Bound by the clock: The experiences of youth with FASD transitioning to adulthood from child welfare care

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a condition that affects a significant proportion of children and youth in the care of child welfare agencies in Canada. Few studies have heard from the voices of youth with FASD themselves as they are leaving care. This article describes a qualitative study that focuses on the lived experiences of 20 youth with FASD in Manitoba as they were preparing for the transition from child welfare care to adulthood (or had recently emancipated from the system). The experiences and insights of these youth highlight the supports and services required by youth with FASD transitioning out of care, from both the child welfare system and from services for adults with FASD.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) has been recognized as one of the leading causes of preventable birth defects and developmental delay in children in Canada (Canadian Pediatric Society, 1997). FASD is the umbrella term used to describe the range of conditions caused by alcohol-exposed pregnancies (Paley, 2009; Warren et al., 2004), including Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), partial FAS (pFAS), alcohol-related neurodevelopmental disorders (ARND) and alcohol-related birth defects (ARBD). FASD results in a wide range of impairments on a continuum from mild to severe, with considerable variation in the effect on individual functioning (Abel & Hannigan, 1995; Barr & Streissguth, 2001), with both direct effects on functioning as a result of prenatal brain damage and secondary effects as a result of coping strategies to manage environmental expectations (Malbin, 2004).

In recent years, much attention has been given to the issues confronting youth who age out of the child welfare system and the deleterious outcomes experienced by many of these youth have been well documented (Reid & Dudding, 2006). Research shows that adolescents who are emancipated from the child welfare system at age of majority are more likely than those who have never been in care to be undereducated, experience homelessness, become a young parent, be unemployed or underemployed, if

employed to have earnings below the poverty line, be on social assistance, be incarcerated or involved with the criminal justice system, have mental health issues, and be at high risk for substance abuse issues (Courtney, Dworsky, Lee, & Raap, 2010; Tweedle, 2005). Youth with disabilities who are also in care face even greater challenges as they reach emancipation. In addition to the adverse outcomes experienced by many youth in care as they leave the system, youth with disabilities endure more placement breakdowns than other youth in care (Geenen & Powers, 2006), and are less likely to complete high school, pursue post-secondary education, or find gainful employment (Geenen, Powers, Hogansen, & Pittman, 2007). Being a youth with FASD results in further complications, such as needing supported living arrangements in adulthood, life skills training, and support services for mental health issues and addictions (Child and Youth Officer of British Columbia, 2006).

It is also well documented that Aboriginal children are significantly over-represented in child-in-care populations across the country, especially in the western Canadian provinces (Blackstock, 2007; Blackstock, Prakash, Loxley, & Wien, 2005; Blackstock, Trocmé, & Bennett, 2004; Canadian Council of Child and Youth Advocates, 2011). Aboriginal children come into care more frequently, partly as a result of the presence of multiple risk factors such as poverty, oppression, compromised parenting abilities as a result of the impact of the residential school system, and other social, economic and cultural variables (Fluke, Chabot, Fallon, MacLaurin, & Blackstock, 2010). These variables can lead to the use of alcohol to cope with adverse life conditions, with substance use during pregnancy a risk factor for the occurrence of FASD (Pacey, 2010).

While several studies have confirmed the risk of adverse outcomes for individuals with FASD, this study is unique in its effort to hear directly from the youth themselves and learn their needs to manage the transition to adulthood from child welfare care more successfully. Hearing the perspectives of these youth is critical for child welfare agencies, given the parental responsibility the child welfare system has taken on for so many youth with FASD under child welfare guardianship. These insights can inform policy development and service delivery, as well as set the stage for future outcomes research to assess how supports can make a difference for youth in care transitioning to adulthood including: attainment of early adulthood milestones (education, employment, life skills, personal autonomy, etc.), and reduction of more costly, problem-oriented services (such as criminal justice involvement, adolescent pregnancy services, reliance on income assistance, addictions treatment, and/or intensive mental health services).

Brief literature review

Adolescence is a challenging stage of development for youth, characterized by the tasks of physical maturation, identity formation, exploration of close relationships with peers, and achieving independence and autonomy (Christie & Viner, 2009). Recent research suggests that the process of maturation continues into early adulthood as the parts of the brain responsible for impulse control, emotional regulation, delaying gratification, and resistance to peer influence do not fully mature until an individual reaches his or her mid-twenties (Magyar, 2006; McGregor, 2009; Steinberg, 2007). Middle adolescence (age 15 – 17 years) is characterized by experimentation and risk-taking behaviours; in contrast, late adolescence (age 18 – 21 years) is marked by greater capacity for planning for long-term goals and incorporating a stronger sense of personal values (Christie & Viner, 2005). Contemporary families often afford adolescents and young adults a lengthy period of time to explore various roles and identities (e.g.

trying out different jobs, post-secondary education, dating relationships) in an emotionally and financially supportive environment that fosters identity formation well into early adulthood.

Youth in care, however, are often pressured to complete these developmental tasks before they reach legal age of majority, the age that often necessitates leaving child welfare care to live independently (Kools, 1997). Adolescents in care may be forced to complete the task of identity formation prematurely and at an earlier age than their peers who have not grown up in care. Additionally, Aboriginal youth often also have to deal with the developmental task of identity formation in disconnection from their family of origin and cultural heritage, which exacerbates identity integration. As Kools (1997) explains, "without a socially sanctioned or supported time frame for identity experimentation, identity development may be interrupted, incomplete, and potentially damaged or foreclosed" (p. 269). Consequently, youth transitioning from care at age of majority experience "a frustrating paradox, where they have little or no opportunity to practice skills of self-determination while in care, but are expected to suddenly be able to control and direct their own lives once emancipated" (Geenen & Powers, 2007, p. 1090). Although remaining in care past age of majority is increasingly recognized as an important opportunity to support the adolescent's more complete psychosocial development (Courtney, Dworsky, & Peters, 2009; Rutman, Hubberstey, & Feduniw, 2007), many youth find that the child welfare system does not recognize or support their need for independence and autonomy within a child-oriented structure once they reach legal adult age (Mccory, McMillen, & Spitznagel, 2008).

A high proportion of youth with FASD grow up in child welfare care (Besharov, 1994; Fuchs, Burnside, Marchenski, & Mudry, 2005), and these youth experience even greater challenges as they navigate the developmental tasks of adolescence. The effects of FASD on an individual's functioning have been characterized as both primary and secondary in nature (Malbin, 2004). Primary effects refer to the direct impact of damage incurred to the brain as a result of prenatal exposure to substances and include difficulty with executive functioning tasks (planning, organizing, setting goals, and following schedules, for example), memory problems, impaired judgement and decision making, difficulty with change and transitions, and impulsivity. Secondary effects are behaviours that develop in reaction to, and as a way of coping with, the primary disability, including fear and anxiety, poor self-concept, pseudo-sophistication, school behaviour problems, depression, frustration, aggression, and trouble with the law. By the time an individual with FASD reaches adolescence, these secondary behaviours may have become well established patterns with harmful outcomes (Malbin, 2004).

The impact of FASD is also mediated by environmental factors, such as living with an alcoholic parent or being subjected to child abuse or neglect, or other adverse life conditions such as poverty (Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004), factors which often lead to child welfare's involvement and a child's admission to care. This is a particularly salient point as it pertains to Indigenous populations, who frequently are affected by low socioeconomic status and the drinking patterns that are associated with coping with impoverished living conditions (Abel & Hannigan, 1995; O'Leary, 2003), conditions which can contribute to the occurrence of FASD.

A number of protective factors have been identified that can help to ameliorate the damaging effects of FASD. These protective factors include the early diagnosis of FASD which can aid in responding more appropriately to the child's behaviour (Streissguth et al., 2004), a steady caregiver who understands the disability (Graef, 1998), a stable and nurturing home environment (Streissguth et al., 2004), and adjustments to the environment to meet the child's needs rather than expecting the child to adapt to the environment (Malbin, 2004).

However, the secondary behaviours resulting from FASD may exacerbate the issues facing youth in care throughout adolescence and compromise these protective factors. Placement breakdowns occur with concerning frequency, especially in adolescence (Geenen & Powers, 2006; Hyde & Kammerer, 2009), disrupting school stability and increasing the drop-out rate for youth in care (Courtney & Hughes Heuring, 2005; Stott & Gustavsson, 2010), and contributing to a higher incidence of aggressive and anti-social behaviour (Ruest, 2000). Youth with FASD in care are also at high risk for mental health issues and substance misuse (Child and Youth Officer of British Columbia, 2006). Throughout these experiences, key relationships with caregivers, peers, teachers, and communities are also broken, leaving youth with little feeling of belonging or a focus of control in their lives (Stott & Gustavsson, 2010). As youth reach age of majority, many seek out relationships with biological family members, partly to make sense of their identity but also to replace formal relationships with foster parents, social workers, and other professionals that often end in adulthood (Collins, Paris, & Ward, 2008), only to find that family members may be still struggling with the issues that initially led to the involvement of the child welfare system.

In summary, youth in care with FASD face daunting obstacles to their future success posed by the dual challenges of being in care and coping with their disability. Both the primary effects of brain damage from prenatal alcohol exposure and the secondary behaviours resulting from a poor fit between the individual and their environment complicate the needs of adolescents with FASD, especially as they reach age of majority and are conferred with the immense responsibilities of emancipation that are not congruent with their abilities.

The voices of youth with FASD leaving care

Methodology

This study involved semi-structured qualitative interviews of youth with FASD who were in care of Manitoba's child welfare system to hear about their experiences of transitioning out of care with their disability. Child and Family Services agencies in the province were sent an information package about the project with a request to distribute invitation letters to youth with a diagnosis of FASD who were permanent wards (or who had been in long-term care until adulthood) between the ages of 16 and 21 years of age. Interested youth contacted the researchers directly to arrange an interview. A consent form was signed by the youth and, if they were currently in care, co-signed by their caseworkers. A gift card to a local department store valued at $50 was given to each youth who participated in an interview. Interviews were digitally audio-recorded, transcribed, and then analyzed with the NVivo computer software for qualitative research. The constant comparison method was utilized to identify themes and categories that emerged from the youths' narratives.

Limitations

Due to the challenges in recruiting youth with FASD to talk about their personal experiences, the findings of this study are based on a small group of participants whose perspectives may not be generalizable to a wider population. Formal confirmation of a diagnosis of FASD was not sought from the participants or their caseworkers; referrals were accepted on the basis of the identification of FASD by the young person and his/her caseworker. Although care was taken to ensure that participants understood the questions they were asked in interviews by phrasing questions in plain language and restating in alternative words to enhance clarity, it is possible that their disability affected their interpretation of the questions or influenced how they responded to questions. Finally, information provided by the youth such as length of time in care or number of placements was not cross-referenced with agency records.

Demographic portrait of the youth participants

Interviews with twenty youth ages 16 to 21 were included in the study, ten males and ten females representing all four Child and Family Services Authorities in Manitoba: one from the Metis Authority, three from the General Authority, five from the Northern Authority and eleven from the Southern Authority. The majority of youth were of Aboriginal descent (90%). Twelve of the youth lived in urban settings, seven lived on reserve, and one lived in a rural area. Fourteen of the participants were still in care at the time of the interviews, with nine under the age of 18 and five in an extension of care past age of majority (the age of 18 in Manitoba). Four youth who had left care at the time of their involvement in the study had received an extension of services prior to emancipation from the child welfare system.

Eight youth reported entering care prior to age one, nine reported they were admitted to care between the ages of one and six, and three came into care around age twelve. Half of the youth had experienced between two and five placements, six had between six and ten placements, two had between eleven and twenty placements and one reported more than twenty placements.

More than half of the youth (eleven) reported that their longest placement had lasted more than ten years, although four of these placements had broken down in adolescence. Six youth stated that their longest placement was less than two years while three reported placements lasting between three and five years.

Six of the ten female participants had a child, and two of these youth were pregnant with their second child at the time of the study. Nine of the twenty youth were still in school, with three having returned to school after a period of disruption in their education. Two youth had completed high school with no disruptions in their schooling. The remaining nine adolescents had left school without completing high school and were not currently enrolled in school.

Findings

The perspectives shared by the adolescents in this study reveal a compelling description of the lives of youth with FASD in child welfare care, a story that has rarely been told by youth themselves. Their experiences are critical for child welfare agencies and foster parents to understand. Further, those who form policy and legislation and develop programs will benefit from understanding the experiences of these youth, in order to ensure that services and policy frameworks are best suited to meeting their needs. The results of this study can be organized around five main themes: (a) the role that FASD plays in the lives of adolescents in care; (b) the critical need for consistent relationships; (c) developmental experiences for youth with FASD; (d) challenges in adolescence; and (e) transition planning for youth with FASD at age of majority.

Role of FASD in the lives of youth in care

Very few of the study participants had a thorough understanding of FASD as a disability. Seven of the youth acknowledged having been informed that they had FASD by a social worker or foster parents, but could not recall having an assessment done. Four youth were not sure if they had been diagnosed with FASD, while six stated that they did not have a formal diagnosis. Two youth were not even sure what FASD was. Those who had been diagnosed reported carrying a significant amount of shame about their disability and actively rejected the label due to their belief that others would expect less from them if they had FASD.

Despite the variations in their awareness of FASD, many youth expressed feelings of not being 'normal', a sense that they were different from others. They were quick to blame themselves when things did not work out in their lives, attributing their struggles to personal shortcomings. Placement breakdowns were especially internalized. The youth reported feeling argumentative, fatigued, anxious, frustrated, angry, aggressive, and destructive, and described experiences of being picked on, causing fights in the home, fighting at school, running away, being in trouble with the law, addictions, and mental health problems. Many of the struggles reported by these youth are characteristic of the secondary behaviours associated with FASD as described by Malbin (2004) and Streissguth et al. (2004).

Although the identification of 'learning differently' and not feeling 'normal' among the participants of this study was not attributed specifically to FASD, the perception of not feeling 'normal' was a source of considerable distress for these youth. Frequently, they expressed the desire to be like other people, who had life skills, jobs, and families, and succeeded in life. They were not always sure that these outcomes were possible for them, sometimes expecting that a program would teach them how to be 'normal' and comparing themselves to others for evidence that their achievements were approximating those goals.

Importance of relationships

The importance of relationships in the lives of the participants was a dominant theme in this study. Throughout their interviews, youth reflected on their desire for 'real' family connections. They acknowledged the limitations of their own biological families, many citing how family members were struggling with health concerns, substance addictions and other life challenges. Frequently, adolescents disclosed how much emotional pain the lack of relationship with biological family caused for them, describing this gap "like a hole", suggesting a depth of unresolved grief and loss issues.

Even when contact with biological family did occur, the youth reported that it was often intermittent and unpredictable, and for the most part, they could not rely on biological family to be a support in their lives. For most of the youth, family relationships had been disrupted since early childhood, with 40% having entered care at the age of one year or younger, and another 45% entering care between the ages of 2 and 6, making the maintenance of relationships with biological families over the years a challenge. Instead, many adolescents seemed to direct their yearning for family connections to their foster families, quite understandably given the proportion of their lives spent in care. Although many youth had positive relationships with their foster parents, they still expressed their recognition that these relationships were created in a professional forum and were likely to terminate at age of majority. There was no guarantee that relationships would continue into adulthood, and some youth spoke poignantly about their lack of control over this facet of their lives (for example, "It's hard knowing that they have the option of just shutting the door as soon as [you're] 18, and it makes you feel like you don't belong, because family is someone who cares for you and loves you").

Additionally, some youth recounted that there had been no conversations between themselves and their foster families about whether continuing to live with them into adulthood was an option or what the nature of their contact might be after emancipation. There was great sensitivity around this issue for many youth, especially for those in long-term placements, one of whom worried that he might "become a burden" to his foster family for continuing to live with them into adulthood. For those youth who experienced disruptions in foster placement in later adolescence, relationships with foster parents may not have been long enough to even expect continuation into adulthood.

Some adolescents turned their feelings about not having family connections (whether foster family or biological family) to self-blame, identifying themselves as not worthy of relationships, as being difficult to live with, or difficult for others to care about. Others attributed family relationship problems to their behavioural choices and breaking the rules, which elicited the disapproval of others and, on occasion, placement breakdown. Few of the youth identified FASD as being a factor in these experiences.

The respondents also spoke about desiring stronger and closer relationships with their social workers, although they were cognizant of the professional nature of these relationships and that they shared their workers with other children in care. In particular, they wanted social workers to know them more intimately, their interests and needs, their strengths and weaknesses, and they wanted workers to be more genuine in their interactions with them. Much of their commentary about better relationships with workers was related to the professional context – involving youth in decisions about their lives and engaging them in planning for their futures – but with a degree of personal caring attached, perhaps to "keep in contact after they have transitioned, just to make sure they are okay". At the same time, many youth shared that they had been assigned several different workers throughout their years in agency care, yet another example of relationship disruption in their lives.

Adolescent development for youth with FASD in care

The participants in this study identified ways that they tried to exert their independence throughout adolescence and the challenges they experienced. Most frequently, these challenges were related to their status of being a child in care and not attributed by the youth to having FASD. Many youth described difficulties that they had experienced when trying to follow the rules set by their agencies and foster parents. For these youth, the problem was not the rules themselves, but their inability to follow those rules. Other youth recounted instances of becoming so frustrated with the rules, especially when their desires were not being considered by foster parents or social workers, that they took matters into their own hands by running away or visiting siblings without permission. The limits to self-determination imposed by the child welfare system intensified the differences the youth in this study perceived between themselves and their peers who were not in care. They saw their peers as able to come and go as they pleased (within the general boundaries set by their parents), yet knew that this same freedom was not necessarily afforded to them by the child welfare system.

Many respondents experienced being in care as engendering dependence on others, as a result of being told what to do and suffering consequences for acting independently (especially if it involved breaking the rules). Several youth expressed their frustration with the control of the child welfare system, tension which often translated into strong statements about the participants' desire to leave the care and control of their child welfare agencies. For many participants, discharge from child welfare care simply meant more opportunity to make their own decisions. Other youth, comparing themselves to their peers, felt that they needed to be able to leave care in order to do the things that 'normal' people do. Although most youth in this study were provided with an extension of care, it is significant to note that two of the three youth who declined this opportunity did so expressly to be free from agency control. This outcome is particularly concerning, as having more time in care provides a valuable opportunity to develop the necessary skills and readiness for more successful transitioning at adulthood.

Many of the older respondents (age 18 – 21) in this study reflected back on their earlier adolescence, describing it as marked with "making mistakes" and "poor choices". But shifts in their perspectives were evident with growing maturity as youth reached age of majority or were already into early adulthood. This shift was evidenced in their descriptions of being ready for 'new beginnings', a sense of strength that had come from overcoming the past, and the identification of goals and ambitions. Older youth were also more cognizant of the challenges of independent living; although they looked forward to the opportunity, they also feared the responsibility and wondered who would help them if they had difficulty.

Younger youth (under 17 years) in the study presented an outward display of confidence that they would be able to manage independently at emancipation, citing "I can do it on my own" while also conceding there were many life skills they still needed to learn – an interesting contradiction. Future goals were non-specific; youth planned to "go day by day" and "see what happens". Their confidence might be interpreted as typical for this stage of development, when many adolescents are interested in emancipation from adult rules without fully appreciating the complexity of supporting one's self independently. However, even these younger adolescents knew that, unlike their peers who were not in care, they would need to act on their desire (and the necessity) for independence much earlier, but had developed no concrete strategies to navigate this transition.

Although older adolescents in this study were the only ones who demonstrated a capacity to reflect on the past and considered themselves to be at the threshold of a fresh start in their lives, all of the respondents expressed strong worries about the future and struggled with planning for the future and making their independent living plans a reality. Even many of those who were ready for 'new beginnings' did not have specific plans in place, and were not sure who might help them develop and implement any plans. A common reaction to looming independence was avoidance, with some youth admitting that thinking about the future created considerable anxiety.

Additional challenges during adolescence

In addition to the tasks of adolescent development, being a child in care, and living with FASD, six of the ten female respondents in this study also had children to raise. Although not all were necessarily parenting at the time of the study, all were intent on parenting as soon as they were deemed capable of doing so by their child welfare agencies. Some who had their children removed from their care stated that they had been advised by the agency that it was due to their developmental disability of having FASD, while others identified their poor behavioural choices as the reason they were not parenting at the time of the study.

Although more than half of the study participants had experienced disruptions in their education, they continued to identify high school graduation as an important indicator of success in life. Still, many found the traditional approach to education to be restrictive and they hoped to have more success at specialized school programs, while others reported difficulty in attending school consistently while also juggling the responsibilities of parenting. However, the main challenge identified by these youth was their different learning style which made it "hard to learn", although FASD was not specified by youth as the reason behind their learning difficulties.

Experimentation with alcohol and drugs is not unusual in adolescence. However, some of the youth in this study attributed their involvement with substances as a by-product of reconnecting to biological family who still struggled with substance abuse issues themselves, while others provided the rationale that they had no other activities to occupy themselves. There was a degree of recognition that substance abuse was a concern and some participants had already taken steps to distance themselves from those who had substance abuse issues, whether biological family, partners, or peers. Others were no longer using substances presently, but acknowledged usage in the past.

Preparing for age of majority

Despite policies for Manitoba child welfare agencies guiding transitional planning for youth in care, the participants in this study revealed in their narratives a concerning disengagement from and lack of awareness of this process. Further, their stage of adolescent development and self-protective strategies predisposed them to casting a pretence of readiness for the challenges of adult autonomy, which in reality concealed their fears and their paucity of solid plans for the future. Of further concern, as reported by this study's participants, extensions of care did not appear to enhance their involvement in actively planning for their futures.

Most youth could not recall having discussions with their social workers or their foster parents about what would happen to them at age of majority. Those who asked for help reported that they received little response. Many were planning to rely on themselves to figure things out, although their plans were vague, or they preferred not to think about the future and have just faith that things would work out. Younger youth were the least likely to be involved in specific planning for emancipation, but also expressed the most confidence in their ability to take care of themselves. Many youth were also confused about what transitional planning was even about, an indication that this process requires more leadership and transparency by the adults in their lives.

Perhaps one exception to transition planning that was initiated by caseworkers was the option to extend care beyond age of majority. In this study, almost all of the older adolescents had been offered (and accepted) the opportunity to extend care, usually to continue with school or to attend an independent living program.

However, extensions of care appeared to be offered "at the last minute", very close to age of majority. Youth in care were not in a position to initiate these discussions, and either had to wait for transitional planning options to be raised with them or resign themselves to the need to plan on their own. The disconnections in relationships that these youth have experienced may play a significant role. As noted earlier, youth described feeling disconnected from their caseworkers, which makes it difficult for them to advocate for support in transitional planning (assuming they knew that such planning was important). It also appears that the youth were not sure if they had a strong enough relationship with their foster families to even broach the subject of continuing to live in the same foster home past age of majority, and reportedly, the adults in their lives were not raising the topic on their behalf, leaving them with fears about having to leave placement and agency care at age of majority.

Most respondents in this study described themselves as not involved in formal programming for independent living skill development. They were aware of the general types of skills they would need (for example, as related by one respondent, "how to cook, pay bills, and how to keep a steady job"), and recognized that they required assistance of some kind (usually identified as "programs") to teach them the necessary skills. However, foster parents were cited as the most common source for assistance in developing independent living skills, although most youth in the study struggled to specify what skills they had mastered. Four youth were involved in independent living programs, but still struggled to articulate how these programs were helping them to develop specific skills they needed for successful emancipation. Often, the participants' self-assessment of their independent living skills perpetuated the pattern observed in other aspects of this study: a veneer of confidence in one's abilities, which served to conceal considerable gaps in substantive skills.

Although the participants in this study mainly did not identify FASD as a specific factor that interfered with their attainment of skills for independent living, older respondents had a more realistic appreciation of their skill strengths and deficits and commented on learning from past mistakes, suggesting a growing readiness to manage the responsibilities of emancipation over time. The findings from this study show that persons with FASD, much like their peers who are not affected, develop more capacity to think abstractly and to contemplate the cause and effect of their actions as they progress into young adulthood. However, only two youth identified FASD-specific services as something they would require in adulthood, an indication that better awareness of their disability and the availability of adult FASD services are needed.

Summary

In many respects, the findings from this study reflect what is reported in the literature concerning youth in care. The youth desire genuine relationships with people who will love them for who they are, not simply care for them because they are paid to do so. Yet their previous experiences – dysfunction in the family of origin, frequent moves, changes in foster parents and social workers, and the feeling that they are not in control of their own lives – have made it difficult for them to trust the adults in their lives, thereby hindering the development of meaningful relationships.

They have difficulty planning for the future, and although they are generally aware of the skills that they will need to live independently, they have been given little opportunity to practice those skills. However, they also exhibit a confidence in their abilities that belies their lack of skills and concrete plans for the future. Consequently, planning for the transition to adulthood is fraught with disengagement and rejection of potential supports, despite policies intended to ensure that youth are supported through emancipation.

The findings from this study are also consistent with the literature on youth with FASD in many ways.

The respondents reported having experienced difficulties in school, which frequently ended in school disruptions. The youth also exhibited secondary behaviours that are frequently associated with FASD, including anger, aggression, anxiety, poor self-concept, addictions, and mental health problems. Unfortunately, these youth don't have a good understanding of their disability and therefore blame themselves for the failures and disappointments in their lives.

Recommendations

FASD is a condition with significant and serious lifelong implications which are well documented in the professional literature. Comparable effects of FASD were evident in the lives of the youth who took part in this qualitative study. In conjunction with the impact of FASD, however, was the experience of growing up in child welfare care. An extensive body of research describes the adverse effects of long-term child welfare care on future outcomes, many of which had already been experienced by the participants of this study.

Yet, although they face formidable challenges, the adolescents in this study expressed determination to achieve the same characteristics of a positive life that seemed available to their peers who did not grow up in care: family, friends and meaningful work. Their spirit and resolution was striking and undiminished by the hardships they faced in life as they exited the child welfare system. Their fortitude should serve as inspiration, but our awareness of the very real barriers they face must remind us of the importance of providing FASD-affected youth with the services and supports they require to meet their goals as they transition into adulthood. Our challenge as practitioners, caregivers, policy-makers and researchers is to determine the most effective strategies to assist youth with FASD in child welfare care on their journey to adulthood, to mitigate both the impact of FASD and of growing up in alternate care on their lives.

The impact of FASD

The impact of FASD on the lives of youth in care can be ameliorated in several important ways. Canadian guidelines on the diagnosis of FASD are clear that professionals are obligated to ensure that all adults who work with a child with FASD (biological family, alternative caregivers, day care and school personnel, early intervention workers, etc.) should be informed of the diagnosis and assisted to develop strategies to best manage the impact of the condition on the child's functioning (Chudley et al., 2005). However, what may not be contemplated are the changes in membership in the child's support network that occur over time and how information is maintained and transferred among the support network members throughout these changes. Admissions to care and changes in caregivers, case managers and schools each may contribute to an erosion of information, leaving those who work most closely with a child uninformed about the exact nature and impact of the child's diagnosis. Further, children's capacity to understand their diagnosis changes as they mature; periodic discussions with the child to review how their condition affects their functioning at different stages of development helps to ensure that they have stronger self-awareness and positive coping skills.

Therefore, additional policies in the national guidelines are required to ensure that this information is regularly reviewed and updated throughout the child's life, to ensure that new members of the child's support network are well informed of the specific impact of FASD on that unique child's functioning. Preferably, each child should have a case manager identified within the FASD diagnostic team who retains an ongoing oversight responsibility for his/her FASD-related issues, such as periodic re-assessments of the child's functioning and coordination of team interventions to meet the child's changing needs.

The role of child welfare agencies merits specific mention in the national guidelines, given the central role that child welfare plays for so many children with FASD. Child welfare agencies are in a key position to manage the living arrangements, school enrollment, health care services and mental health supports of children with FASD who are in care. In particular, foster parents need to be identified as primary team members in supporting children with FASD. Strategies to ensure a strong linkage between the FASD service community and the child welfare system and its care providers, ideally through an FASD case manager as noted above, will be most helpful in this regard.

Reciprocally, the child welfare system needs to consider how the national guidelines impact its own standards of practice for children in care. Principles of the national guidelines point to the importance of early diagnosis, cultural sensitivity, and early intervention. Special focus on practice policies with regard to children with FASD are warranted, given the current proportion of children in care with FASD.

With FASD having life-long implications, expanding the range of adult FASD services becomes a priority. Data from the 2005 study by Fuchs, Burnside, Marchenski, and Mudry identified that up to 17% of all children in care in Manitoba had FASD, a figure that is considered to be a conservative estimate. Due to that research, a known and growing population of children with FASD will be approaching adulthood with considerable needs for services. The magnitude of those needs is underscored by the findings of this qualitative study. It is therefore an opportune time to begin development of a comprehensive range of support services for adults with FASD.

Relationships in the lives of youth with FASD

Like many children in care, the participants described their challenges in finding and maintaining supportive relationships with significant adults in their lives, experiencing great difficulty in this process which they often attributed to their own faults and failings. Biological family relationships are significantly disrupted when children come into care and may not be remediated during the course of the child's time in care. Those who did reconnect with biological family in adolescence or early adulthood often found family members still struggling with issues that prevented them from being reliable sources of support or guidance. While relationships with foster parents may be positive, the youth recognized that there were no guarantees that foster parents would love them and care for them the way biological families might be expected to do. These youth were acutely aware that their experience of living in foster care was markedly different from that of 'normal kids' who did not grow up in care. Consequently, they realized that they had to take responsibility for themselves at a much earlier age than their peers. Relationships with caseworkers were also identified as an important source of support.

Foster parents are indispensable supports in the life of a child in agency care. This study has demonstrated that children growing up in care from a young age direct their need for attachment to those who provide consistent care to them – their foster parents. Without opportunities to live with biological family, children in care seek bonding with their caregivers, yearning for genuine relationships, a real family, and a place to belong and call home. Uncertainty in relationships with caregivers may contribute to misbehaviour in adolescence, adding strain to the fostering relationship and increasing the risk of placement breakdown. Consequently, roles that all parents need to undertake in relation to adolescents, such as monitoring adolescent behaviour while also promoting age-appropriate independence, identifying and responding to risk indicators (such as signs of depression or substance use), assisting youth to develop greater responsibility in decision-making, role-modelling skills in conflict resolution, and advocating on behalf of the youth with external systems including schools (Small & Eastman, 1991), may not be fully employed by caregivers. This often leaves youth without the structure and guidance they need while navigating the challenges of adolescence.

It is critical, therefore, to develop alternative ways to ensure permanence for children in long-term care, subsequent to ascertaining a permanent placement. Specialized training for foster parents who are making a commitment to parent a permanent ward of a child welfare agency should address issues of role clarity, decision-making, transitional planning, and relational continuity. This will lead to foster parents having a stronger sense of their responsibilities and a stronger degree of sanctioned empowerment to engage in active decision-making on behalf of a child permanently in their care (VON, 2006). Permanent Ward Foster Parent Training will also need to focus on the many themes identified by the youth in this study, including attachment between the youth and the caregiver, the impact of child welfare care on adolescent development, methods to help adolescents acquire decision-making skills, techniques to assist youth with the development of independent living skills, and understanding the impact of disabilities such as FASD on child and adolescent functioning.

With stronger sanctioned status and affirmed commitment as a foster child's long-term parent, caregivers may be in a stronger position to take on the full range of roles and responsibilities otherwise expected of biological or adoptive parents. As relational permanence is established, foster parents may be more willing to preserve a relationship with a youth who presents with challenging behaviours in adolescence, a period that is often marked with placement breakdown. Additionally, foster parents can play a key intervention and advocacy role by engagement, involvement in community activities, and positive peer relationships. Their investment in the adolescent's life may yield considerable benefits for the youth, such as an enhanced ability to form trusting relationships, stability in the youth's support network, academic advancement, and a reduction in problematic behaviours, thus diminishing the risk of placement breakdown and promoting an environment in which youth can thrive and become better prepared for the responsibilities of adulthood.

Role of child welfare agencies

The importance of stability for youth in care cannot be over-emphasized; for youth with FASD, consistency is an essential element in managing the impact of the disability on functioning. Recent research suggests that the biggest issue facing foster children is not the fact that they are growing up in care (which often has protective benefits) but the impact of disruptions in their social networks when placements breakdown, youth move to new neighbourhoods and transition to new schools, leaving behind an established network of caregivers, foster siblings, peers, and community supports (Pecora et al., 2005; Perry, 2006). Given that disruptions to placement are more likely in early and middle adolescence, agencies should plan for their services to involve a good deal of crisis intervention, conflict resolution, strong advocacy, risk management, and relationship preservation. In short, any and all efforts should be employed to resolve crises that arise to maintain continuity of placement and school, as long as that continuity remains in the child's best interests. Partnering with foster parents in these endeavours is critical, given the daily contact caregivers have with their charges, but if placements break down, the agency and the social worker become the youth's main source of advocacy and support.

Despite proactive strategies to preserve foster home stability, placement breakdowns still may occur for a variety of reasons, and alternative strategies to maintaining relational bonds are necessary. One alternative described by Greeson, Usher, and Grinstein-Weiss (2010) is supporting the establishment of natural mentors for youth in care: a stable, caring adult who is already present in a youth's environment and who is willing to take on a committed role in assisting youth throughout life, including the transition into adulthood. Termed "one adult who is crazy about you" (p. 576), the authors demonstrated that natural mentors provide an opportunity for role modelling and social learning for youth in care, resulting in guidance and advice, emotional support, and practical help, and increasing the likelihood that the youth achieved concrete assets (e.g. bank account, vehicle) in adulthood. However, Perry (2006) cautions that if that one supportive relationship ends, the impact of that disruption of supports can be devastating for a vulnerable youth. Therefore, having multiple strong support networks is recommended.

Further, the relationship between the adolescent and the child welfare worker is critical. The youth who were involved in this study conveyed their desire to have closer relationships with their social workers, even though they acknowledged the professional origin of the relationship and the limited availability workers had, given their broader caseload responsibilities. In particular, the adolescents were looking for personalized qualities of the worker-client relationship, something that showed them that they were known as unique individuals by their workers. Strong connections between youth and their workers can be a powerful influence, using the basis of trust to negotiate compromise and facilitate stabilization in the midst of crisis.

Having close relationships with youth in care can contribute to a greater awareness of issues that may arise during adolescence, such as mental health concerns, substance abuse, sexual exploitation, gang involvement, or criminal activity. A key function of child welfare workers is supporting youth through their involvement with other systems when these issues surface, ensuring that the adolescent's needs are met and they receive the services they most require. Advocating on behalf of youth in care and coordinating services across systems, and with the foster home, are other important worker functions that are facilitated by a strong relationship between workers and youth in care.

Transition planning with adolescents

Another theme identified by the youth participants in this study was their disengagement from transition planning for future emancipation from child welfare. A number of youth-related factors may contribute to this phenomenon: their stage of adolescent development, their veneer of self-reliance, or the degree of crisis and disruption in their lives, for examples. Nonetheless, it is important to also consider how agency workers can improve youth engagement in transition planning.

Although standards of practice with regard to transitional planning for age of majority are well documented, many child welfare agencies in Manitoba do not consistently meet these expectations. Speculation as to why this occurs includes staff turnover, high caseloads, placement breakdown in adolescence, and unfamiliarity with the standards of practice. Regardless of the barriers, it is clear from this study that youth do not feel sufficiently involved in planning for their futures, and child welfare workers hold significant responsibility for addressing this.

Transitional planning with youth must include attention to the planned living arrangement at age of majority, eligibility for an extension of care, an assessment of independent living skills, referral to appropriate resources to develop life skills, and plans for education or vocational training. Some agencies offer their own set of support services to assist youth in developing independent living skills, while others rely on community-based programs. In general, though, there are not enough programs available for youth who need to prepare for emancipation, particularly in rural and northern regions of Manitoba, and none with a specialization in assisting youth with FASD.

Re-conceptualizing services for adolescents with FASD in care

It is clear that the participants in this study have confronted the same adverse risks of living with FASD and growing up in care as evidenced in the professional literature. While policies and programs exist to mitigate these risks and assist youth with the transition to adulthood, these efforts do not appear to be sufficiently meeting the needs of the participants in this study. The youth respondents spoke of not being engaged in transition planning and not knowing what specific skills they might require to manage the responsibilities of adulthood, but still portrayed a facade of self confidence that they could figure it out once they were on their own. Only the older respondents, already into their early twenties, showed an appreciation of the challenges they faced and acknowledged any degree of fear about how they would manage without the support of biological family, foster family, or their child welfare agency.

One of the most striking outcomes of this research is the clear progression of insight that developed as youth matured in early adulthood, leading to the assertion presented earlier that there is a significant mismatch between the timing of transitional planning activities/independent living preparation and the developmental readiness of youth in care. At age sixteen, when transitional planning is to begin, youth are still struggling with behavioural issues, school disruption, placement breakdowns, criminal justice involvement, experimentation with drugs and alcohol, and other well-known troubles of an adolescence spent in care. Child welfare workers may expend considerable energy responding to crisis issues experienced by the youth, leaving them little time to focus on transitional planning. But more importantly, at this stage the youth themselves are not able to focus on the future. Initiating transitional planning measures when youth are still in middle adolescence and not yet developmentally prepared to take full advantage of these processes proves to be a disservice to youth in care.

The timing of transitional planning is bound by the clock, stipulated by policy that endeavours to provide at least two years of preparation for emancipation before the youth exits care at age of majority. Only formal extensions of care for those youth who are willing and eligible provide any opportunity for matching developmental maturity with the provision of transitional planning services. However, the periods of extension provided to many of the respondents in this study tended to be a few months in duration, not long enough to reach a stage of more advanced maturity.

An obvious solution to address this mismatch is to ensure that more youth in care, especially those with FASD, are granted sufficiently long extensions of care to allow them to more thoroughly complete the developmental tasks of adolescence and become better prepared for emancipation. Once the crises of middle adolescence have stabilized and passed, youth are more capable of focusing on their future goals and applying the focus and energy required to build the skills and knowledge they will need in adulthood. In other words, extensions of care that continue into the young adult's early 20s have a better chance of matching transitional planning measures with developmental readiness.

However, this direction is not without its drawbacks. Extensions of care require the availability of caregivers, funding, case managers, and other agency resources to provide the kind of supports that these youth desperately need into early adulthood. Most jurisdictions struggle with high caseloads, limited foster care options, and financial constraints just providing adequate protection and care services to the children they already serve. Expanding the services of child welfare agencies into adulthood for an increasing proportion of vulnerable youth may strain the capacity of an already overburdened system to meet its mandate. While it can be argued that all youth who are permanent wards are vulnerable and likely in need of extended care, one alternative to managing the increased demands on the child welfare system may be to prioritize those youth who have FASD for extensions of care, viewing this disability as a compromising condition that merits special consideration.

More importantly, youth who are offered an extension of care are, for all legal purposes, adults. Extension of care that are merely a continuation of the same kinds of services provided to adolescents prior to age of majority do not adequately recognize the status of young adults receiving care. Although they can choose whether they want to accept extended care services from a child welfare agency, young adults in extended care do not have any choice in the kinds of services they will receive or the manner in which they will be provided. Failure to address this shift in status may keep young adults in an infantilized position, further perpetuating their feeling of being different from their peers. If the supports provided to them through extended care have the same features as the services received as children (characterized by the youth in this study as rigid rules, agency control, limited autonomy in decision-making, and risk of placement termination that is outside of their control), many youth will understandably refuse or tire of the constraints that go along with extensions of care. Further, providing services intended for children to an adult population perpetuates the mismatch between service provision and developmental need, even if those extended child welfare services include an emphasis on transitional planning and training in independent living skills.

An extensive reconceptualization of adolescence as experienced by youth in care is required, leading to the development of a robust range of services aimed at young adults who need additional support beyond age of majority to master the tasks of emancipation. While arguably beneficial for many youth who have grown up in care, the most vulnerable of the children-in-care population are adolescents with FASD, therefore this discussion will focus mainly on the needs of this focused population as they reach age of majority.

The literature reviewed for this study and the youth interviewed in our study indicated that at age of majority most youth have not yet attained the developmental readiness to live successfully on their own but are now at a stage where they can take advantage of services that prepare them for independent living. This would indicate that a program of transitional support services (including care) for young adults aged 18 – 21 is an ideal bridge between being a child in care and being a fully emancipated adult. In addition to age, criteria for eligibility in transitional support services would include being a permanent ward or a child who has been in care consistently since age 14, a diagnosis of FASD (to the extent that a diagnosis can be made under accepted diagnostic standards), and the consent of the young adult. Features of a robust transitional support services program for young adults with FASD at age of majority would include:

- negotiation of a transitional support services contract between the youth and the agency, including any additional supports such as alternative caregivers, community programs, educational/training programs, etc., outlining the nature of services being provided, the rights and responsibilities of the young adult in accepting services, and the roles that each party to the contract will play;

- development of a wide range of living options that approximate living on one's own, such as supported independent living, proctor arrangements, supported room and board, as well as foster homes and group homes that place heavy emphasis on the development of independent living skills, allowing youth more choice in where/how they will live as they make the transition to independence;

- wherever possible, the opportunity to continue in one's current foster home at age of majority, with redefined roles, rules and responsibilities of the youth and foster parent clearly articulated to provide youth with an appropriate balance between protection/ oversight and autonomy into adulthood;

- training for caregivers in the instruction of life skills, with special attention to adaptations required for teaching youth with FASD;

- development and evaluation of formal independent living skills programs for youth with FASD, including sufficient opportunity to practice skills frequently and receive feedback and guidance;

- the availability of youth mentors and life skills coaches to assist youth in the practical application of independent living skills and independent decision-making;

- vocational planning, including skills/interests assessment, training in employment-readiness skills (e.g. being on time, following directions, etc., including adaptations required as a result of the impact of FASD), job placements, and job coaching;

- the right of the young adult to leave the transitional services program at any time, but also to return to the program up to six months prior to reaching age 21.

Serious consideration should be given to the merits and disadvantages of offering transitional support services under the auspices of the child welfare system. There is no easy answer here: the opportunity to maintain child welfare placements while youth move through the latter stages of adolescence and transition to independence clearly supports investing transitional support services in child welfare agencies. However, the goal of normalizing transition and promoting adult independence favours a standalone program structure that supports residential care (whether foster placement, group home, or independent living) but exists separate from the child welfare system. Similar services currently exist through Manitoba's supports for adults with cognitive disability, although these youth generally do not meet the IQ disability criteria for these adult services.

While establishing a unique program of transitional support services for young adults leaving care may be the ideal goal, moving in that direction may take time that youth with FASD currently in care cannot afford. In the interim, legal provisions for extensions of care in child welfare legislation currently offer a mechanism for making services into adulthood possible for permanent wards with FASD who have reached age of majority. A defined extension of care program can be developed by creating a comprehensive cluster of transitional services and supports, accompanied by policies that articulate a different working relationship between young adults with FASD and the agencies that serve them, and between young adults with FASD and the caregivers who provide them with support.

Conclusion

This study demonstrates again the long term and significant personal and social impacts of prenatal exposure to alcohol. The challenges are felt broadly because of the number of children affected. They are also felt deeply due to the significance of their primary and secondary impacts on the life of each individual affected. Because many children with FASD are forced to rely on the child welfare system to provide safety and nurturing, social policy and practice must keep pace with their needs.

The adolescents and young adults with FASD, who shared their stories here, demonstrated both strength and courage as they moved through a child welfare system that struggled to address their needs first as children in care and then as children with a particular disability. Like other children leaving agency care, they experienced deficits in educational preparation, life skills, and social supports, elements that are critical to success as adults. In addition their disability created further barriers to acquiring the necessary education, life skills and social network.

This research suggests services to those with FASD could be improved at two intervention points. First, while children are in care, it is essential to increase a) the stability of their placements and b) their ability and that of their caregivers and service providers to recognize and manage the disability. Second, it is necessary to step away from a system that determines readiness for independence in a purely arbitrary fashion (i.e. "bound by the clock") to establish a practice that would recognize the adaptive skills of the individual leaving care and plan for them according to their needs. Ideally that plan would recognize the adult status of those who reached the age of majority by increasing independence and choices without curtailing support or shutting the door on those who need more than one try at independence.

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