

**POSTSECONDARY EDUCATIONAL EXPERIENCES OF ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDER**

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*The postsecondary experiences of adults diagnosed with Fetal Alcohol Spectrum Disorder (FASD) were examined in this qualitative research. Tinto's Student Integration Model (SIM) (1975, 1997) provided the theoretical framework that guided the study. Tinto posits that the interplay of background characteristics, academic integration, and social integration affect persistence in postsecondary education. The participants included four adults with FASD (3 males and 1 female) and their parents. In-depth interviews were conducted with the adults with FASD and their parents responded to open-ended questions in an online survey. Only one of the adults completed a postsecondary program. It was found that the background characteristic factor, and specifically having FASD, affected academic and social integration. Suggestions for revisions to the SIM are proposed, recommendations for postsecondary course instructors and academic counselors are made, and factors to consider when selecting a postsecondary program for an individual with FASD are described.*

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that refers to a range of outcomes including mild to severe disturbances of physical, behavioural, emotional, and/or social functioning that have been observed among individuals with prenatal exposure to alcohol (Streissguth & O'Malley, 2000). It encompasses a range of different diagnoses including fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND). Although only FAS is associated with specific physical and facial characteristics, all of the diagnoses involve permanent brain damage. Researchers have reported that some individuals with FASD have below average IQs (Steinhausen, Willms, & Spohr, 1993) and that prenatal exposure to alcohol is the leading cause of developmental disability in Canada (Health Canada, 2003). However, other researchers have indicated that children exposed to alcohol in utero may score within the normal range of development, but below what would be expected given the child's environment and background (Chudley, Kilgour, Cranston, & Edwards, 2007; Clark, Lutke, Minnes & Ouellette-Kuntz, 2004; Mattson & Riley, 1998; Riley, Mattson, Li, Jacobson, Coles, Koditwakkhu, Admans, & Korkman, 2003). Moreover, that potential ability is compromised by much lower scores on adaptive functioning (Odishaw & Snart, 2005) and significant cognitive deficits in attention, memory, and executive function (Kerns, Don, Mateer, & Streissguth, 1997).

The incidence of FASD in Canada is difficult to calculate due to problems in obtaining a diagnosis (complexity of the process and omission), the variance in the rates of FAS among populations, and different research methods used to study the problem (Chudley, Conry, Cook, Looock, Rosales, & LeBlanc, 2005; May & Gossage, 2001). However, Canada's Public Health Agency (2003) estimated the incidence of FASD to be approximately 9.1 per 1000 live births. Stade and her colleagues (2006) reported that the total adjusted annual costs associated with FASD per individual aged 1 to 21 years in this country were over \$14,000, depending on the severity of the child's condition and proximity to services. More severe cases of FASD may require surgeries to correct heart defects, skeletal problems, and sensory impairments, as well as specialized health and educational services (Stade, Unger, Stevens, Beyene, & Koren, 2006). When the individual resides in a remote area of Canada, travel to and from the service delivery facility is required and additional expenses are incurred. Over a lifetime, the costs associated with FASD are estimated to be \$1.5 million per person (Health Canada, 2003). These figures

point to the substantial direct and indirect costs of FASD and long-term economic impact of prenatal exposure to alcohol.

#### *FASD and Adulthood*

Although etiology, assessment, diagnosis and prevention have been studied (Clark, Lutke, Minnes, Ouellette-Kuntz, 2008), little attention has been paid to the issues faced by adolescents and adults with FASD (Rutman & Van Bibber, 2010). Most individuals with FASD do not receive a diagnosis until adulthood (Chudley, Kilgour, Cranston, & Edwards, 2007). Moreover, obtaining a diagnosis is often difficult for adults because in most cases there are no physical signs and there is no biological test available (Chudley, et al., 2007). For an assessment referral to be made, FASD must first be suspected and there is insufficient knowledge of FASD among physicians, social workers, psychologists and psychiatrists. Confirmation requires an assessment that is best carried out by a multi-disciplinary team and there is a shortage of personnel qualified to make a diagnosis (Ryan, Bonnett, & Gass, 2006). It has also been noted that adults with FASD are at substantial risk for mental health problems (Chudley et al., 2007; Clark, Lutke, & Minnes, 2004), which suggests that some individuals may be diagnosed with FASD following an initial diagnosis of mental illness (Streissguth & O'Malley, 2005).

Primary disabilities associated with FASD include disturbances in attention, cognition, learning, memory, language, motor coordination, complex problem-solving, and abstract thinking (Connor & Streissguth, 1996; Kerns, Don, Mateer, & Streissguth, 1997). They are unique to each individual and persist over the lifespan (Hartness, 1998; Streissguth et al., 1994). These primary disabilities refer to those problems directly associated with FASD, while secondary disabilities refer to the acquired difficulties individuals with FASD develop as they mature (Streissguth, Barr, Kogan, & Bookstein, 1996). Secondary disabilities include: one or more mental health problems; disrupted school experience (suspension, expulsion, dropping out); trouble with the police, being charged, convicted of a crime, confinement as an inpatient for mental health or substance abuse problems or incarceration for a crime; inappropriate sexual behaviour; substance abuse; and difficulties with living independently, getting a job, and maintaining employment (Streissguth, et al., 1996). Factors that may reduce the rate and severity of secondary disabilities include: an early diagnosis (before 6 years), appropriate interventions, living with a caregiver, requiring a minimal to low level of support (suggesting higher levels of adaptive functioning) and not being vulnerable to manipulation (Clark, Lutke, Minnes, Ouellette-Kuntz, 2008; Streissguth, 1997).

The outlook for adults with FASD is not full of hope. Although perceived as *normal*, they have neurological problems that result in functioning far below normal (Ryan, Bonnett, & Gass, 2006). Even with IQ scores in the normal range, they continue to exhibit clear deficits in attention, memory, verbal learning, and executive function (Kerns, Don, Mateer, & Streissguth, 1997). Given these challenges, it is not surprising that 60% of individuals with FAS either drop out or are suspended from high school (Streissguth, Barr, Kogan, & Bookstein, 1996). Additionally, a gap between adaptive skills and measured IQ contributes to the individual's difficulty performing day-to-day activities (Clark, Lutke, Minnes, Ouellette-Kuntz, 2004). Unemployment, inability to live independently, and trouble with the law have also been identified as problems for adults with FASD (Spohr, Willms, & Steinhausen, 2007; Streissguth, Barr, Kogan, & Bookstein, 1996).

However, other research has shown that living with a caregiver reduced the number of confinements (hospital or prison) and run-ins with the law (Clark, Lutke, & Minnes & Ouellette-Kuntz, 2004; Spohr, Willms, & Steinhausen, 2007). Duquette and her colleagues (2006) also found that parental advocacy was a protective factor against dropping out of high school and that some individuals with FASD do go on to postsecondary education (Duquette & Stodel, 2005). To date, there are no studies on adults with FASD who have engaged in courses after high school and their educational experiences. Therefore the main purpose of this research was to examine the postsecondary educational experiences of adults with FASD with a view to understanding their perceptions and persistence.

#### *Theoretical Framework*

Tinto's (1975, 1997) student integration model (SIM) provided the theoretical framework for this study. The SIM explains why postsecondary students drop out or persist and graduate. Tinto (1975) originally developed the SIM as a model of dropping out that presented three factors that explain the phenomenon. The SIM involves an interplay between (a) background characteristics (i.e., personal attributes such as ability; academic preparation; and family situations) which in turn affects the level of goal commitment, (b) level of academic integration (e.g., grades, intellectual development), and (c) level of social

integration into the institution (e.g., informal peer group associations, extracurricular activities, interaction with faculty) that determine whether or not a student will graduate. In 1997, Tinto revised the SIM and changed the focus from dropping out to persisting and posited that institutions should promote the development of learning communities in order to retain students.

Tinto's SIM has been used to predict persistence among university and college students. Academic integration and social integration were both reported as influencing persistence among 151 Russian immigrants attending an Israeli university (Sagy, 2000). However, academic influence appeared to be a stronger predictor as at this university there were relatively few opportunities to engage in campus social activities. In a study involving 2,236 freshmen in the US, Pascarella and Chapman (1983) found that the type of institution affected persistence. Specifically, for students in a four-year residential university, social integration had a greater influence on persistence than academic integration, but for individuals registered in four-year and two-year commuter institutions, academic integration was the most important factor affecting persistence.

The SIM has also been used in studies involving persistence among community college students. Nora (1987) surveyed 3,544 Chicano students and demonstrated that goal commitment was the most important factor affecting persistence. Academic integration was of lesser importance and social integration had little influence. In contrast, Bers and Smith (1991) reported that among 1,142 students in a community college, academic and social integration both influenced persistence, with social integration being more important. Napoli and Wortman's (1998) meta-analysis of studies involving persistence among college students showed that academic integration predicted term-to-term and year-to-year registration, whereas social integration only predicted term-to-term registration.

While the SIM has been used in many studies to examine persistence among various groups of postsecondary students, the research on students with disabilities is thin. DaDeppo (2009) used the SIM to guide her research involving 97 college freshmen and sophomores with learning disabilities (LD) who were registered in a four-year public institution in the US. The results of this quantitative study demonstrated that academic integration was a significant predictor of intent to persist, but social integration was the more powerful predictor of these students' intent to persist. In the only qualitative study involving the SIM, Duquette (2000) reported that goal commitment, academic preparation, and academic integration were more closely linked to persistence than social integration among the 36 Canadian university students with various disabilities (LD, hearing impairment, visual impairment, medical impairment, and physical disability). Almost none of them were involved in campus-based social activities and they did not socialize outside of school with their classmates. Instead, they relied on their families for emotional support.

As shown above, research involving the SIM show mixed results for postsecondary students in general and for university students with disabilities. In various contexts and with different groups of students, either academic or social integration was the stronger influence on persistence. What is clear, however, is that the literature on persistence consists mostly of quantitative studies and there is no research on the SIM among college students who have disabilities.

#### *Research Questions*

The main objective of this qualitative research was to examine the postsecondary experiences of adults with FASD, and Tinto's (1975, 1997) SIM provided the theoretical framework from which to study this phenomenon. The research questions were as follows:

1. What are the background characteristics of the postsecondary students with FASD?
2. How are the students with FASD academically and socially integrated into postsecondary institutions?
3. What are the facilitators and barriers to persistence until graduation?

#### **Methodology**

This qualitative study followed a phenomenological approach, as knowledge was socially constructed by the people active in the research process (Schwandt, 2000). The intent of this retrospective research was to understand and describe the events from the point of view of each of the participants (Creswell, 2007), using Tinto's (1975, 1997) SIM as a lens through which to view the phenomenon. This research is part of a larger study on the postsecondary educational experiences of individuals with FASD and their subsequent employment and individual living situations. It involved 12 parents in Canada and the US and four adults with FASD. Parents of adults with FASD who had attended postsecondary programs

responded to open-ended questions in an online survey; then four of these parents recruited their son or daughter to participate in an individual interview. Only the data on educational experiences gleaned from the questionnaires and the interviews are described and discussed in this research.

#### *Participants*

The participants of this study resided in Canada and the US and included four adults with FASD and their respective adoptive parents. A recruitment notice was sent across North America through the e-mail list serve of an Ontario FASD Support Group and FASlink. The selection criteria for the adults were (a) to have a diagnosis of some form of FASD and (b) to be enrolled in a postsecondary program (transition, apprentice, college, or university) or to have been enrolled in a postsecondary program. The selection criterion for parents was to have an adult child with a diagnosis of some form of FASD who is enrolled in a postsecondary program or who was enrolled in one. In all cases, a parent completed the online survey and four of them indicated that their son or daughter would be willing to participate in an interview. Early in the data collection process it became obvious to us that there were very few adults with FASD who had attended postsecondary programs, which is reflected in the small number of parent participants (12). Comments of parents who wanted to participate in the study suggested that (a) individuals with FASD leave high school with a certificate of attendance and not a diploma and (b) some young adults with FASD with a high school diploma decide not to pursue postsecondary studies. Additionally, it is possible that some people with FASD who are registered in postsecondary programs have another diagnosis, such as learning disabilities or mental illness.

#### *Data Collection*

Data were collected from the adults with FASD through in-depth interviews. The items for the interview schedule were written simply to facilitate understanding. Sample questions were *What accommodations do you need to be successful in your courses?* and *Were you involved in any school activities?* (see Appendix A). During the interviews, participants were given the opportunity to elaborate on their individual stories (Marshall & Rossman, 2006). The interviews were conducted in person or by telephone, lasted about an hour each, and were digitally recorded. All of the interview participants were provided with a copy of their transcript and given the opportunity to read and amend it, if they felt it would clarify or better represent their answers. Data from parents of the adults with FASD were collected through an online survey consisting mostly of open-ended questions. Sample questions were *What can an instructor do to help your child(ren) learn the material?* and *What can colleges or governments do to help people with FASD get into postsecondary programs and graduate?*

#### *Data Analysis*

The interview transcripts of the adults with FASD were read repeatedly, text was underlined, and notes were made in the margins (Miles & Huberman, 1994). Then the data were grouped into the following categories: diagnosis, elementary school, secondary school, and postsecondary education. Data for each participant were summarized on a table and arranged according to the above categories. The data were compared across each category and similarities and differences were noted (Strauss & Corbin, 1998). The data related to elementary and secondary school experiences were further examined for patterns in background characteristics, then the postsecondary data were analysed for themes in the areas of academic and social integration. The analysis was done by hand (Charmaz, 2000) to increase engagement with the data and interpretations were made using inductive reasoning (Patton, 2002). The qualitative data from the parent surveys were analysed similarly to the process described above.

#### *Trustworthiness*

The researcher must establish indicators that provide evidence that the data collected in the study are authentic and believable (Freeman, de Marrais, Preissle, Roulston, & St. Pierre, 2007). The two main indicators used in this study were credibility and confirmability. Credibility refers to the correspondence between the researcher's portrayal of the participant's viewpoints and the way those individuals actually perceive the phenomena (Mertens, 2005). Conducting member checks and negative case analyses enhanced the credibility of the findings. First level member checks were conducted by having the participants review and confirm the accuracy of the transcripts (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). A negative case analysis was also done by looking for data that was inconsistent with categories that had been identified (Brantlinger, et al., 2005). A confirmability audit was conducted by the first author to ensure that the summaries of the data could be traced back to the original sources (Mertens, 2005). Finally, the two investigators analysed the data independently to ensure agreement on the findings.

### Findings

#### Diagnosis

Four adults with FASD (Johnny, Ted, Alan, and Sonja) and their parents participated in this research (see Table 1). All of them were adopted at a young age and were raised by their adoptive parents. Only Johnny was from the US and the other three participants were born and raised in British Columbia, Alberta, and Newfoundland. Johnny is 26 years and his mother explained that she and her husband became foster parents when their son was 15 months. She was told he had FAS, and she did some research on it, but added that they had *no clue what we were in store for*. Johnny stated that he knew at age seven years that he had FAS and stoically commented, *I'm stuck with this thing for the rest of my life*. Ted is 39 and was diagnosed when he was 29 years. He explained that he was initially diagnosed as *bipolar*, but when it was determined that he lacked *the serious manic episodes* associated with bipolar disorder, the diagnosis was changed to clinical depression. The mental health diagnosis was later seen as a secondary disability stemming from ARND. Ted expressed that this diagnosis helped him understand *why things have been so damned difficult*. However, Ted harbours negative feelings about it: *I think it has taken me a long time to try to figure out exactly what it all means. I felt ashamed of myself. I felt like less of a person*. Alan is now 31 years and was adopted by his parents at the age of one. Like Ted, Alan was first diagnosed with a mental health problem and through a referral from a family physician the second diagnosis of ARND was made at age 19 years. Also like Ted, the second diagnosis provided an explanation for some of the difficulties he had experienced throughout his life. Alan seemed to accept this assessment and he claimed not to think much about it afterwards. Sonja, aged 43 years, had been diagnosed with dyslexia in her early teens but realized four years ago that she also has FASD. Unlike the others, she read an article in a magazine about FASD and became aware that the symptoms were consistent with her own experience. The self-diagnosis was later confirmed by a family physician working in her home province. Like the other participants diagnosed later in life, she felt relieved to know the source of her problems and commented that it *answered a lot of questions about why I was not in the same place as other people my age*.

**Table 1. Participant Characteristics**

Name	Age	Province/State of Residence	Diagnosis	High School Graduation	Post-Secondary Program	Post-Secondary Graduation
Johnny	26 yr.	Texas	FAS, 7 yr.	Yes	Welding	No
Ted	39 yr.	British Columbia	ARND, 29 yr.	No	GED	No
Alan	31 yr.	Alberta	ARND, 19 yr.	Yes	Culinary Arts	No
Sonja	43 yr.	Ontario	ARND, 39 yr.	Yes	Dental Assistant, Legal Assistant, Ready for Work	Yes

#### Elementary and Secondary Schooling

As Johnny had a diagnosis as a child, he was able to obtain placements in special classes throughout his schooling. The other three individuals were in regular classes during their elementary school years. Alan commented that at that point he *was like everyone else*.

In high school, Alan was enrolled in a private school by his parents because there had been some drinking and trouble with the law. He was the only one of the four participants with FASD who took regular education classes in high school. His mother described him as articulate and a good reader, but recognized that he had difficulties with written expression and socializing with peers. Alan said, *We thought it was a phase and I'd grow out of it. Apparently, I didn't though*. During high school Ted and Sonja both began in regular classrooms and were later placed in special classes with reduced academic demands. Sonja explained that she was assigned to this class for *difficult and slow students* during her second year of grade 9, but was removed after *a week or two ... [when] they knew I didn't belong there*. However, Ted remained in special classes until grade 12. Johnny continued to be placed in special segregated classes, which included some vocational preparation courses. Johnny, Ted, and Sonja all exhibited behavioural problems in school. Ted and Johnny commented that they were angry and *not able*

to concentrate. Sonja explained that due to her FASD, she would *lose focus easily* and *get bored*, and to provide some stimulation, she became the class clown.

The three older participants enjoyed English and art classes. All of them experienced problems with math, and Alan commented that having difficulties in this subject area *is one of the hallmarks of FAS*. Sonja explained that math word problems were particularly difficult as the words and numbers were *jumbled in my brain and I would get things backwards*. Johnny's program included work experience at Target and Walmart, neither of which he claimed to enjoy. None of the others had any work experience or coop in high school, although Alan did receive some instruction on career and life management, which he did not find helpful.

Sonja and Alan participated in sports in elementary and high school, and their parents also enrolled them in extracurricular arts programs (e.g., music and art lessons). In high school Johnny and Ted were both involved in military organizations (Naval Junior Reserve Officer Training Course and Air Cadets, respectively). For both of them, it was a positive experience. Ted enjoyed it because the program was structured and the instructional strategies were appropriate for someone with FASD. He explained, *They do things for the lowest common denominator so they dumb things down as much as possible to try and get everybody on track [and] there is a lot of repetition*.

Although there were positive aspects to their school experiences and their parents provided academic assistance at home, only Johnny and Alan graduated with their peers. Alan stated that he had considered quitting many *times*; however, he perceived that this would be his only opportunity to obtain free schooling and therefore persisted. His mother added that she advocated for him to take his grade 12 English exam using a computer, otherwise she stated that he would not have attempted it.

Ted and Sonja both became involved with the *wrong* friends and eventually dropped out. At the end of grade 10 and with only four credits, Sonja quit school and left home. By that time Sonja's parents had her assessed and she was diagnosed as having a learning disability. Ted left school at the end of grade 12 because he was failing some courses and decided to take a job on a *cruise ship that took people fishing*. Ted was considered an underachiever and felt misunderstood. He explained, *Back then, nobody understood what the problem was. Everyone was getting frustrated. It was to the breaking point. They figured I was being a twit for the sake of being a twit*.

#### *Postsecondary Education*

Ted enrolled in a GED program offered by the local school board and took courses in English and math. He enjoyed the creative aspects of his English classes, had a positive relationship with the instructor, and received a mark that was *just short of honours*. However, he had a *really hard time* in the math class. The math teacher *figured [he] was goofing off all the time* and in the end, he just *squeaked through*. Those were the only courses Ted took after leaving high school and he did not complete his GED.

Johnny, Alan, and Sonja attended college programs. Johnny enrolled in a welding course at his local junior community college because *I thought it would be something neat. You get to melt metal together and make stuff*. Alan went into culinary arts as he always enjoyed cooking and thought that this might be an area in which he could succeed. Although both men entered their programs with high hopes, neither completed them. Johnny quit after one year because he *wasn't focusing on welding. I was focusing on other stuff*. Alan left his program after a few weeks because it became overwhelming. He explained that he had difficulty remembering the cooking terms in his classes and his poor spelling inhibited his performance on written assignments. He also described the practical aspects as being very stressful, *... doing all of those different things at once. I'm pretty good in the kitchen, but if I get frustrated, everything stops working*. When Alan began the program, he was being assessed for FASD and had just started new medication for depression. He described his emotional state as *up and down all the time*. Moreover, the instructor was not informed about his FASD or his medications, and with the stress of the program, Alan felt he could not cope with all of these elements at the same time. He stated that he experienced a *psychotic breakdown*, causing him to quit the program, and *crash* for a few months.

Like Ted, Sonja wanted to obtain her high school diploma and went back to adult high school. She said, *I had a purpose, you know, a goal; that is I wanted to finish high school. So I wasn't a so-called 'loser dropout'. So that's what I did*. Sonja graduated from grade 12 and returned to take English and math at the advanced level so that she could earn her grade 13 diploma. She then enrolled in a dental assistant program because she felt that it was best suited for her. Unfortunately, after completing her studies,

Sonja was unable to find a job as *they all wanted someone with experience*. Years later, she entered a program to be a legal assistant because she always had an interest in law; however, she did not realize that it would be so stressful. She explained, *It's just overwhelming and it's too much for someone with FASD. You really have to be on the ball to do that type of job. You can't forget things*. She felt that if she had done more research into the actual duties of a legal assistant and had known her diagnosis, she would never have gone into the program. Nevertheless, Sonja did complete it and she acknowledged that her parents' support of her academic work over the years had been critical to her success. Most recently Sonja was enrolled in a 10 week work preparation program that lead to certificates in workplace and food safety.

*Accommodations and instructional strategies*. While at college, only Johnny received accommodations because his mother contacted the instructors and asked if he could work at his own pace. Johnny described how he learned the skills, *You just had to practice over and over and over...It took time and patience*. However, his mother added that her son became distracted easily and often did not do the work. She later found out that when assigned to watch instructional welding videos on the computer, Johnny would view inappropriate material during class time. Additionally, he succumbed to peer pressure and left class to drink. Alan, Ted, and Sonja had no accommodations while enrolled in their courses. Sonja did not feel she needed them and the two male participants did not request them.

When asked about accommodations, Alan felt that smaller class sizes and assistance with the assignments would have helped him in his culinary arts program. His mother added that breaking the modules down into smaller chunks would reduce the amount of information to be memorized at one time and the feeling of being overwhelmed. She added that students with FASD should be allowed frequent breaks and the option of completing assignments using a computer. Johnny's mother perceived that her son needed more supervision, particularly when using the computers. She commented, *I don't think he is capable of this type of experience without close supervision. Most people do not know about FAS here*. Ted's mother believed that her son required a quiet, non-judgmental setting where he could work at his own pace and get one-to-one explanations from a patient instructor whenever he needed. She cautioned that distractions and pressure should be minimized.

**Sonja** Sonja stated that she did not require any accommodations: *I didn't need any help. Well, obviously, I'm high functioning – that's the word they like to use*.

Nevertheless, she did recommend the use of the following instructional strategies with students with a FASD diagnosis who are registered in postsecondary classes:

- One-on-one instruction to decrease distraction and feeling *stupid in front of others*.
- Present one thing at a time because students with FASD become overwhelmed.
- Speak slowly and provide clear explanations.
- Avoid placing too many things (e.g., posters) on the wall because it is too distracting.
- Use a variety of instructional methods that involve different senses: auditory, visual, and tactile.
- Limit the homework because *people with FASD need their down time*.
- Be aware of the lighting, temperature, and noise levels in the classroom as many people with FASD are more sensitive to them than other students.

*Future plans*. The three males thought about returning to school, but have not done so. Johnny would not resume the welding program but stated that he enjoys physical activity and has looked at courses that would help him become a personal trainer. However, he has not gone beyond investigating this possibility. Both Ted and Alan think about going back to school, but don't think they can bear to experience another failure. Alan explained, *I can't deal with another big crash. It just takes too much time to recover now*. The physical and emotional outcomes of trying something new and failing are just too much of a risk.

## Discussion

### *Background Characteristics of the Participants*

The participants with FASD had varying degrees of primary and secondary disabilities associated with FASD (Connor & Streissguth, 1996; Streissguth, Barr, Kogan, & Bookstein, 1996). Johnny had been diagnosed with FAS as a child and not surprisingly as an adult he had trouble learning and required close supervision by the instructor (Connor & Streissguth, 1996). His mother also wrote that he was easily influenced by peers and had developed a secondary disability: substance abuse problems (Streissguth, Barr, Kogan, & Bookstein, 1996). Sonja also had a diagnosis (learning disabilities) that had been made when she was in her early teens. After earning her grade 12 high diploma, she knew her learning

strengths and weaknesses and along with her personal interests likely selected the dental assistant and later the legal assistant programs with them in mind.

When Ted and Alan began their postsecondary studies, neither of them knew they had FASD. Alan had been diagnosed with mental illness, but Ted's depression had not been formally identified. However, both of them were first diagnosed with mental illness, which were later found to be caused by FASD (Chudley, Kilgour, Cranston, & Edwards, 2007). While in their respective programs, Ted had difficulty with math and Alan had problems with written expression and responding to more than one instruction at a time. Ted's difficulty with math and Alan's problem with written language were likely linked to FASD (Connor & Streissguth, 1996) that continued into adulthood (Hartness, 1998; Streissguth et al., 1994). Moreover, Alan's difficulty in responding to multiple instructions simultaneously might have been exacerbated by his mental health problems (Manalo, Ede, & Wang-Toi, 2010) and his new medication.

In terms of academic preparation for college, three of the four adults with FASD had achieved a high school diploma. It is possible that the curricula included in Johnny's special education program did not adequately prepare him for the academic requirements of postsecondary courses. With the accommodation of being able to take his grade 12 English exam using a computer, Alan entered college with a high school diploma. Unfortunately, at the time he began his program in culinary arts, Alan was depressed, did not know he had FASD and had not yet grasped the full extent of his illness. Like Alan, Sonja had completed high school and had taken academic courses which likely prepared her for success in her postsecondary studies. However, unlike the others, she did not have any secondary disabilities, specifically mental illness or substance abuse that might jeopardize the achievement of her goal – graduation.

Transition and career planning are recommended for individuals with FASD (Shepard and Hudson Breen, 2007) and might have been helpful for these participants. However, none of the participants described the preparation of Individual Transition Plan documents, visits to various colleges, or meetings with special services personnel in colleges. The three older participants likely did not have a formal transition plan because they were in high school before legislation mandating these documents was passed. Additionally, they began their postsecondary studies after taking a break from school and when they resumed their studies, it did not occur to them to ask for any academic assistance. Only Johnny entered college directly from high school and he did not appear to have any accommodations in place until his mother spoke to one of his instructors.

While better transitional planning might have affected the outcomes, it is clear that any career and postsecondary education plans for a person with FASD must be based on accurate diagnoses of primary and secondary disabilities and an understanding of the learning strengths and needs of the individual. At the time when the three older participants began their postsecondary studies, they did not know they had FASD and were therefore unaware of the pervasive and negative effects it could have on their ability to learn and adapt to the demands of their programs.

#### *Academic Integration*

Of the four individuals, Sonja likely had the highest degree of academic integration because she passed all of her college courses and successfully completed the programs in which she was registered. She had taken the advanced-level high school courses that prepared her to do postsecondary work, did not require any academic accommodations to be successful, and was able to follow through on her goals. During the one year that Johnny was in his program, he was able to do the hands-on welding with a lot of practice and at a slower pace. However, he admitted to being easily distracted from his studies, which limited his academic success. Alan appeared to have the least academic integration, as he left his postsecondary studies after one month. Despite the help from his mother, he was overwhelmed by the memorization required in the course work and was stressed by the pace and demands of working in a kitchen. These two participants would have benefited from accommodations such as closer supervision, a slower pace of instruction, and reduced memorization.

In this study, the degree of academic integration in college-level programs appeared to be linked to the students' learning problems that were symptoms of FASD, such as deficiencies in memory and attention, inability to work independently, and the need for slower paced instruction. These problems could also be compounded by the symptoms of a secondary disability, such as anxiety and depression that may have been triggered by the demands of academic studies (Manalo, Ede, & Wong-Toi, 2010; Stevenson, 2010).



A second factor related to academic integration was the goodness of fit between the demands of the program and the cognitive levels and learning strengths and needs of the student. With more careful investigation, Alan might have understood that cooking at home is not the same as cooking in a restaurant kitchen. Similarly, Sonja stated that if she had understood the day to day requirements of working in a legal office (e.g., multi-tasking and remembering things), she would not have registered in a program to be a legal assistant. In these two instances, knowledge of the nature of the jobs for which they were being trained should have been a consideration when selecting a postsecondary program. Although the hands-on welding program, appeared to be a good fit for Johnny, he did not have the academic skills to do the course work and had difficulty sustaining a focus on school. This mismatch between mental and personal capabilities and vocational skill requirements was also noted by Spohr and his colleagues (2007) in their longitudinal study of German patients with FASD.

#### *Social Integration*

Only Johnny spoke of engaging in social activities with friends from college. His mother described him as being easily influenced and that he had problems with alcohol abuse. Although Johnny met some *friends* at school, they were unfortunately a negative influence, which eventually contributed to his withdrawal from the welding program. Alan had experienced difficulties socializing with peers since he was a child, and within the one month that he was in school, he did not likely have time to make friends. Ted and Sonja did not speak of having friends in their programs. It is possible that because they both had the *wrong* friends in high school, they were cautious about making new ones in their respective academic settings.

Hence, in this study only Johnny was socially integrated, but not in the positive way described by Tinto (1975, 1997). Being vulnerable to manipulation and having the *wrong* friends who influenced him to participate in negative activities (e.g., drinking) was linked to his dropping out of school. Therefore, positive social integration was not achieved by the participants, and unlike DaDeppo's (2009) students with LD, social integration did not contribute to persistence among these adults with FASD.

In summary, unlike the previous studies on postsecondary studies using the SIM, it was shown that the background characteristic of having the primary disability of FASD could have serious negative effects on learning and the ability to make *positive* friendships, which was an important factor related to persistence in college. Additionally, secondary disabilities also had a negative effect on persistence. For these participants, academic integration appeared to be more important than social integration (Duquette, 2000; Napoli & Wortman, 1998; Nora, Attinasi, & Matonak, 1990; Pascarella & Chapman, 1983; Sagy, 2000). Similar to the results of Duquette (2000) and Sagy (2000), most of the participants in this study were not socially integrated into the postsecondary institution. Moreover, due to the symptoms of FASD (background characteristic), one of the participants was socially integrated in a *negative* way which compromised his academic integration and persistence. Tinto (1975, 1997) stated that the background characteristic of goal-directedness could strengthen academic and social integration and in turn, persistence. In this research, it was found that another background characteristic – a developmental disability – could weaken academic and social integration, thereby increasing the possibility of withdrawal.

#### *Facilitators and Barriers to Persistence in Postsecondary Education*

One facilitator for Johnny and Alan was the assistance they received from their parents in understanding the course material and memorizing it. A second facilitator was parental advocacy. For example, Johnny's mother informed his instructor that her son has FAS and was able to negotiate work at a slower pace for him. Although Johnny and

Alan both dropped out of their respective college programs; parent tutoring and advocacy were helpful. In Sonja's case, her academic abilities and preparation, goal-directedness, and the absence of mental illness were beneficial. Despite having FASD, these background characteristics enabled Sonja to experience academic integration.

Although the factor of background characteristics was a relative facilitator for Sonja, it proved to be a barrier to persistence for the three other participants. The primary and secondary problems associated with FASD were ultimately at the root of their inability to achieve academic integration and in Johnny's case, positive social integration. A second barrier to completion of postsecondary programs was a poor match between the participants' background characteristics and the demands of the chosen program. For

all but one of the participants with FASD, it appears that the barriers were too much to overcome as three of the four individuals did not complete their postsecondary programs.

#### *Considerations before Registering in Postsecondary Programs*

The data suggest that for people with FASD there are three factors that should be considered when making the decision to enrol in postsecondary courses: the individual, the institution, and family support. At the individual level the symptoms of the primary disability that are manifested in the person and his or her academic preparation in high school should be examined. The presence or absence of secondary disabilities (e.g., mental illness) and goal directness also need to be considered. There are two elements to think about at the institutional level: potential academic integration and potential positive social integration. Potential academic integration refers to the fit between the program demands and the individual's abilities, academic preparation, and mental health. Additionally, if accommodations are required, they must be known to the course instructors and how they will be provided must be determined. Potential positive social integration refers to the ability to resist selecting the *wrong* friends who might engage in negative activities. The third level is family support, which includes advocacy efforts to obtain accommodations and the ability to provide academic support for the individual.

**Table 2. Factors to Consider When Deciding to Enroll in a Postsecondary Program**

Individual	Symptoms of the primary disability Academic preparation in high school Symptoms of secondary disability Goal directedness
Institution	Potential academic integration (e.g., fit between programs and individual characteristics, need for and availability of accommodations, grades) Potential social integration (e.g., ability to select the <i>wrong</i> friends, engage in negative activities)
Family Support	Advocacy or assistance with self-advocacy to obtain accommodations Academic support for the individual

#### *Limitations*

One limitation of this study is that only one interview was conducted with each of the adults with FASD. It was difficult to contact these participants and arrange the interviews with them, and consequently we chose to schedule a single interview so that all of the data could be collected in one session. A second limitation is that this research is a retrospective study and the accuracy of the memories of the adults with FASD might be in question. However, the information provided by the parents helped to confirm their recollections.

#### *Conclusions and Future Research*

In this study, Tinto's (1975, 1997) three factors related to persistence as described in the SIM were used to examine the postsecondary experiences of four individuals with FASD. It was found that the background characteristic of having a disability could affect academic and social integration, and ultimately persistence in a community college. Therefore, one of the important findings of this research is the need to include the presence or absence of disabilities in the background characteristics of the SIM. Depending on the nature of the disability, there may be little or no effect on persistence as shown by Sonja and also found by DaDeppo (2009) and Duquette (2000). However, as illustrated in this research, persistence was negatively affected by the presence of primary and secondary disabilities.

On a practical level, the findings of this study provide tips for college instructors on how to work with students who have FASD and three factors to consider when selecting a postsecondary program for an individual with this disability. These findings have not been previously reported in the literature. Additionally, this study adds to the body of work that calls for the medical profession to become better informed about the symptoms of FASD, including the secondary disability of mental illness that may be associated with it. Early and accurate detection may help individuals with FASD and their families make informed and realistic plans for postsecondary education, if it is appropriate.

One implication for colleges is to provide information about program requirements, working conditions, and non-academic abilities associated with various careers. This type of information could be put online and would be helpful for prospective students who do not have experience in the specific career for which they are seeking training. It would assist them to gauge the degree of fit between their strengths and needs and the demands of the program and the potential jobs. Moreover, access to this information could possibly lead to better choices made by students, parents, and high school personnel. Additionally, part-time and full-time instructors at colleges should have opportunities to obtain training (e.g., in-person sessions or online) about various disabilities and accommodations to develop an understanding of potential student needs.

Future research should include studies in which the SIM is used to guide investigations on postsecondary educational experiences of students with other disabilities. The dimension of the nature of the students' disabilities and their effects on academic and social integration should be examined in particular. Research should also be conducted on the transition plans and the planning process for high school students with FASD. Studies of this nature could also include the three factors to consider described previously (individual, institution, and family support). The findings of this research add to our understanding of how FASD can affect development across the life-span and they support the growing body of literature that attests to the ability of individuals with FASD to discuss their experiences and bring insightful observations to light.

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**Appendix A**  
**POSTSECONDARY EXPERIENCES OF ADULTS WITH FASD**  
**INDIVIDUAL INTERVIEW QUESTIONS**

**Demographic**

1. What is your age?
2. Are you married or single?
3. Have you ever been married?
4. When were you diagnosed as having FASD?
5. How did you feel about having FASD then?
6. Were you raised by your birth parents? Foster parents? Adoptive parents?
7. Do you live at home? If not, where/ with whom?

**Elementary and Secondary Schooling Experiences**

8. Tell me about your elementary school experiences.
9. Tell me about your secondary school experiences.
10. Which subjects did you enjoy? Which subjects did you not like?
11. Did you participate in extracurricular activities or sports? If so, what were they?
12. What type of academic assistance did you receive in school? (For example going to the resource teacher or being in a special class.)
13. Did you participate in a coop program at high school? If so, tell me about it.
14. Did you graduate from high school?
15. If yes, did you ever think of quitting? If so, why? What kept you in high school?
16. If no, why did you leave school? What did you do afterwards?
17. Did your parents help you when you were in high school? If so how (e.g., help with homework)? Did anyone else help you? If not, who did help you and how?

**Postsecondary Experiences**

18. Are you enrolled in a postsecondary program now?
19. What type of postsecondary education program are/were you in? Tell me about it. Why did you choose this program?
20. What accommodations do/did you need to pass your courses? (Prompt: extra time for exams)
21. How did you get the accommodations? Did they help you?
22. What parts of the program are easy? What parts are hard? Why?
23. What can an instructor do to help you learn the material?
24. What do you do to learn the material?
25. Are/were you involved in any school activities? If so, tell me about them.
26. Is/was there a coop in your program? If so, tell me about it.
27. Have you thought of dropping out? If yes, why? What keeps you in school? Or Why did you leave the program? What did you do afterwards? Have you thought of going back to school? Why or why not? If yes, in what type of program and why?
28. How do/did your parents, other relatives, or friends help you?
29. What things can the college or government do to help people with FASD get into programs and graduate?
30. When do you expect to graduate/did you graduate? Will/did the training lead to a job?

**Reflections**

31. What are your future goals? (Career, personal)
32. How can you reach them? What help will you need to reach them? Who can help you?
33. How do you feel about having FASD now? How do you think it will affect your future goals?
34. Is there anything else you would like to add?