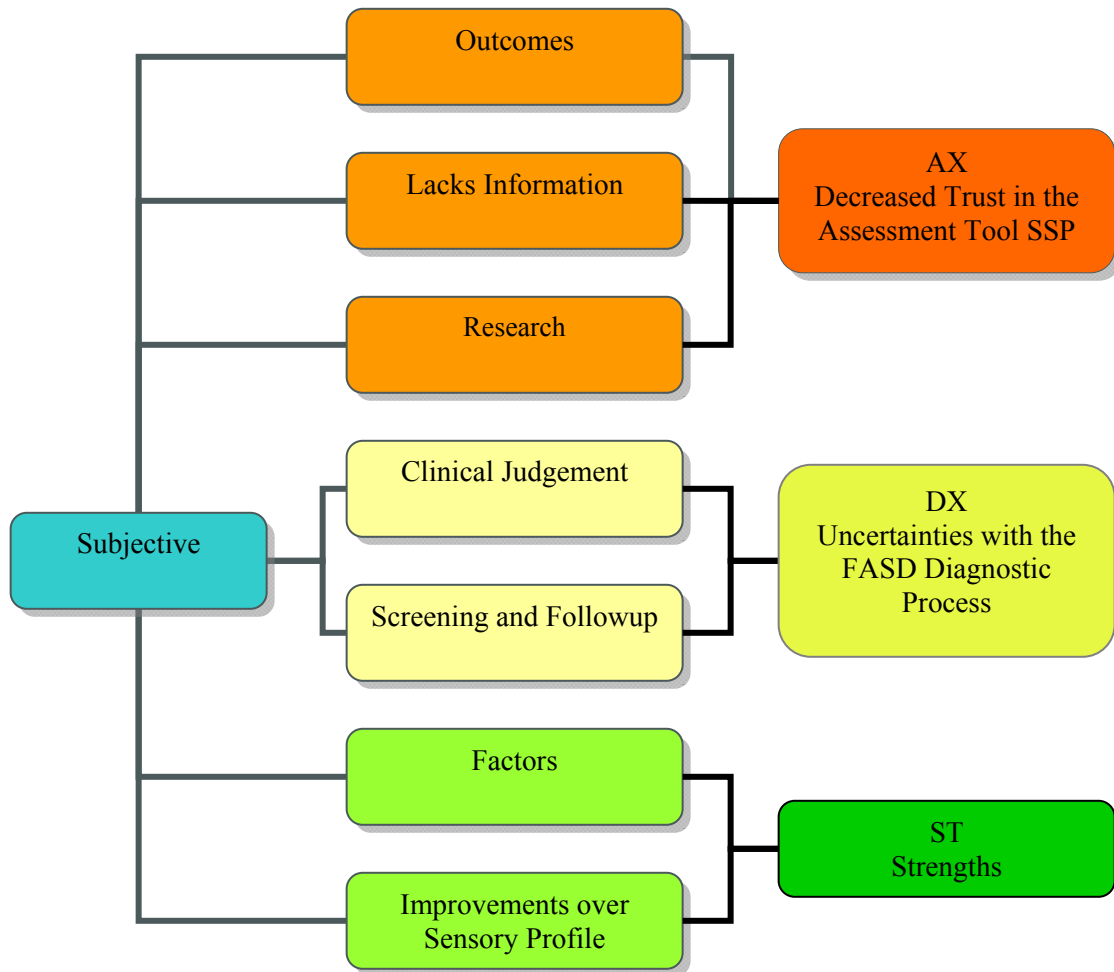
Code: Screening Tool



Code: Sensory Systems



Code: Subjective



Code: Time

