Youth with Fetal Alcohol Spectrum Disorder: Suggestions for Theory-Based Career Practice

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Abstract:

Fetal Alcohol Syndrome Disorder (FASD) in youth is increasingly recognized as a disability that has critical implications for career development. The readiness skills needed for successful transitions to adulthood may be delayed by several years and these youth will require ongoing support. Youth with FASD require modified career counselling services and career interventions. However, there is a clear lack of attention to advancing career theory and practice to persons with disabilities particularly for individuals with neurological impairments. The goal of the present article is to encourage practitioners to use Social Cognitive Career Theory (SCCT) as a means to develop appropriate transition planning and career interventions for young people with FASD.

Introduction

Yesterday Eric learned how to tabulate and record the number of items sold at the local craft store where he was employed. Yet today Eric clearly can not remember the steps involved in completing the task. When his employer gave him notice, Eric seemed unable to understand the consequences of not fulfilling his agreed upon duties.

The scenario offered above gives insight into the impact of alcohol use during pregnancy and its complex effect on behavioural and cognitive functioning of affected individuals. The continuum of disabilities that are experienced as a result of brain damage caused by prenatal exposure to alcohol is referred to by the umbrella term, Fetal Alcohol Spectrum Disorder (FASD). FASD is a life-long disability that affects an esti-

mated 9.1 per 1000 live births in the United States (Chudley et al., 2005). Currently no national statistics are available on the rates of FASD in Canada. The effects of alcohol exposure vary by individual depending on amount, timing, and frequency of exposure (Chudley et al., 2005). FASD is a largely invisible disability, characterized by cognitive, neurological, social, and/or emotional challenges (Streissguth, 1997). The effects of prenatal alcohol exposure carry heavy costs for the individual, their family, and society (Premji, Serret, Benzies & Hayden 2004). Youth with FASD and their caregivers require appropriate career counselling services and career interventions. However, there is a clear lack of attention to advancing career theory and practice to persons with disabilities (Cummings, Maddux, & Casey, 2000), particularly those with neurological impairments.

In this article we apply concepts from Social Cognitive Career Theory (SCCT; Lent & Brown, 1996; Lent, Brown, & Hackett, 2000) to potential career counselling interventions for youth with FASD who are making the transition to adulthood. The recent literature that has sought to understand the connections between individuals with neurological disabilities and career options has tended to focus on the barriers that negatively influence their career development (Cummings et al., 2000; Ettinger, 1996; Levinson, 1998). For example, some challenges include low self-esteem, difficulties in establishing routines, challenges related to information processing, and a tendency toward passive learning styles. Other contributions have sought to expand our understanding by emphasizing strengths and resources (Malbin, 2002). Following the idea of building on the strengths of young people with FASD, we use

SCCT (Lent & Brown, 1996; Lent et al., 2000) to provide a conceptual framework for understanding how personal attributes, the environment, and overt behaviours can be harnessed to awaken the potential and strengths that are within the reach of this population. As such, the goal of the present article is to encourage practitioners to use SCCT as a means to develop appropriate transition planning and career interventions for young people with FASD.

FASD: An Invisible Disability

The leading cause of developmental disability among Canadian children is Fetal Alcohol Syndrome (FAS) (Public Health Agency of Canada, 2005). The umbrella term, Fetal Alcohol Spectrum Disorder (FASD), is used to depict a range of disabilities as well as the diagnoses related to prenatal exposure to alcohol including Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), Alcohol-Related Neuro-developmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD).

The effect of prenatal alcohol exposure varies greatly among individuals, but the specific neurological impairments all impact abilities related to adapting to daily living as adolescents and adults (Streissguth, 1997).

... affected people exhibit a wide range of expression, from severe growth restriction, intellectual disability, birth defect and characteristic dysmorphic facial features to normal growth, facial features and intellectual abilities but with lifelong deficits in several domains of brain function (Chudley et al., 2005, S1).

Alcohol-related central nervous system dysfunction includes memory impairment, attention deficits, specific learning difficulties (e.g., mathematics or verbal reasoning), difficulty in abstracting, and difficulty with impulse control, all of which have implications for education and career planning. Difficulty in tasks that involve planning and following through with goal-directed action is a particularly common issue (Olson, Feldman, & Streissguth, 1992).

A considerable range of intellectual dysfunction is found among individuals with FASD. While organic brain damage does create particular cognitive and behavioural issues for individuals with FASD, individuals may have normal IQ scores (Streissguth, 1997). The effect of the brain damage is such that individuals' ability to access and utilize their intelligence is impaired. Unfortunately, standardized test scores in the normal range may mean that those individuals do not qualify for special educational and vocational services that use mental retardation as their qualifying criterion (Streissguth, 1997).

Impairments that develop or become evident over the course of the individuals' lifespan are referred to as secondary disabilities. These secondary disabilities associated with FASD may be more debilitating for the individual than the primary disability (Fast & Conry, 2004; Streissguth, 1997). Mental health issues, drug and alcohol addiction, trouble with the law, and difficulty with employment and life management are commonly cited (Famy, Streissguth, & Unis, 1998; Streissguth, Barr, Kogan, & Bookstein, 1997). Early diagnosis of FASD is in itself a protective factor, as this allows the individual to receive appropriate services and support from a young age (Streissguth et al., 1997). However, many young adults living with the disorder may have no formal diagnosis because they do not meet the out-dated criteria for a formal diagnosis or are unable to access limited diagnostic services (Premji et al., 2004). Those individuals with less severe symptoms are often at higher risk for secondary disabilities due to lack of understanding of the source of their behavioural problems (Streissguth, 1997). In addition, the most common secondary disability - mental health issues - may further complicate the presenting situation for these individuals. Comorbid conditions including depression, anxiety, and substance use highlight the need for practitioners to be sensitive to this combination of disability and mental health problems. These clients are neither solely organically brain-damaged nor solely emotionally disturbed (Streissguth & O'Malley, 1997).

Given the gaps and limitations of the current FASD career literature; there is a clear need for theory-based career development interventions that will address the unique needs of alcoholaffected individuals. In addition to the challenges that these young adults face, they also have strengths and abilities upon which to build. These strengths include good visual memory and verbal skills, persistence, commitment, success in low-stress, structured situations, a strong sense of fairness, and success in learning with hands-on tasks (Malbin, 2002). By recognizing and building on these strengths, suitable systemic transition planning can be engaged in for young people with FASD.

Transition to Adulthood

During the period from ages 18 to 25, referred to as emerging adulthood (Arnett, 2001), young people face a multitude of new opportunities and responsibilities that require the addition of new information, knowledge, and skills (Arnett, 2001; Mortimer, Zimmer-Gembeck, Holmes, & Shanahan, 2002). Successful transitions to adulthood appear to rest on a number of "readiness" factors and include objective and psychological aspects (Phillips, Blustein, Jobin-Davis, & White, 2002; Solberg, Howard, Blustein, & Close, 2002). Readiness is acquired objectively by engaging in work-based learning and exploration and through the instrumental and emotional support of adults who can orient youth to the world of work. Additionally, readiness is acquired through internal psychological contexts, for example, facilitative attitudes of curiosity and sustained attention, confidence about one's future plans, and flexibility in responding to challenges and obstacles (Blustein & Flum, 1999; Phillips et al., 2002).

FASD is a condition that children do not outgrow. Biological, adoptive, and foster parents have noted that raising children with FASD to adulthood is full of uncertainty for a number of reasons. Individuals with FASD lag behind developmentally when compared to other youth their age. Therefore, the readiness skills needed for successful transitions to adulthood may be delayed by several years and these youth will require more support between the ages of 18 and 25 years compared to their counterparts (Malbin, 2002). Additionally, adolescents with FASD are likely to display poor judgement, difficulty in perceiving social cues, and failure to understand the consequences of one's actions (LaDue, Schacht, Tanner-Halverson, & McGowan, 1999). In the transition to adulthood, lack of social skills may affect the ability of those with FASD to gain positive workbased learning experiences. However, emotional and instrumental support may be provided by caregivers and professionals. Although the majority of children diagnosed with FASD are being cared for in foster or adoptive homes (Hess & Kenner, 1998), foster and adoptive caregivers tend to be highly committed to maintaining long-term, stable, and nurturing environments for their children (Streissguth et al., 1997).

Social Cognitive Career Theory and FASD

Traditional career models imply that individuals have the ability to choose a preferred career based on values, interests, and abilities, and to plan and implement their choice. For individuals with FASD, this is not the case. However, little is known about how these individuals can successfully navigate life-career pathways. In essence, "the people who are in greatest need of assistance with career development are the ones about whom the least is known" (Harmon as cited in Chartrand & Rose, 1996).

Effective support of alcohol-affected youth requires that practitioners appreciate the impact of social environment, as well as the effects of the brain damage (Streissguth & O'Malley, 1997). The appropriate career development model must therefore take into account the individual's abilities and disabilities as well as family, school, and other socio-cultural factors or contextual affordances that have influenced the individual's development up to this point, and may continue to influence

the success of any intervention. A life-span approach is also called for, as individuals with FASD will need strategies and support to manage their disability throughout their lives.

Social Cognitive Career Theory (SCCT), an evolving model of lifecareer development, provides a conceptual framework for understanding how individuals develop interests in educational and career areas, make choices, and implement these choices with varying levels of success. SCCT incorporates Bandura's triadic reciprocal model of causality which assumes individual characteristics, environmental/contextual factors, and behaviour interact and influence each other throughout this process. Self-efficacy beliefs, outcome expectations, and personal goals are highlighted within this model of reciprocity and can be conceptualized as a developmental-contextual model made up of environmental layers, where the individual (with her/his personal characteristics) is embedded within their immediate family system, and within consecutively larger layers of context (Lent et al., 2000). Developmental-contextualism emphasizes the dynamic interaction that occurs between individuals and their environments (for example: community, sociocultural context, educational environment, and family situation). In this model, neither contextual factors nor individual characteristics (e.g., ability) are sole determinants in the life-career development process. Rather, individuals are able to exercise agency within the dynamic relationships that exist (Patton & McMahon, 1999). An individual filters and interprets information from the environment, which in turn affects self-perception and perceptions of the environment.

Personal resilience factors identified in the literature on disabilities include attainment of clear goals, ability to reframe the disability to recognize strengths, and the development of strategies and techniques to enhance performance (Dolyniuk et al., 2002; Garber, 2001). Environmental factors which foster positive interactions include supportive social environments, mentors who teach and guide performance, and the goodness of fit between the individual and their job or career (Garber, 2001; Hurlbutt & Chalmers, 2004).

Status variables such as disability affect individuals, not through the meaning or fact of the disability itself, but through the intrinsic effect of responses from the sociocultural environment with regards to the disability (Fabian, 2000). Attitudes based on myths, stereotypes, or on a lack of knowledge are likely to create substantial barriers including physical barriers, policy and procedural barriers, and attitudinal barriers. If, on the other hand, an individual's disability is not recognized, as is often the case, responses to behaviour cannot be interpreted through that lens of understanding. Individuals with alcohol-related effects as a result of maternal alcohol exposure are likely to experience frustration and low selfesteem, contributing to secondary disabilities. The relationship between an individual and his/her environment is seen as directly influencing life-career decision-making, which has important implications in planning career development programs.

The emphasis on the individualcontextual relationship is a departure from traditional models, which tend to place greater emphasis on values and aptitudes. In SCCT, values and aptitudes are seen as only one aspect of an individual. Individual characteristics influence career choices and behaviour through self-efficacy beliefs, outcome expectations, and personal goals. Selfefficacy beliefs are a dynamic combination of beliefs about oneself, linked with performance experiences (Lent & Brown, 1996). Outcome expectations are beliefs about projected results of behaviours. A type of outcome expectation that is particularly relevant to this discussion are those in relation to one's view of the environment – specifically, barriers to employment (Lent et al., 2000). Contextual affordance, or how environments may promote or obstruct one's ability to translate personal strengths into life-career possibilities (Patton & McMahon, 1999), is an important area to address in career counselling, as unaddressed barriers will hamper any progress that is made on the individual level, negatively affecting self-efficacy beliefs.

For individuals with FASD, self-efficacy beliefs, outcome expectations, and contextual barriers to employment may have an especially

strong influence on personal goals. Self-efficacy beliefs are formed through "(a) personal performance accomplishments, (b) vicarious learning, (c) social persuasion, and (d) physiological states and reactions" (Lent & Brown, 1996, p. 311). Given that alcohol-affected individuals may be operating on experiences of failure, are easily influenced by others, and have difficulty in managing difficult emotions, self-efficacy beliefs may be particularly low for these individuals. Improving self-efficacy beliefs is a key step in career development, as negative self-beliefs may lead to avoidance behaviour (Lent, Hackett, & Brown, 1999). The importance of realistic self-appraisals must also be stressed as unduly negative or unrealistically optimistic self-appraisals will have detrimental effects on progress in forging life-career pathways.

In terms of occupational choice, SCCT proposes a linear progression in which self-efficacy and outcome beliefs influence life-career interests, which in turn are translated into career choice goals, and result in motivation and action towards the goals (Lent & Brown, 1996). While the first part of this process - the influence of self-efficacy and outcome beliefs on interests and goals - is likely to hold true for individuals with FASD, translating goals into action will likely require support and advocacy on the part of the counsellor. Novick and Streissguth (1996) found that although clients often spoke about their situation as though resolution of problems would be easy to accomplish, "in reality they are often unable to follow through in obtaining services on their own behalf" (p. 21) and "memory problems, attentional problems, and poor organizational skills make these patients dependent on a strong infrastructure" (p. 21). Premji and colleagues (2004) highlight the need for structure and consistency in all areas of life for individuals diagnosed with FASD, particularly in regards to transitions, which should be gradually structured so as to ease anxiety and behavioural problems.

Counselling Strategies and Implications

The following recommendations represent a combined understanding of the spectrum of FASD, drawing on existing practical applications for career counselling with individuals diagnosed with other neurobehavioural disorders (e.g., Cummings et al., 2000; Hutchinson, 1995; Reekie, 1993; Schmucker, 1997) and from the personal experience of the first author in working with this population. Additionally an extensive review of peer-reviewed and grey literature databases by Premji and colleagues (2004) further inform the ideas presented in this paper. A broad understanding of career development is taken and includes psychological, social, educational, and physical factors that shape the career of an individual over their life-span (Herr & Cramer, 1996).). Suggestions include strategies for relationship building and assessment, identifying and building on individuals' strengths, and creating structure and support. It is essential that these suggestions be instituted in accordance with a prior multidisciplinary assessment of the individual's executive functioning, neuromotor or motor and sensory impairments, emotional functioning, medical treatment including diagnosis, and speech/language function usually undertaken by a team of health professionals.

Relationship Building and Assessment

General strategies for working with youth with FASD involve observing patterns of behaviour which reflect developmental stages in different life arenas; eliciting clients' understanding of what it is like to live with FASD; reframing their behaviour as a neurodevelopmental disorder; establishing concrete routines in the counselling sessions to avoid client frustration and to increase retention; preparing clients for transitions by posting activities to engage in during the session with time allotments; modeling positive interpersonal behaviours and providing feedback on body language and facial expressions; using visual aids; providing simple instructions using concrete examples from a multi-sensory approach; and making certain that the physical environment is organized, low

in sensory stimuli, quiet and comfortable; and providing templates and examples of written components such as resumes (Malbin, 2002; Reckie, 1993; Stade, Clark, & D'Agostino, 2004).

An individualized approach is mandatory, as individuals with FASD will have varying abilities and disabilities (Burgess & Streissguth, 1992; Olson, 1994). Rather than expecting the client to fit the intervention, the intervention should be designed to be flexible and adaptable to meet the unique and changing needs of the affected youth (Burgess, 1994; Olson, 1994). If a client does not identify as having a diagnosis of FASD, and the counsellor suspects that this could be an issue, the possibility of diagnostic testing should be discussed (Premji et al., 2004). Although testing can be expensive and difficult to access, for individuals with more severe symptoms on the spectrum, obtaining an accurate diagnosis may help individuals to access available services. Particularly helpful would be an individual support worker who can help to co-ordinate the various supports that the individual may need, for example, ongoing therapy, housing, job coaching, transportation, and financial assistance (Novick & Streissguth, 1996). Although an individual's IQ may fall within the average range, other features associated with alcohol-related birth disorders may affect the individual's ability to function at that level (Burgess, 1994; Premji et al, 2004.). While superficially youth with FASD may present as more competent than they actually are, when expectations are too high, they may show signs of disintegration (Coe, Sidders, Riley, Waltermire, & Hagerman, 2001; Dyer, Alberts, & Niemann, 1997). Positive correlations were found between IO and symptoms of moodiness, depression, aggression, inattentiveness, and hyperactivity of alcohol-affected individuals and high IQ (Coe et al., 2001), suggesting greater susceptibility among this group. In any case, a comprehensive evaluation "which identifies areas of strength and need, is critical to develop realistic expectations, secure appropriate supports, and develop effective interventions" (Premji et al., 2004, p.

Involving an individual's family in the career counselling process is an asset as sustaining progress in behaviour change is heavily dependent on the individual's receiving adequate understanding and support from their family (Novick & Streissguth, 1996; Premji et al., 2004). Most foster or adoptive parents of a youth with FASD want information in order to understand the physical, intellectual, and behavioural concomitants of their diagnosis (Brown & Bednar, 2004) and to use this information to develop reasonable expectations and to assist in the planning process. Biological parents, on the other hand, may first need support in working through possible feelings of guilt and shame before they will be able to provide support to their youth (Chudley et al., 2005). In family sessions, clients can receive comments on FASD traits that affect their performance, for example, how rigid and inflexible thinking gets in the way of learning new skills. Family members can be involved in counselling sessions, either as supportive observers, or actively, in eliciting strengths and resources, in teaching functional skills, and in interviewing or self-advocacy skills role-plays.

Sources of Self-Efficacy and Outcome Expectations

From a strengths-based perspective it is important to include an appreciation of strengths in our work with these youth. Rather than an exclusive focus on the challenges faced by alcoholaffected youth in the transition to adulthood, solutions may be found in the unique experiences, strengths, resources and skills of the youth, their caregivers, the family, and even the community in which they live (Prenji et al., 2004). Such strengths-based information provides indications of the solution that is likely to best fit the youth's unique circumstances. This is particularly true in working with youth who have experienced a history of school failure and early drop-out, social isolation, and behaviourial problems (Reckie, 1993). The shift from exploring the nature of problems and how they affect clients to exploring how clients have responded and coped with these problems in the past can be empowering in that it assumes an active coping response on

the part of the client (Wade, 1997). Efforts to teach new skills must build on areas of strength, as memory impairments and other issues impact the ability of individuals with FASD to maintain new learning.

Many alcohol-affected youth are tactile and visual learners. They benefit from "hands-on" activities and enjoy moving while they are learning. Their visual learning style encourages the use of "to-do" lists and day planners that also provide them with the structure and routine that is so critical to their wellbeing. Amundson (2003) suggests the use of chart paper to map out activities in the counselling session, for example, in goal setting. Concrete representations might be particularly useful in helping to retain new knowledge by accessing visual memory. Audio/visual playback is another technique suggested by Amundson, where audio or video is used to record parts of sessions, which may then be reviewed as a memory aid. This might be useful for rehearing behaviours, and also in tracking client progress to provide concrete proof of progress.

Structure and consistency provided by caregivers or professionals is known to positively impact the performance of youth with alcohol-related disabilities. Timler and Olswang (2001) suggest applying Vygotsky's theory of the zone of proximal development to youth with FASD. According to this theory, the adult gradually moves the youth to more complex levels of performance while structured support is provided and then faded out. Scaffolding, the term used to describe the manner in which an adult adjusts or modifies the support to the youth, could be used by career counsellors to best facilitate careerrelated behaviours, for example, conducting a follow-up call by telephone.

Novick and Streissguth (1996) indicate that cognitive-behavioural approaches are most effective for individuals with FASD, as these interventions may be designed so as to take into account the executive functioning challenges faced by many of these youth including storage and retrieval of information, interpretation of information, and utilization of information (Premji et al., 2004). As individuals may be unable to generalize skills learned in

counselling sessions to other settings, it may be more effective to teach the consistent use of rules of behaviour that can guide and structure behaviour across multiple situations (Novik & Streissguth, 1996). Premji et al. (2004) also emphasize the need to focus on developing an individual's functional skills through concrete learning experiences and cognitive rehabilitation approaches. One successful cognitive career-related education program for individuals with learning disabilities (Hutchinson, 1995) focused on increasing participant's awareness of self and of career areas through the use of an interactive computer program. Employability skills that address the vocational, social, and emotional skills necessary to enter a training program included listening, problem exploration, goal setting, and decision making. Interpersonal skills including cognitive rehearsal, imagery, and stress testing experiences were also taught. Programs for individuals with FASD could build on such a model, modifying it to include more behavioural strategies, modelling, and practice in implementing basic life skills in real life situations, for example, filling out a job application, keeping a job, interacting socially, managing time, and decisionmaking.

Promoting Supportive and Structured Environments

The relationship between self-efficacy beliefs and success proposed by the SCCT model illustrates the need for training and work experience situations in order to provide individuals with opportunities to improve life-work skills and enhance feelings of self-efficacy through positive experiences. Volunteering, 'take your child to work' initiatives, job shadowing, and structured, supervised work situations where outcome measures are adjusted to a realistic and attainable success level, are some practical work experience suggestions (Mader, 2004). In order to assist alcohol-affected youth to make successful transitions to adult roles, community leaders can redesign jobs to accommodate the capabilities and limitations for persons with FASD. Youth with alcohol-related disabilities need job duties, responsibilities, expectations, and rules clearly described ahead of time (Stade et al., 2004). Receiving positive feedback during such experiences enhances feelings of self-efficacy, which will in turn influence success. Group counselling settings are recommended for youth with learning disabilities (Hutchinson, 1995). This may also be beneficial for youth with FASD. Job clubs, for example, may provide opportunities for positive social experiences and skill development which will enhance self-efficacy beliefs as alcoholaffected youth require learning in multiple settings to increase transferability (Prenji et al., 2004).

As the disabilities are not going to change or go away, modifications to the environment to accommodate disabilities are essential (Schmucker, 1997). The provision of a personal tutor, mentor, or job coach may be necessary to help them learn skills and to maintain the job. Potential employers or mentors may need to be educated about FASD, and education, training, or work situations may need to be modified to accommodate the individual's particular strengths and limitations. For example, neuromotor impairments may manifest as sensory sensitivities which may necessitate changes to workplace temperature, lighting, and noise levels (Premji et al., 2004) or modifications to productivity demands based on client's capacity for speed and efficiency may need to be made. Advocacy may form an important component of the counselling relationship. Counsellors may need to exert pressure on community agencies and to orchestrate a variety of people, resources, and services to meet the needs of their clients and caregivers.

Conclusion

Youth with FASD encounter specific obstacles in their career development that are often due to a lack of awareness and sensitivity on the part of educational institutions, employers, and the public. Providing effective career development interventions requires practitioners to possess the requisite knowledge, skills, and awareness for addressing the career needs of alcohol-affected youth. The overarching recommendation for career counsellors is to keep in mind that each client with FASD has a unique combination of strengths and disabili-

ties, which must be understood within that individual's life context. A thorough neurobehavioural assessment can highlight assets and challenges in executive functioning, neuromotor and sensory areas, and speech/language. SCCT provides one possible framework for identifying barriers and building on strengths of youth with prenatal alcohol effects. However, there is an acute need for research and theory to inform career counselling practice that accounts for the individual's special needs as related to the specific experience of FASD, and the complex contextual factors which influence the life-work success of these individuals.

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