

EVIDENCE-BASED PRACTICE GUIDELINES FOR FETAL ALCOHOL SPECTRUM DISORDER AND LITERACY AND LEARNING

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Evidence-based Practice Guidelines for Fetal Alcohol Spectrum Disorder (FASD) and Literacy and Learning are derived from an inductive analysis of qualitative data collected in field research. FASD is the umbrella term for a spectrum of neurocognitive and physical disabilities caused by prenatal exposure to alcohol. Data from a sample of N=150 was collected using sharing circles with Aboriginal elders and community members; conversational interviews with parents and their children with FASD; and interviews and focus groups with professionals who support children with FASD and their families. Special protocols were followed in collaboratively planning and participating in research involving Aboriginal communities. Aboriginal research methodologies utilized are situated among emerging, multi-disciplinary, qualitative research methodologies suitable for understanding the complexity of natural phenomena such as FASD. The goal of dissemination is to further translation of research findings regarding evidence-based guidelines for FASD to the clinical or practice levels, across disciplines and sectors, as well as across the life cycle, in order to prevent adverse life outcomes.

Introduction

The current qualitative research study explored the impact of Fetal Alcohol Spectrum Disorder (FASD) on the lives of individuals with FASD, families, caregivers, elders, professionals and communities. FASD refers to a range of diagnoses for physical, cognitive and neurobehavioral disorders that can result from prenatal alcohol exposure (PAE). FASD is an umbrella term for various diagnoses including fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) and alcohol related neurodevelopmental disorder (ARND) (Chudley et al., 2005). The present qualitative research study focussed on what practices and approaches worked well for individuals with FASD, their families and caregivers. The research was undertaken in partnership with elders, Aboriginal communities, and a parent led FASD Support Group, in compliance with the *CIHR Guidelines for Health Research Involving Aboriginal People* (Canadian Institutes of Health Research, 2008). The research is an attempt to address the gap in formulating an FASD and Holistic Literacy and Learning framework, useful as guidelines for effective practice across disciplines and sectors, as well as across the life cycle. Six interrelated themes constituting *FASD and Literacy and Learning Practice Guidelines* emerged from an inductive analysis of participants' transcribed interview data, as well as field notes, informed by the literature review and the researcher's experiences with children diagnosed with a condition within FASD, including her three adopted children who have diagnoses within FASD. The interviews or discussions took place in Aboriginal sharing circles, family groups, professional focus groups or individual interviews.

Method

Participants

The Social Sciences and Humanities Research Council (SSHRC) funded a three year project (with a two year extension) for a qualitative research study of literacy and learning needs of individuals with FASD. Although no national prevalence data is available for Canada, FASD comprises 2-5% of the school-age population of younger children in United States and some western European countries (May et al., 2009). Participants and key informants for the current study were recruited through calls distributed by community partners, such as the FASD Support Network of Saskatchewan at its various conferences, workshops and other events, or on its web-site, as well as through a First Nations tribal council and a Métis federation. In order to protect anonymity, participants were asked to contact the researcher

directly and accordingly researcher contact information was provided in the notices. Each community partner provided a letter of support for the research, as well as negotiating and signing a research partnership agreement. The community partners, particularly elders from the tribal council, were active participants in the design of the research methodology and in the conduct of the research. Elders were insistent in wanting qualitative, not quantitative research data, as they felt the latter might further stigmatize their children. Therefore, a quantitative approach was to be used only for global numbers, but was to be avoided for individual cells for the themes arising from data analysis. Such an approach is in compliance with *CIHR Guidelines (Ibid.)* requiring both community and individual consent, and respect for Aboriginal protocols, including a preference for a qualitative, participatory research.

Of the individuals interviewed in sharing circles, focus groups, or conversational interviews, although there is some overlap among categories which is corrected for in the total number of active participants, the group tallies are as follows: 13 adults with FASD ages 19 to 30 years; nine children with FASD, ages several months to 18 years, present at the interview with parent(s), mentors or in a family group; 16 parents or caregivers of individuals with FASD, five of whom are also individuals with FASD, that is the condition was intergenerational (note that 10 children with FASD were discussed by these parents, but were not present at the interviews); nine mentors of individuals with FASD including two court workers; four teacher-educators; two lawyers; four medical doctors; four occupational therapists (two also being parents of children with FASD); four FASD researchers (two also being parents of children with FASD); one Director of an inner city supported housing complex, onsite, who supervised 67 high-risk residents, many of whom had FASD or other co-occurring behavior problems including mental health and addiction issues; and one Director of a downtown, drop-in youth centre on-site, which also provided home-style, supported housing for 40 young women ages 12-18 years who were at risk of being victimized in the sex trade, both facilities including individuals with FASD.

Focus groups and circles were organized by respective governing bodies or delegated to administrative personnel, including a focus group of seven who worked as an interdisciplinary, professional health team to assess, diagnose, and provide supports to children with FASD in a northern Saskatchewan health district. After discussion and planning meetings with the Director of Justice, as well as the General Manager of Services at an urban tribal council, a two-day circle of 19 First Nations elders was held at the tribal council's board room. This circle of elders further led to a two-day circle comprised of four elders, 10 parents of children with FASD, as well as three individuals with FASD, at the White Buffalo Youth Lodge, an inner city venue which was accessible to families and more conducive to protecting their identity and privacy than the tribal council's board room. Following discussions and meetings with the President of an urban Métis federation and the Director of a Métis health and wellness centre, a two day circle was held at the health and wellness centre. The participants in the circle included seven Métis elders, seven FASD mentors, and an adult, male client with FASD.

Subsequent to a half-day meeting and interview with a Justice Coordinator of a rural First Nations, a one day Circle of 27 community members of a remote, rural reserve, two of whom were elders, was attended, with a representative of the Ministry of Justice participating, as well as the Justice Coordinator who acted as facilitator.

Four Elders played a further leading role in meeting individually or in pairs with the researcher in order to advise, plan and facilitate the various circles. When two day circles were held, one was a follow-up circle held a few months after the initial circle, to review the results of the first circle and to communicate further. The conversational interviews generally lasted up to two hours; however, the sharing circles took place over several days, the focus group one-half day, and the community group, one day. Overall, a considerable degree of gender balance was maintained in the various categories comprising the active participants in the interviews, sharing circles and focus group. A global N = 150 for active participants was arrived at by correcting for any overlap among the categories by not counting participants twice if they fit more than one category. Please refer to Table 1, Participants in Research by Category.

Most of the participants were from Western Canada (130), with a contingent from the Eastern Canada (four), as well as a global component of participants from United States (six), Australia (one), New Zealand (one), and South Africa (eight) as part of a planned research visit to South Africa, the country with the highest measured prevalence of FASD.

The goal of the research was to gather experiential data observing participants and their children in their natural surroundings (as opposed to a laboratory or clinic) and through open-ended conversational

interviews, focus groups or sharing circles to elicit participants' first hand experiences, including what practices and approaches worked and did not work for them in relation to FASD and literacy and learning across sectors and the life span.

Table 1: Participants in Research by Category

<u>Category of Participants</u>	<u>Number of Participants</u>	<u>Overlap Among Categories</u>	<u>Net Total Tally</u>
Adults with FASD	13		13
Children with FASD	9		9
Parents of children with FASD	16	5	11
FASD Mentors	9		9
Teacher-Educators	4		4
Lawyers	2		2
Medical Doctors	4		4
Occupational Therapists	4	2	2
FASD Researchers	4	2	2
Directors/Officials	7		7
Professional Diagnostic Team Focus Group	7		7

Circle Participants

Métis elders + 7 FASD mentors + 1 adult with FAS	15
1 Facilitator + 1 Justice official + 27 community members, 2 of whom are elders, at a remote reserve	29
4 First Nations elders + 10 parents + 3 individuals with FASD	17
19 First Nations Elder	19
TOTAL PARTICIPANTS	150

Data Collection

Conversational interviews, focus groups and sharing circles.

The present researcher established a relationship of trust with the community partners, elders, individuals with FASD, families, caregivers, professionals and service providers before they consented to participate in the conversational interviews, focus groups, sharing circles or field notes. Conversational interviews were employed with individuals diagnosed with an FASD and their families; a focus group was used with an interdisciplinary diagnostic and treatment team; and two-day long sharing circles were the choice of elders who, in turn, convened and facilitated such circles with parents and individuals with FASD whom they invited. Following First Nations protocols, gifts of tobacco, coloured cloth, prayer, smudging, or a pipe ceremony commenced the sharing circles. Elders gave advice and prior approval about questions to be discussed at the circles and notes of the proceedings were recorded with coloured markers on large, mounted experience charts for all participants to see. Notes could be corrected in real time if they did not represent what the circle participants had intended to share. Interviews and focus group sessions were audiotaped and transcribed for approval by participants, while elders' sharing circle notes were transcribed and printed for their distribution and approval.

A community group met on a remote, rural reserve in Saskatchewan, as a follow-up to a sentencing circle. Twenty-seven participants attended the full day circle, lunch was served, and notes of the proceedings were recorded by hand and then transcribed and approved.

Observations and field notes.

A morning was spent in an urban, inner-city school which operated two dedicated FASD classrooms. The researcher observed two teachers, two educational assistants and 15 students going about their daily routine of teaching and learning, including interactions among and between teachers and students in the environments of specialized primary and intermediate classrooms, as well as a music room. There were nine students present in the intermediate classroom and six in attendance in the primary classroom, as well as a teacher and teacher aides or helpers in both classrooms. All students in the dedicated classrooms had diagnoses within FASD. Aboriginal children comprised 95-98% of the students in the school, along with a complement of immigrant and refugee children. In addition, a meeting was held

with the principal to discuss the FASD dedicated program and to clarify any queries. A support team consisting of a psychologist, social worker, occupational therapist and speech and language pathologist was available to support the teachers and students in the FASD dedicated program. Field notes of the visit were recorded by hand and then transcribed.

The 20 subjects observed or consulted in the school, but not interviewed either individually or in a group forum, were not included in the participant tally of N = 150 for the conversational interviews, focus groups, or sharing circles, but are in addition to that.

Data Analysis

The data consists of qualitative data collected through observation and direct experience gathered during conversational interviews, focus groups, sharing circles and field notes. Transcribed data from these sources was then coded, collated and grouped into interrelated, recurring themes and patterns as discerned by the current researcher through an inductive process. The method of constant comparison was used to compare new data to be sorted with existing data and categories to approach a best fit when selecting, merging and refining coding categories or themes and in making connections between them. Data triangulation assisted in validating the categories or themes by comparison to related data derived across the data-collection spectrum (e.g. various interviews, focus groups, sharing circles and field notes) (Cohen et al., 2007). Such multiple data collection strategies lend legitimacy to research because when data from multiple sources are triangulated, validity and reliability of results increases (Kanu, 2002). Induction *per se* is the scientific process of deriving general principles, theories, themes, models or frameworks from a large array of data, informed by the researcher's knowledge and understandings of the data and field of study. In order to ensure consistency, only one researcher, the current researcher, analyzed, coded and collated all the data into six inductively derived themes which function as *FASD Literacy and Learning Practice Guidelines*. As noted by Wilkinson (2000) the number of categories or themes which inductively emerge from data depends on a number of variables, such as the amount of data collected and the breadth of views it contains, as well as whether only a broad view or a more detailed picture of the complexity inherent in the phenomenon the data represents is required. The complexity and diversity of the effects of FASD on learning and behaviour, and the implications of that complexity for instructional planning for the individual learner with FASD have been well documented (Kalberg et al., 2006; Ryan, 2006; Ryan et al., 2006; Bredburg, 2010; Koren et al., 2010; Mitten, 2011).

Results and Interpretation

Six inductively derived themes (along with a number of sub-themes) collectively termed *FASD Literacy and Learning Practice Guidelines* emerged from an inductive data analysis which was informed by the researcher's background knowledge, research and experience with individuals with FASD, including being a parent of three children with FASD.

Theme 1: Multi-modal Learning

Multi-modal learning involves as many senses as possible, as well as a variety of modes and media (Jewitt & Kress, 2003; New London Group, 1996). Multimodal, holistic approaches to learning engage and stimulate children, accommodating their learning styles, whether visual (images, page or screen), auditory (music, speech, noise and other sounds), spatial (three dimensional), kinesthetic (movement) or multimodal (involving more than one sense modality), rather than relying mainly on didactic oral or textual modes. For children with FASD, visual, spatial or kinesthetic stimulation may be particularly important to activate certain parts of the brain to find or generate new, alternate neural pathways to replace those damaged by prenatal exposure to alcohol. The latter process is termed neuroplasticity of the brain (Kolb et al., 2003).

In the opinion of a teacher-educator interviewed, flash cards, workbooks and commercial tests do not assist very much with diagnosing and developing engaging literacy programming for children with FASD. What does work is qualitatively observing and listening to children as they read, to determine the metacognitive strategies they use, and particularly the approximations or miscues they make as they read. Miscues are the exciting, teachable moments that occur when a learner is challenged to progress to the next step in learning. Miscues illustrate the learner's zone of proximal development, as coined by Vygotsky (1962) and should not be coded as errors or mistakes. Rather these are approximations learners make as their reading strategies progress. Teachers can model metacognitive skills for students at these critical points, using problem solving self-talk through which students can learn to make their own meaning of the text. For instance, in response to miscues, the teacher educator interviewed

recommended responding *Good try, you're using a strategy, or you're a problem-solver. Can you suggest what else the word or meaning could be?*

As the English language does not make phonetic sense consistently (Smith, 2003), children must learn to read using a variety of complementary strategies to include cues related to the context and structure of the story, such as visual cues presented in the story, and the child's own background knowledge, culture and vocabulary. A study in the Western Cape of South Africa provides supporting evidence for Smith's contention that phonics alone is not sufficient in learning to read. After nine months of treatment and training one hour a week on phonological awareness, a group of children with FASD aged 9- 10 years in their third formal year of schooling improved in tests of phoneme knowledge and pre-literacy skills compared to an age- matched control group with FASD who received no such training. However, their reading scores and other general scholastic tests dependent on reading skills did not improve significantly in comparison to the control group (Adnams et al., 2007) as Smith would have predicted.

According to Gardner (1993) there are multiple intelligences, including but not limited to linguistic, mathematical, musical, kinesthetic, spatial and interpersonal intelligences, all of which need to be recognized in learning. In the opinion of the teacher-educator interviewed, learning must be multi-sensory and include visual arts, practical and applied arts, apprenticeships, physical activity, outdoor activities, adventures and field trips, social interactions and other forms of experiential learning, in addition to the conventional text-centered and oral or language-centered processes.

Engagement, demonstration and immersion are key conditions for learning (Cambourne, c1988). According to the teacher-educator, the first step is to engage learners with demonstrations, field trips, concrete visuals and artifacts. Otherwise, it is unlikely that learning will be set in motion, especially for children with FASD, Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD). Picture-walks through a storybook before reading the story can engage the child. Drawing before, during and after reading can scaffold memory, sequencing and meaning making. Accompanying text can be added to students' drawings, with the help of the teacher if necessary or by reference to a word wall, to describe what is happening in these series of drawings, creating a storyboard. A word wall is an organized collection of frequently used words prominently displayed in the classroom. It is an interactive tool for teaching reading, writing and spelling to children as they can refer to the word wall when trying to compose their own text, as on a storyboard. Storyboards are graphic organizers which utilize a series of illustrations or images displayed in sequence to tell a story, while text is added to supplement the images.

Experiential Learning.

John Dewey (1938) recognized the intimate relationship between experience and learning, and the need for teachers to actively construct interactive processes involving hands-on, experiential learning for students, as well as through social interaction with teachers and peers. For instance it is best to learn mathematical relationships, $3 + 3 = 2 + 2 + 2$, concepts like number, length, quantity and volume, through making muffins, or playing in the sandbox, than through flash cards, workbooks or computer drills. Moreover, through stories or play, children learn self-restraint, taking turns, collaboration and cooperation. Brain development is varied and stretches out for a long time so children should not be hurried nor discouraged (Wolf, 2007). They learn best through being active, not passive, through integrated learning that is social, creative and innovative. The natural trajectory of experiential learning is trans-disciplinary or interdisciplinary inquiry, the making of connections rather than fragmentations, building meaning, acquiring self-regulation through flexible pacing, which is especially important for those with FASD who have slower auditory processing speeds as well as requiring more time for memory retrieval (Shanker, 2010, and Shanker & al., 2012).

An adoptive mother of a son diagnosed with FAS, (age 4.5 years when adopted, age 18 at time of interview) and a daughter diagnosed with pFAS, (age 27 months at the time of adoption and age 15 years at time of interview) was interviewed. The mother was a key informant, as not only was she the adoptive mother of two children who had diagnoses within FASD, but she was also an occupational therapist working in early childhood special education. In fact, both adopted parents in this case were very active in engaging their children in various family and community literacy and learning experiences, such as visits to a children's museum for hands on learning experiences from an early age (weighing and measuring items, motion and speed activities, mixing colors, obstacle courses involving motor planning, experimenting with textures, cutting, colouring, pasting and creating) as well as re-enacting certain historical events using period costumes and props. In the home they measured food and liquid items and

read recipes when helping their parents in the kitchen; helped to build tree forts at the cottage; took trumpet and piano lessons, as well as Tae Kwon Do; engaged in many art activities using a wide variety of media; and worked with their father in his workshop, measuring, sawing, painting and making things, and taking care of the cars. Through these activities they learned functional math, reading, music and motor skills as well as basic mechanics and construction. However, the adoptive mother cautioned about the need for on-going supervision during experiential learning for children with FASD, because they do not understand boundaries as evidenced when her children started experimenting with cell phones. Problems ensued, including incurring large telephone bills as well as getting onto trouble with the law.

Participants in the elders and parents circle noted that individuals with FASD are *hands-on* learners, that is, they learn by watching and doing. Traditionally this was accomplished by working side by side with a parent, grandparent or other family member. Individuals with FASD like culturally relevant activities such as sewing, beading, and learning how to make moss bags which are traditional baby carriers. Sports are important as individuals with FASD function better when physically active, and, additionally, sports have built in reward systems to motivate them. Playing on a team and team sports are important for them. By watching and doing, they learn how to be team players, how to do things together, how to make friends, and how to follow rules, so that they can gradually come to cope with these important social skills. They don't learn these things if they are excluded. They also learn from puzzles and board games, if done together as a family in an intergenerational group. Again, they watch and do, and learn sharing, rules of the games, social skills, manual skills, spatial perception, organization and communication skills. Family activities also facilitate emotional attachment and bonding, which can be lacking in children with FASD, particularly if they have experienced multiple placements.

Holistic language and literacy approach to integrating drawing and other visuals with storytelling, reading and writing.

Holistic language and literacy approaches view notions of reading and oracy as components of an overall process of language development; they view children as natural, active learners as they develop their own conceptualizations of the world and learn language. Children do not learn alone, but rather in a social context of family, community, peers and teachers, whether in play, on a field trip, or in a didactic setting. Just as they learn language through hearing it and using it, through conversation, storytelling and narrative, similarly they learn to read through being read to and through reading itself, in a kind of transaction among reader, text and language. An instructional approach recommended by the teacher-educator interviewed is one of stimulating meaningful experiences through play, activity, story, or field trip, then drawing a picture of the experience, and telling a story based on the picture, followed by writing (or printing) the story, at first with the teacher's assistance, and finally reading aloud the story they have written, while utilizing cues from the picture they have drawn. In addition to visual cues, they also make use of vocabulary, semantic and syntactic cues, as well as phonics. For a longer story, they could draw a series of pictures, illustrating beginning, middle and end of the story, and inscribe a story underneath each picture, forming a storyboard. For children with FASD, this method can scaffold deficits in memory, attention, sequencing, processing speed (encoding and decoding) and comprehension. The key is to begin with their strongest learning mode, usually visual learning, then progress to reading and writing in an integrated manner.

Alternatively, those who do not like to draw may enjoy finding pictures on the internet, printing them and using them in their stories. A teacher-educator interviewed had a group of boys with FASD she taught who liked to find pictures of vehicles from the internet to use in their storyboards, their favorites being about motor bikes and monster trucks.

Theme 2: Scaffolding Memory, Processing Speed and Sequencing Skills

Memory depends on neural pathways in the brain. The development of these networks or pathways in the brain is dynamic and flexible, constantly changing with experience and simulation, thus allowing the network to grow, strengthen, or to rewire itself if damaged. Neuroscientists term this phenomenon *plasticity of the brain* (Kolb et al., 2003.). A stimulating environment, including multi-modal and experiential learning, is important for building neural networks or pathways in the brain, including those damaged by prenatal alcohol exposure (PAE).

These complex neural networks are needed for the development of memory and abstract thought, but may be delayed in developing due to PAE. Moreover, thoughts need to be held in memory long enough to connect to one another, so that problem-solving and other executive functioning can occur. A sense of time, a temporal sense, is abstract, therefore sequencing or organizing memories in a sequential order of

steps, or identifying stages of a plot or a story (such as beginning, middle and end) may be challenging for learners with FASD who are largely concrete thinkers. Moreover, individuals with FASD may not be able to discern what needs to be done first, second and third to complete a task, such as when brushing one's teeth, getting ready for school, or the steps involved in reading a story, telling a story, or solving a mathematical problem. Visual anchor charts and lists of steps, or storyboards, may serve to sequence the steps and prompt memory. Generally, directions and instructions using visual cues and fewer and simpler words will be understood more readily by those with auditory processing delays characteristic of many individuals with FASD.

The key informant mother, special education teacher and occupational therapist related how she used magnetic picture lists for chores on the fridge door, with a *do* and a *done* column. Pictures of what was expected were in the *do* list, so the children could look at the picture list to see what needed to be done, do the task, and then move this picture to the *done* column, thus reducing frustration and power struggles. At school her daughter keeps a daily schedule book of homework which needs to be done and gets help to maintain this by a teacher aid and a social worker. She brings the book home, shows her mother each piece of work completed, and then her mother signs both the work and the homework book, and the child takes both back to school. The mother also makes a copy of the homework done, as the child has been forgetful about handing things in at school and then gets into trouble for not having it completed.

Theme 3: Sensory Integration and Self-Regulation

Certain pinpointed areas of the brain respond selectively to various types of stimuli, whether visual (sight), auditory (hearing), olfactory (smell), kinesthetic (physical movement), tactile (touch), proprioceptive (sense of one's position in space, vertical or horizontal) or vestibular (sense of balance). The brain has to respond to continuing feedback from all these senses. At birth, the brain is immature and integration of sensory input is not complete, but develops with maturity, although such immaturity persists in disabilities such as Autism Spectrum Disorder (ASD) and FASD. Individuals in which sensory integration is not complete may exhibit sensory defensiveness (an aversive response to stimuli), tactile defensiveness, an over- or under-responsiveness to stimuli, and a resulting inability to regulate arousal states or to control impulses. With proper control of stimuli, affected areas of the brain can mature and adapt and the brain can begin to function as an integrated, self-regulating whole (Ayres, 2005; and Shanker et al., 2012).

A First Nations woman interviewed who practices as an FASD mentor suggested various accommodations to better serve those with sensory integration issues in the classroom. These included using natural light rather than fluorescent lighting which constantly flickers, having fewer distracting displays and posters in the classroom, controlling for noise, having the student sit at the front near the teacher, and minimizing change in the classroom routine and seating arrangements. She stressed that it was important that a student with FASD be prepared ahead of time for any changes in classroom organization or routine so that the student could prepare for the transition and learn new cues required. Because individuals with FASD may have slower information processing speeds, one needs to be patient with them, and should not rush or overload them, otherwise one is setting them up for failure. She recommended only 10 to 15 minutes of homework a day because learners with FASD have to try harder to accomplish the same task as someone without a disability, and their brains tire from the increased effort. She further recommended only a few simple questions on a page, for instance, only three or four math problems that are plain and simple. Students with FASD will stay calmer and better able to perform whereas a page full of questions may be overwhelming. Oral testing is recommended to reduce anxiety and to ensure that they understand the questions, as well as open book testing to calm them and to scaffold their memory problems. If they do their work in the resource room, they should also be tested in the resource room, so that environmental cues and learning associations are the same in both cases, and they feel more relaxed in a familiar setting.

The adopted mother of a female student diagnosed with pFAS reported that her daughter, now age 16, was easily distracted in a busy environment. She learned to cope by using headphones to screen out noise, and special music which is calming to her. At school she takes her tests in a quiet area and does homework/assignments away from the noise of the classroom. She also pays better attention if she has something to fiddle with, so has fidgets to use at home and at school, such as squishy porcupine balls, and stretchy animals and bracelets. Fidgets need to be quiet and small to be permitted in school, but they are important as *calming crutches*. Gum or chewy candy provides oral stimulation which calms her daughter and helps focus her attention, but gum may not be allowed in schools. When engaged in

conversation her daughter flips from topic to topic and needs reminders to slow down her thoughts and speech. The adopted son in the family was diagnosed with FAS, and later with ADD. He was put on medication for a brief period of time. Medication did seem to help him focus better and pay more attention to detail, however when he became a runaway, *meds* were terminated as he was doing street drugs.

A First Nations adult male with FAS, living on his own, learned to shop at night when stores are less crowded, as he gets over-stimulated and panicky trying to function in crowds. He described the experience as trying to take in everything all at once and becoming overwhelmed. Because of his sensory integration issues, he avoids crowds, often stays at home or goes to his sister's place. Because his sister has children he stays downstairs out of the commotion, not because he is anti-social but as a defensive reaction against sensory over-stimulation. He had a job he liked working in a restaurant, but when management changed, the new management kept changing the work schedules, staffing and menu. He would confuse whether he worked Saturday from 7 to 12 or Sunday from 4 to 7, and other changes, and as a result lost his job, then his apartment, and was on the street again for a time, until he met his FASD mentor.

A First Nations adult male in his thirties with PAE, married, and father of a 13 year old girl, a three year old boy, and an infant of several months, told how he is very sensitive to certain sounds. For instance, when his baby cries, her cries are so high-pitched and piercing that he cannot stand it. Once he even punched a hole in the wall because it hurt so much. Now he and his family have a two-storey house, so he can go to the other floor to get away from the crying sound. His wife and mother-in-law also live in the home and they help to manage his extreme defensiveness to high-pitched sounds, and he also has an FASD mentor.

Occupational therapists interviewed recommended *How does your Engine Run*, also known as the Alert program, as a useful program for helping learners to recognize, visualize and think aloud about their sensory issues, emotions and attention levels, thereby learning to self-regulate (Williams et al., 1996). Using the engine analogy, children can learn to *rev up* their engines if they are feeling tired or sad, or *gear down* or put on the brakes if they are feeling hyperactive or angry. Alternatively, or in addition, they can put on earphones, close the blinds or dim the lighting, select a wiggle seat, or a fidget toy, select a carrel or individual office to put on top of their desk tops to screen out visual distractions, or move to a comfortable, quiet, enclosed space with low lighting within the classroom, such as a small playhouse or teepee for that purpose, or even pull themselves around on a coaster board if they need physical activity. Some classrooms have introduced stationary bicycles or mini-trampolines for students to use briefly as required, in order to re-set student's internal engines so that they can resume their work more effectively. A smaller, segregated FASD classroom where these approaches are normalized and actively supported and monitored by an occupational therapist, teacher and teacher assistants appears to be the most efficacious circumstance for learning sensory-integration and self-regulation without stigmatization. Although these approaches also have been used in integrated classrooms, it is more difficult to normalize them in integrated settings.

Theme 4: Attention and Related Issues

Deficits in attention have long been associated with prenatal alcohol exposure. In Streissguth's prospective, longitudinal study of 415 individuals having diagnoses within FASD, 61% of the children and adolescents had attention deficits (1996, 2002). Children with FASD display deficits in focusing, selecting, encoding, maintaining and shifting attention, as well as an increase in impulsive responding and sometimes hyperactivity (Burden et al, 2011). Thus, according to teachers interviewed it is important to engage children before beginning to read a story, give instructions, or teach a lesson, in order to make sure their attention is focused, and then use interesting, relevant, visual, tactile or kinesthetic stimuli to sustain attention. Prepare and cue them for transitions from one activity to another, or from one classroom to another, through the use of visual schedules and visual clocks. If impulsive blurting out is an issue, use a talking stick or similar concrete, tactile device that can be passed around to indicate when it is each child's turn to speak. Coloured tape to demarcate personal boundaries may be used so that they do not intrude unduly on another student's space, such as when lining up. Many of these techniques can be modified for use with adults who have a diagnosis within FASD and accompanying attention issues.

Individuals with ADHD have problems focusing and sustaining attention, whereas individuals with FASD have particular problems encoding and decoding information, as well as shifting their attention

from one task or activity to another. They require more time for tasks such as auditory processing which requires encoding and decoding, as well as assistance in making transitions (Coles et al., 1997). However, ADHD and FASD may be co-occurring conditions in the same individual, so such individuals may experience many or all of the above challenges.

In an interview with a birth mother of a son, John, who was diagnosed with FAS and appeared younger than his 17 years, it was noted that John had trouble concentrating, understanding boundaries, had a slower auditory processing speed (so one should speak more slowly with fewer words when communicating with him) and had trouble shifting his attention in order to make transitions. Although he has a normal IQ, because of his attention deficit he could not complete assignments at school and thus had homework to bring home every day. A year earlier he was charged with sexual touching on the playground when reaching out to catch a ball his arm accidentally touched an adjacent female student's breast. John was not sexualized and did not understand why what he did was wrong. His mother (a single Mom) called the police wanting a male role model to explain these issues to John. Instead of explaining to John, the police charged John with sexual touching. He was very traumatized by the resulting court processes, including five to eight court appearances, even to the point of regression by standing up and urinating on his bed. A judicial reprimand was the outcome of his guilty plea, the mildest sentencing alternative available to the judge. It is very difficult to prepare individuals with FASD for a court appearance, but a visit to the court room beforehand as well as role playing to rehearse court processes could have been utilized to assist in preparing John. Otherwise, his problems with attention, including the processes of encoding and decoding, might raise his anxiety levels and interfere with his comprehension and behavior.

Theme 5: Speech, Language, Communication and Social Skills

Children with FASD usually exhibit some degree of language disability, either a language deficit or delayed language development. They may have problems learning to produce certain sounds correctly, or may have fluency problems such as stuttering, making their speech more difficult to understand. They may develop language skills and acquisition at a slower rate, and may have immature vocabulary, grammar or syntax. For instance, they may have trouble putting words together to make a phrase or sentence. Often they know a word but cannot retrieve it from memory or may substitute another word from the same general category, like *sheep* for *goat*. Neurocognitive and hearing deficits, or dental and craniofacial anomalies such as cleft lip or palate may affect speech (Wyper et al., 2011), impacting on social and other life adjustments.

Expressive language skills exceed receptive language skills.

In individuals with FASD, expressive language skills (what they say) tend to exceed their receptive language skills (what they can understand and apply). A retrospective clinical chart review of over 100 children under the age of three years, with prenatal alcohol exposure (PAE), confirmed this gap, as well as confirming the delay in both receptive and expressive language skills for children with PAE compared to children without PAE (Proven, 2011). On the other hand, Wyper et al. (*Ibid.*) studying an older group of 27 children with FASD ages five to 13 years found no difference between receptive and expressive language skills in these children, although they were lower in both skills compared to 23 normally developing controls.

Language deficits may persist into adulthood. Individuals with FASD may be able to repeat or parrot back what a parent, teacher, employer, police officer or judge says to them, but not understand the substance of what was said, and thus not be able to follow instructions nor to comply with a court order. They may neither understand nor remember without the use of concrete, visual, hands-on experience or supervision. They may need to be *walked through* instructions in order to be able to comply, and if instructions involve being on time, catching a bus or getting to a correct address they may need special aids or a mentor to accompany them, according to court workers interviewed.

Communication skills can affect social, academic and employment adjustments. Due to problems with auditory processing, they may require considerably more time to respond to instructions or to questions posed, according to a psychologist interviewed. The danger is that they may be passed over by the teacher, employer, judge or lawyer if they don't respond initially. Using fewer and simpler words for them to sort out usually helps to alleviate the auditory processing difficulties. In addition, one should ask them to repeat what was said to them as a rough gauge of their comprehension, although comprehension does not always imply being able to remember and apply what was said.

They often have problems with social cognition and communication, best assessed through formal or informal narrative discourse analysis (Coggins, Timler et al., 2007; Coggins, Friet et al., 1998). Executive functioning, or problem solving deficits, are associated with deficits that children with FASD have with social processing and development of related language skills. Modeling, role-playing, coaching and discussion in real life situations are useful techniques for teaching social skills. In a dedicated FASD classroom observed, the teacher ate lunch with a group of five students all seated comfortably around a small, circular table. Each student would respond, in turn, to a simple, non-intrusive question and would be coached to make eye contact while responding and to listen carefully to other students' responses when their turn came to speak. The students were coached to use appropriate language and tone of voice, to adapt their body language to show respect and interest, and to use polite table manners. Due to deficits in social cognition, communication, memory and self-regulation, these individuals have difficulty using language in more sophisticated social contexts. They may lack the problem-solving skills and critical communication abilities required to enter peer groups, resolve conflicts, negotiate compromises, and maintain friendships and primary relationships. Modeling, role-playing, coaching and discussion in real life situations are useful teaching techniques for learning these social skills (Olswang, Coggins et al., 2007; Olswang, Swensson et al., Dec., 2010; O'Malley, 2007; Kully-Martens et al., 2012; and Stevens et al., 2012.).

Speech and language challenges.

Children with an FASD may have speech and language challenges, such as a language deficit or delayed language development, including problems learning to produce certain sounds correctly and fluently, resulting in speech which may be difficult to understand.

An interview was scheduled with a First Nations mother of two boys diagnosed with FAS, ages seven and nine years. When the researcher arrived at the family residence for the morning interview, a knock on the door resulted in two little boys' heads peeping out the door. The researcher told them that she had arranged to meet with their mother that morning. They indicated that their mother was asleep, pointed to the bedroom, and then eventually went and got their mother. The researcher could not understand the speech of either child very well, although they were very polite and friendly, and really wanted to communicate, they did so mainly through smiles and gestures supplementing their speech. The mother said that one had begun and the other was beginning speech therapy through the school. While they understood what was said to them, and knew what they wanted to say, they could not coordinate the movements of lips, jaws, and tongue to articulate and speak clearly.

Another parent interviewed said that her adopted daughter diagnosed with pFAS had received speech therapy for the previous three years. She described her as talkative, but as having *marble mouth* and said the therapy helped her slow down and improve her enunciation and clarity of speech. Sometimes there is poor articulation when the front teeth need to contact the tongue in a certain way, or the lips are to come together, to make various sounds.

Social skills, life skills and adaptive functioning levels.

Due to emotional, social and language delays, as well as delays in executive functioning (planning, organizing and problem-solving) and memory problems (including slower processing speed) individuals with FASD lag in age-appropriate development, termed adaptive functioning level. There can be a great deal of variability in their adaptive functioning levels, known as dysmaturity. For instance an 18 year old may be physically mature with strong expressive language, but the individual's social maturity may be that of a 12 year old, with math skills of an eight year old and reading decoding skills at age 15, but reading comprehension at age nine (Malbin, 2002). When dealing with inappropriate behavior for FASD individuals it is recommended to *think younger* and to consider that problem behavior may be due to dysmaturity rather than non-compliance. Inconsistent performance is characteristic of individuals with FASD, having *on* and *off* days, or performance variability, which is also characteristic of those with memory problems. The gap between expectations and performance is greatest at adolescence, a time of rapid growth and development, along with increased freedom and responsibility.

A 29 year old First Nations single mother of two boys, ages seven and eight years old (both the mother and the two boys having diagnoses within FASD) explained how an Aboriginal sharing circle with other women her age helped her to adjust to the many demands and frustrations of being a single parent of two young boys having diagnoses within FASD. (She had separated from the father of the boys due to spousal abuse.) She learned how to deal with her emotions, such as anger and frustration, on the one hand, and depression, on the other. Life skills training in another program helped her to learn to deal

with budgeting and running a household, thus helping to create more stability in the lives of herself and her children.

Dysmaturity in adaptive level, social skills and life skills were evidenced in Mark, diagnosed with FAS, and Mary with pFAS. Mark was egocentric in development, characteristic of a person younger in age than his 18 years. At adolescence he started to become more dysfunctional in terms of social relations, addictions and problems with law enforcement agencies. Mary, on the other hand, at age 15 years liked to play with younger children, was not interested in boys nor personal appearance and grooming (the lack of grooming concerned her mother), again characteristic of a younger level of development than her chronological age.

Theme 6: Motivation, Engagement and Retention in School

In Streissguth's seminal research (1996, 2002), 60% of a prospective longitudinal study cohort of 415 individuals with FASD experienced problems with school, such as suspensions, expulsions and dropping out, and 60% experienced problems with the law. The reluctance of educational systems to come to terms with the medical model of disabilities such as FASD, may be a contributing factor which could be ameliorated by viewing an FASD diagnosis as something to contribute to eligibility criteria for special services, planning, programming, placement and retention of students with FASD at their respective levels of adaptive functioning (Bredburg, 2011). Moreover, according to an interviewee who was a researcher, occupational therapist and mother of two adopted Aboriginal adolescents with FASD, disciplinary measures need to be informed by and accommodate students' disabilities. Such measures need to include de-escalation and calming techniques, and an awareness that suspension and expulsion may lead to involvement with high risk elements in the community to which vulnerable individuals with FASD are more susceptible than their age peers, as Bredburg (*Ibid.*) has noted.

Another interviewee related that her teenage son diagnosed with FAS dropped out of school, followed by addiction to and warrant for arrest for making and selling crystal methamphetamine. It is often very difficult for parents to maintain children with an FASD diagnosis in school during the volatile years of adolescence. Special learning tools and strategies to ameliorate the problem include those that assist with sensory issues, meet the needs for multi-modal, active, experiential, one-to-one instructional support, full-time supervision, and the realization that learning and maturity may take longer for many of these students. In addition, mentors and advocates acting as *external brains* for those with FASD can help to retain them in school and community (Chudley et al., 2007). Otherwise, absent accommodation for their disabilities, individuals with FASD may fall by default into the justice system, where they are likely to be victimized and deteriorate further (Mitten, 2004).

Considering factors such as attention deficit disorder, sensory and self-regulatory problems, slower auditory processing speeds, and high rates of school leaving, ongoing motivation and engagement are necessary to assist individuals with FASD in focusing and maintaining their interest and attention in order to retain them in school. Motivation is more effective if it is intrinsic to the task, rather than extrinsic such as money, a token, or a piece of pizza, although both types of rewards have their roles. The key is to get to know the individual so as to discover interests, activities and modes of learning to which the individual can readily connect. If the individual cannot learn readily through textual and auditory modes, try visual, experiential, hands-on or interactive digital modalities, with supervision. Key to the success of experiential learning and interactive modes is the flexible pacing they provide which is especially important for successful learning and development of individuals with FASD who may be functioning at a younger age than their chronological age, have slower processing speeds, and require more time for memory retrieval, yet do not want to become stigmatized as less capable in front of their peers.

Conclusion

Through the vehicle of qualitative research the present researcher strove to understand the complexity of FASD and its impact on the lives of individuals, their families, schools and communities. The inductive themes emerging comprise clinical applications in the form of evolving FASD Literacy and Learning Practice Guidelines. According to Denzin and Lincoln (2000, 2005) qualitative research involves the studied and systematic use and collection of a variety of empirical materials, including interviews, observations and artifacts. The six inductive themes derived herein are a synthesis of both FASD and Literacy and are intended to do justice to the complexity of both phenomena, without either leaving significant gaps, on the one hand, or becoming too large and unwieldy in application, on the other. Extensive observations of teaching and learning applying the guidelines proposed, in various sectors

(home, school and community) and for various age groups, as well as a comparison of outcomes with conventional methods, are the next steps in moving from practice guidelines to full-fledged FASD pedagogy.

The inductive themes or guidelines derived from the qualitative data are meant to further the translation of research to the clinical or practice level. Moreover, the themes or guidelines are not meant to be applied in a formulaic or mechanistic manner, but rather require discretion of the teacher, parent, caregiver or service provider in selecting and applying the themes on an individual basis, alone or in combination. Often, an ongoing balancing process will be required in their application as the challenge is to balance sometimes disparate requirements of diagnostic brain domains (Lang, 2006) and background factors, with the need to fashion rich, dynamic, holistic literacy curricula and pedagogies for learners with FASD, from a culturally contingent perspective. The application of themes, as noted, may require balancing, for while a learner with FASD may be prone to sensory over-stimulation, he or she may, at the same time, also be attention deficit and so may need an amount of stimulation to become engaged in learning. In addition, the learner may have memory deficits and problems with abstract thinking that require visuals and hands-on activities to reinforce. Having a quiet, pleasant and partially enclosed place with low lighting for the individual to retreat to when over-stimulated may help the learner with FASD to calm down or *slow his or her engine* before incrementally introducing further enriching stimuli. An adjoining room or a partially enclosed, comfortable, softly illuminated playhouse or culturally relevant teepee within the classroom may serve this function.

Significantly, through metacognitive techniques such as modeling and thinking aloud about the strategies used, learners with FASD can progress to manage and monitor their own learning needs and with support gradually move along a gradient to greater independence. The inductively derived FASD and Literacy and Learning Guidelines are intended to be applicable across sectors (home, school, and community) as well as across the life span.

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