

Intervention of Hope: Sustaining Caregivers of Children with FASD through Therapeutic
Psychoeducational Camps

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Abstract

Parents, whether adoptive, foster or biological, raising alcohol-affected children contend with the exhaustion of the care taking role. This article is a summary of the qualitative phase of a mixed-method study investigated the effect that attendance at a therapeutic caregiver-involved camp, Whitecrow Village Camp, had on caregivers of children with FASD. In the qualitative phase, eighteen caregivers completed semi-structured interviews. Eight major content categories were identified in the data and five metathemes emerged under the overarching metatheme of a Life-Changing Experience: Providing Hope. Analysis of the data suggests that attendance at Whitecrow Village Camp had a positive influence on the coping behaviour of caregivers of children with Fetal Alcohol Spectrum Disorders (FASD).

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Introduction

Families raising alcohol-affected children must contend with the exhaustion of the care taking role (Brown, Sigvaldason, & Bednar, 2005; Doig, McLennan, & Urichuk, 2009). Caregivers have reported feeling alone in dealing with the complexity of the mental health and physical needs of their child (Brown et al., 2005). In their multiple roles as parent, teacher, advocate, and therapist, it is not surprising that caregivers struggle to cope with emotional stress while maintaining the parent/child bond. Increased awareness of compassion fatigue has raised questions as to the professional and social supports needed and specific interventions required to reduce caregiver stress (Caley, Winkelman, & Mariano, 2009).

Recent research indicates that caregiver well-being is affected not only by specific parenting tasks and the child's behaviour but also by the person-environment interaction (Beckman, 2002; Worcester et al., 2008). Parents of children with disabilities often feel a lack of support from professionals, support that is necessary if they are to perform optimally as a parent (Green, 2007). Professionals need to affirm caregivers' efforts and collaborate with family and community members and organizations to provide the extra encouragement needed to overcome the numerous challenges families face (Bryan, 2005). Effective counselling and education recognize and build strengths rather than focus on problem reduction and correction (Galassi & Akos, 2007; Smith, 2006).

Recently, summer camps and short-term residential programs are being provided as a place in which children with disabilities can take part in therapeutic activities to assist in making and keeping friends, sports to develop skills and build self-esteem, and recreational activities for fun. Additionally, such camps provide caregivers with respite.

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However, research indicates that positive behavioural changes that occur in such environments are not maintained when the intervention has ended and children return to their unaltered home and school environments (Jenson & Whittaker, 1987; Pearson, 2004). Chamberlain (1999, p. 502) asserts that the “failure to include parents in youngsters’ treatment may be the single largest barrier to generalization of treatment effects from residential care to living at home.” Hooper et al. (2000) and Jenson and Whittaker (1989) would also suggest that school-family-community partnerships are needed in order to maintain advances gained at camp.

Outcomes from recent research (Beckman, 2002; Worcester et al., 2008) seem to indicate that many of the challenges faced by caregivers of children with disabilities such as FASD are due to a lack of environmental supports. Whitecrow Village Camp aims to provide supports by connecting children who have FASD and their caregivers with professionals and other caregivers. Since ensuring an active understanding of FASD in everyday social and professional settings is central to Whitecrow Village Camp’s mission, child-focused professionals take part in camp activities as volunteers, assisting in day-to-day activities and presenting information. The overall purpose of this qualitative study was to evaluate the effectiveness of the camp experience on caregivers’ parenting ability.

Background

Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorders (FASD) describes the range of disorders in children who were exposed to alcohol prenatally. Prenatal drinking has had significant

impacts in the United States and Canada where it is estimated that 1 in 100 children born each year will have FASD (Chudley et al., 2005). Over \$350 million will be spent on affected youth with approximately \$1.4 million spent over one individual's lifetime (Duquette, Stodel, Fullarton, & Hagglund, 2006a; Edmonds & Crichton, 2008).

At the extreme end of the larger spectrum of effects is Fetal Alcohol Syndrome (FAS). Other diagnosis include Partial Fetal Alcohol Syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). The severity depends on a number of factors including dose, timing, and amount of prenatal exposure to alcohol; the manner in which the mother metabolizes alcohol; and the characteristics of birth child and mother (Sokol, Delaney-Black, & Nordstrom, 2003). The effects of FASD can manifest in facial morphology, slow body growth, and neuro-behavioural abnormalities (Edmonds & Crichton, 2008; Sokol et al., 2003). Brain damage, however, can be severe regardless of physical and facial characteristics. In fact, many children with FASD show no physical symptoms at all but display a variety of behavioural and cognitive disabilities.

Even though each individual with FASD is unique, there are certain patterns evident in their behaviour that are a result of brain damage caused by changes in structure, chemistry, and functioning of the central nervous system. The effect of this brain damage manifests in a range of difficulties including memory, cognition, and executive and adaptive functioning including inconsistent behaviour and performance, manifesting as impulsiveness and poor frustration tolerance, poor memory, inability to distinguish between private and public behaviours, displaying poor judgment skills, inappropriate sexual behaviour, and not understanding subtle social cues or the

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consequences of their actions (Edmonds & Crichton, 2008). These wide ranging behavioural characteristics extend into adulthood and affect the ability of those with FASD to cope with everyday life. Secondary disabilities become more pronounced in adolescence through to adulthood often leading to a disrupted home experience, depression, legal problems, substance abuse, difficulties in focusing (e.g., a diagnosis of attention deficit hyperactivity disorder is common), challenges in handling money, victimization, a variety of mental health problems, imprisonment, and poverty (Boland, Chudley, & Grant, 2009; Duquette, Stodel, Fullarton, & Hagglund, 2006b; Edmonds & Crichton, 2008; Sokol et al., 2003). Appropriate interventions and supports that address the special needs of those with FASD and that provide them with practical help are critical to their personal success.

Caregiver Support Needs and Challenges

The primary caregivers of children with FASD "assume[e] a responsibility far beyond that normally associated with parenting" (Giunta & Streissguth, 1988, p. 458) that involves constant supervision and immense amounts of energy, time, consistency, and love as caregivers cope with primary and secondary disabilities (Caley et al., 2009; Giunta & Streissguth, 1988; Wilson & Martell, 2003). While many birth parents are dedicated, involved caregivers to their biological children with FASD, a recent study conducted in the United States estimates that 69% of birth mothers of children with FASD die before the child is four (Granitsas, 2004), illustrating the importance of adoptive and foster parents as alternative caregivers for this population.

Efforts to identify factors that may moderate the effect of having a child with FASD have identified child characteristics and needs as important (McDonald, Poertner

& Pierpont, 1999) as well as social or material features including formal and informal social supports (Bromer & Henley, 2004). Caregivers' beliefs in their ability to influence outcomes and their sense of empowerment have also been linked to how they cope with caregiving responsibilities (Heflinger, Bickman, Northrup, & Sonnichsen, 1997). The needs of children with FASD and their families are best met when families feel competent in the day-to-day care of their child and in communicating and problem solving with professionals who are sensitive and responsive to family goals, resources, and competencies. (Brown et al., 2005; Caley et al., 2009; Helfinger et al., 1997).

Identifying the concerns of caregivers can provide insight into the types of supports needed to successfully raise a child with FASD. The intimate knowledge of FASD that children and their families share through their stories, allows them to be "teachers to communities and societies, providing guiding information that could lead the way in solving the deep fundamental problems that create and are created by FAS" (Wilson & Martell, 2003, p. 35).

Conversely, lack of understanding of FASD creates judgments of parenting techniques and limited tolerance for caregivers' needs (McDonald et al., 1999; McLennan, 2010). Caregivers must receive appropriate supports to reduce burn-out from the high-stress involved in the care of individuals with FASD. When caregivers feel less stress they are better able to adapt to their child's needs and to provide support without limiting or enabling (McDonald et al., 1999; McLennan, 2010). Given the needs of families who live with FASD, interventions must aim at empowering caregivers and providing social and professional supports, knowledge, and understanding (Olson, Oti, Gelo, & Beck, 2009; Singer, Ethridge, & Aldana, 2007).

Family-Involved Camps as an Intervention

A number of specialized camp programs have been developed for children with chronic illnesses and their siblings (Michalski, Mishna, Worthington, & Cummings, 2003; Pridham, Limbo, & Schroeder, 1998). A range of psychological, social, emotional, and physical benefits arising from participation in such camp programs has been recognized (Agate & Covey, 2007). However, one weakness identified is the lack of family involvement and the subsequent generalizations of effects from camp to living at home (Chamberlain, 1999). Family-involved camps would more likely influence the larger ecology of a child's life, specifically the family environment. Additionally, the propensity for maintenance of positive changes would likely be increased if professionals and caregivers worked together as a team at the camp.

Method

Setting

Kee Warner (Whitecrow Village FASD Society, 2008), an adoptive and foster parent to a number of children with FASD, formed Whitecrow Village Camp in 1996 in order to provide a summer camp where her children could experience success. In the third year of its inception, families, community agencies, and professionals became a central part of the Whitecrow Village community model. Since that time, Whitecrow Village Camp programs have served many communities, mostly in British Columbia, Canada. Young adults who have participated in the program now form part of the camp team, working alongside professionals from legal, medical, education, and social services backgrounds who volunteer at various camps.

Whitecrow Village Camps aims to improve the lives of those affected by FASD and to educate communities and professionals about this neuro-cognitive disability (Whitecrow Village FASD Society, 2008). An extensive three day training session facilitated by a behavioural management expert is mandatory for all individuals who volunteer. Topics specific to the care of children with FASD are covered including: team building in the home, school, community and workplace; how to provide appropriate support to individuals and families; and how to implement everyday structure and strategies.

The camps programming is founded on the assertion that a focus on primary disabilities will reduce or eliminate judgments about the meaning of behaviours, allowing the strengths and gifts of people with FASD to be their most notable quality (Whitecrow Village FASD Society, 2008). Four main program objectives include: (1) increasing caregiver self-confidence in coping with their child, (2) decreasing ineffective ways of responding to their child, (3) enhancing caregiver competence in adapting the environment to meet their child's needs, and (4) improving the effectiveness of working with their professional team in their community. The eight day program emphasizes group activities that provide family members with extensive training, information sharing, the expertise of professional speakers, and support from staff and other families (Whitecrow Village FASD Society, 2008).

Sample

Eighteen caregivers, defined as any adult who played a significant role in the care of a child or adolescent with FASD, were included in the study. Three different Whitecrow Village Camps were accessed, each one sponsored by a different agency. In

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total seven foster parents, four adoptive parents, six biological mothers, and one aunt from a diverse range of educational, socio-economic, and cultural backgrounds volunteered to participate. The families had one to five children, with an average of two children per family; however, not all children in the family were affected by FASD. Only one caregiver per family was interviewed.

Data Collection

When families arrived at the various camps, they were given information about the project and, if they were interested in participating, approached the researchers who then gained informed consent and set a time for the interview. The audio-taped semi-structured interviews lasted from one to two hours. Interviews took place at the camps in a convenient location for caregivers.

Data Analysis

All individual and group interviews were transcribed by the research team. Data analysis involved three central steps: (1) clustering data into topics in categories; (2) summarizing core ideas that captured each participant's perspective and meaning; and (3) constructing common themes across participants (Morse & Richards, 2002). As a first step, transcripts were coded "line-by-line" to develop categories using the computer program NVIVO. In order for a category to be designated, information pertaining to that category had to be present in 90% of the interviews. During this process a codebook with definitions was developed. The second step entailed consideration of how the categories were related and what main patterns kept recurring in the data. A data display matrix was developed for analyzing patterns of responses to the interview questions. Themes, defined as similar codes aggregated together to form a major idea in the

database, were developed through a method of constant comparison (Strauss & Corbin, 1994). This is a method of comparing and contrasting across instances to establish significant patterns, then further questioning and refinement of these patterns as part of an ongoing analytic process to form themes. Metathemes, defined as themes that extend across categories, were also designated. Once themes and metathemes were developed, the NVIVO search tool was used to look for themes within categories and metathemes across categories.

Results and Discussion

In the first level of data analysis, eight major content categories were identified including: (1) Birth Mothers' Experiences, (2) Adoptive/Foster Parents' Experiences, (3) Whitecrow Village Camp Experience, (4) Child with FASD, (5) Professional Interactions, (6) Adults with FASD, (7) School Experience, and (8) Information on FASD. Numerous themes were identified within the categories, and five metathemes were found across the categories. Table 1 outlines themes identified within three categories: (1) Birth Mothers' Experiences, (2) Adoptive/Foster Parents' Experiences, and (3) Whitecrow Village Camp Experience. For the purpose of this article, the focus is on these three categories in order to illustrate the context of caregivers juxtaposed against the context of attending Whitecrow Camp.

Birth Mothers' and Adoptive/Foster Parents' Experiences

The categories of Birth Mothers' Experiences and Adoptive/Foster Parents' Experiences consisted of several themes including: (a) Caregiving, (b) Caregiving Needs, (c) Challenges in Caregiving, (d) Existing Supports, and (e) Perceptions of Each Other.

Table 1: Interview Categories and Themes

Category	Theme	Summary of Theme
Birth Mothers' and Adoptive/Foster Parents' Experiences	Caregiving	<ul style="list-style-type: none"> ▪ "Living in Crisis" ▪ Financial strain ▪ Implications of lifelong disability ▪ Caregiving to children with history of multiple foster placements
Birth Mothers' and Adoptive/Foster Parents' Experiences	Caregiving Needs	<ul style="list-style-type: none"> ▪ Lack of safety nets/respite for caregivers ▪ Cycle of unsupported caregiving leading to return to caregiver substance use
Birth Mothers' and Adoptive/Foster Parents' Experiences	Challenges in Caregiving	<ul style="list-style-type: none"> ▪ Crisis-driven ▪ Isolation, often because of impact of stress on other relationships ▪ Judgments of others ▪ Not knowing what is wrong with child/lack of access to formal diagnosis of FASD ▪ Lack of supports post-diagnosis ▪ The legal system
Birth Mothers' and Adoptive/Foster Parents' Experiences	Existing Supports	<ul style="list-style-type: none"> ▪ Need to advocate social service agencies for support ▪ Birth mothers' support group (through PEERS) ▪ Family support ▪ Spousal support ▪ Weekend respite service
Birth Mothers' and Adoptive/Foster Parents' Experiences	Perceptions of each other	<ul style="list-style-type: none"> ▪ Birth parents consider foster parents more knowledgeable and more connected to community ▪ Foster/adoptive parents consider birth parents an "important connection" ▪ Hypothesize that birth parents may be able to keep children if given same supports as given to foster parents ▪ Biggest challenge in maintaining birth parent relationship with foster/adoptive parents is different parenting styles
Whitecrow Village Camp Experience	Benefits of Whitecrow	<ul style="list-style-type: none"> ▪ Sense of being part of a community ▪ Practical information ▪ Understanding of FASD ▪ Recognizing the importance of a formal diagnosis ▪ Sense of hope, particularly from interacting with staff with FASD
Whitecrow Village Camp Experience	Support for the Caregiver	<ul style="list-style-type: none"> ▪ Non-judgmental support ▪ New strategies and skills ▪ Increased information leading to decreased frustration ▪ Validation
Whitecrow Village Camp Experience	Support to the Child	<ul style="list-style-type: none"> ▪ Acceptance leading to experience of success ▪ Bonds with other children ▪ Structure ▪ Concrete rules ▪ Positive experiences with professionals (teachers, physicians, police officers)
Whitecrow Village Camp Experience	Long Term Effects	<ul style="list-style-type: none"> ▪ Development of a broader perspective ▪ Increased confidence

Caregiving

The caregiving experience of birth mothers included times of “living in crisis” based on the experience of supporting a child with FASD, an experience compounded by struggles with addiction. On the positive side, birth mothers wanted to have good relationships with their children and worked hard at developing parenting skills. The birth mothers described how hard they worked at developing positive relationships while dealing with both addiction issues and the behaviours of their children.

I've been his lifeline. Who knows? I had to work really, really hard at developing a relationship with him...I sobered up and he just kind of looked at me and like you're going to tell me do what? I don't think so...my credibility wasn't there at all, so I had to work really hard to build up credibility. (P-WC-05)

When discussing caregiving, adoptive and foster parents described both their commitment to their children and the stress and exhaustion resulting, in part, from the financial strain they experienced. Their life commitment to their child added to this strain through the awareness that the financial hardship would be on-going. One adoptive parent used an analogy to explain their situation.

An interesting kind of way for example... you know it's like that David Suzuki story about the frog in the pot, it doesn't notice that the pot is getting gradually warmer because we have lived with our daughter of 7 years, we just adapted to her needs. (Pre-WC-01)

One participant spoke about the difference in moving from being a foster parent who provided temporary care to that of being an adoptive parent, with the realization that they were going to be “caregiving for the long haul.” In discussing the foster situation, one participant spoke about the particular caregiving issues when caring for children who had experienced multiple placements.

Birth Mothers' and Adoptive/Foster Parents' Caregiving Needs

For some of the mothers, the struggle included not having information on FASD and in not knowing what was wrong with their child. Several participants described the difficulty they had in getting a diagnosis for their children, an essential need for appropriate care.

Birth parents identified a need for more proactive support and pointed to the lack of safety nets and breaks or respite for caregivers. Addiction and the reasons for addictions also appeared. Some participants spoke about the need to address the life events that start the addiction cycle, while other participants discussed society's acceptance of alcohol as a legal drug.

And the one thing that struck me that I heard at the conference that somebody said, the issue is not that somebody drinks, the issue is why. Why in our society are woman drinking, we need to back up a bit. (P-WC-05)

Addiction was described as being the major barrier to parenting. Birth parents of adult-age children stated that there was no discussion about addictions and no interventions at the time their children were born. One participant summed-up the dilemma as the need to protect children while at the same time putting a safety net in place to support the birth mothers. The cycle was described as stress of unsupported parenting of children with FASD leading to the parent's relapse. One participant who worked with the birth parents described the feelings of guilt that many parents had about giving birth to a child with FASD. However, in our interviews, birth mothers had a pragmatic understanding of their role.

In the area of adoptive and foster parents' needs, respite and additional financial support were identified by the majority of participants. These parents again referred to the

demanding nature of looking after children with FASD, with most parents recognizing that their child was unlikely to ever be totally independent.

Challenges in Caregiving

The challenges of caregiving were likened to a crisis-driven existence by all the parents, the analogy of living in a war zone often repeated, reflecting the trauma of their experiences. Caregivers wanted more information and support to help them address their stress and the impact on their relationships with partners and other children in the house. One participant described how the behaviour of the child had the effect of creating crisis in the family. Stressful situations occurred when the child's behaviour deteriorated in public with volatile behaviour described as a major challenge for caregivers. Caregivers often felt judged as parents, a judgment connected to their child's behaviour. One participant described how going to a regular parenting group was a very difficult experience, with people in the group assuming that everyone with FASD was the same. Being judged by those who did not understand their caregiving situation was viewed as being difficult for all the parents.

Challenges in caregiving faced by adoptive and foster parents were similar to that of birth parents: lack of services and high levels of stress. Not knowing what was wrong with their child and the long waiting time for diagnosis and follow up interventions were identified as adding to their stress as parents.

We didn't know how through dealing with the unknown compounded the issue. It probably took 6 months to really get a good handle on what they had...and then move to the most appropriate intervention...it took 34 months, just barely under 3 years to get a diagnosis...it would be I'm sure unacceptable in a country if it were cancer or something that affected another population (Pre-WC-01).

Participants described the challenge of dealing with the unknown prior to diagnosis.

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However, even though receiving a diagnosis was useful in helping the family to understand the child's needs, there were few social and professional supports for their children. The adolescent phase of development was also viewed as being particularly challenging, especially in terms of relationships with the opposite sex. The inability of some children to learn from experience was also a concern and participants voiced that this difficulty would exist throughout their child's lifespan.

Birth Parent and Adoptive/Foster Parent Existing Supports

In terms of support, various agencies serving foster and adoptive parents were described along with support from family. Weekend respite support, which caregivers often had to pay for, was described as a main support. Strong spousal support was identified by one participant as being critical. Parent support groups were also listed as important connections.

There isn't much out there and I'm very disappointed about that because I know what could help and it isn't there and I think that for one thing, mother's need time out, it's so stressful to parent a child with FAS. (P-WC-06)

Perception of Each Other

Adoptive and foster parents were viewed by the birth parents as having more skills in knowing about and accessing available resources. *"The foster parents know what resources can be...the one birth mum I have is so unbelievably grateful that somebody's taking the time to walk her through the system and to help her get connected, you know..." (P-WC-05).* Adoptive and foster parents were believed by birth mothers to have more connections to the community. One birth mother believed that many foster homes were wonderful, but that other homes had adoptive or foster parents who were not willing to work with the birth mothers. Another birth mother expressed that some foster parents

did not understand issues related to addiction.

The pervasive perception held by adoptive and foster parents regarding birth mothers centered on the belief that it was important to keep a connection to the birth parent family no matter the costs. Adoptive and foster parents described how, despite the various difficulties they experienced in dealing with birth parents, they believed in the importance of keeping the connection for the sake of their children. The most challenging aspect of maintaining the relationship was in coping with differences in parenting styles. Adoptive and foster parents often found that they had to re-establish structure and rules after the children had spent time with birth parents, resulting in behavioural changes in the children.

Some participants noted how services were cut off once children were placed back with birth parents while other participants suggested the need for more commitment from birth parents. Though many adoptive and foster parents found the relationship with birth parents to be difficult, they viewed their role as supportive recognizing the lack of support faced by many birth parents.

I think they love their children exactly the same as any mum loves...I think sometimes the addiction creates a problem which means that they can't take care of their children and we have to look at that because it's an important piece but I don't see any difference in terms of how they love their kids. (P-WC-09)

According to both birth mothers and adoptive and foster parents, children appear to receive more support when in foster care than when they are with their birth mothers. According to many participants, birth parents would be able to keep their children and parent their children if they had the same type of support afforded foster parents.

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Whitecrow Village Camp Experience

In the category of Whitecrow Village Camp experience, four themes were identified: (a) Benefits of Whitecrow Village, (b) Positive Interactions at the Camp and with Professionals, (c) Support for Caregivers, and (d) Maintaining Long-term Effects.

Benefits of Whitecrow Village

In this theme, caregivers listed many benefits and none had negative comments to make about the camp.

Just the way things are taught, the way things are presented...when she taught us how the brain works on the projector and stories of her children and the other children that are affected, I could relate to my girls and ah, realized that my girls are going to be okay, you know. Just knowing that I wasn't alone. (WC-01-PI)

One objective of the camp program is to afford environmental support for the primary brain injury by providing opportunities for children and adults living with FASD and their families to belong and to contribute at the camp; guiding families and professionals in establishing a common language; and supporting families and professionals towards meeting their shared goals. Participants were pleased with the practical, easy to understand information they received about FASD. The ease with which they could integrate this information with the parenting of their children resulted from hearing the experiences of other parents. Being able to don a different lens with which to view their children's behaviours was viewed as a benefit.

The morning activities, listening to the facilitator, it was fantastic information. It really helped to understand, to take a step back and not be so reactive with these kids. To understand what they can do. It took a huge weight off to understand this. (F-WC-05-PI)

A key concept of the camp is making accommodations in the environment rather than changing the individual. Consistently modeling appropriate language, actions,

attitudes, healthy nutrition, and self-care were aims of the staff. Nightly campfires allowed campers to reflect on the day's successes and challenges. A talking stick was used to help the children learn abstract concepts of sharing, respect, and listening.

Parents stated it was easier to understand why a diagnosis is so important in accessing effective treatment and interventions. The information gained about the purposes of diagnosis was viewed as useful in interacting with professionals, particularly in the school setting. Relaying that learning to professionals who interact with their children was perceived as a paramount goal. *"It helps open your eyes not only to yourself, not just your children but to other people in the world that you and your children are dealing with"* (P-WC-11/12). Interactions with the staff, particularly the young adults with FASD who worked at the camp, were viewed as contributing to the sense of hope for their children.

Positive Interactions at the Camp and with Professionals

The theme focused on how acceptance by camp volunteers created an environment in which their child could experience success in areas of their life in which they were particularly challenged. Caregivers watched as their children bonded to other children and interacted positively with camp volunteers.

Yeah, it's very different the way they (the professionals) treat these kids as opposed to in a normal camp or a school classroom. They know what they are doing and it clearly, clearly works. These children come here and just flourish, blossom. It's incredible to see. (P-WC-07)

The opportunity to interact with working professionals (e.g., physicians, teachers, and police officers) who attended camp was seen as a highly supportive to children and caregivers who frequently had little positive experience with professionals in their daily

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lives. As one parent noted, *“I never thought I had as much to say as teachers. I thought they’d talk at me.”*

Support for the Caregivers

In the theme, “Support for the Caregivers,” caregivers felt that they could safely examine how they interacted with their children. This supportive, non-judgmental environment encouraged them to be open about what was working and not working in their parenting.

It’s a big self-esteem booster for me to be around people who don’t judge me and who like me just the way I am and that I haven’t been chastised about anything or belittled or...I get compliments from people, I get validated. (P-WC-06)

In learning new information about FASD and strategies that have worked for other families, participants described how new approaches and skills gave them increased self-confidence and more patience. *“I don’t know if I would call it sympathy or empathy I don’t know: it’s not their (their child’s) fault” (WC-05-PI)*. Caregivers developed new parenting perspectives and felt less frustration because they had a better understanding of what they were dealing with instead of *“dealing with the unknown” (WC-05-PI)*. For some it was an opportunity *“to recharge your batteries I think to raise kids facing these challenges, on a really regular basis... We need to find what that is, because the better charged we are, the better outcome for our kids, the better outcome for society (F-WC-03)*. Participants also discussed how supportive it was to have their knowledge confirmed or reinforced, and to hear that other people understood the challenges in caring for their children. The inclusion of birth mothers was a validation of the accepting and non-judgmental environment.

Maintaining Long-Term Effects

Development of a broader perspective was identified as a long term effect, as was increased confidence. *“You walk away with something changed, you don’t see it but it has changed. It is a seed that will continue to grow. I am not so frustrated. Hope, it gives us hope for our children”*(F-WC-PI). The generating of positive feelings within children with FASD was viewed as a long-term effect as was the sense of companionship with other caregivers. Participants noted that key to maintaining a long-term effect was ongoing professional supports. *“I just have to have hope that I can find this type of support in my community among the many professionals that I have to deal with. Then I know that I would maintain the progress I have made long after this week has ended”* (F-WC-03).

Table 2: Overarching Metathemes

Overarching Metatheme: Life-Changing Experience: Providing Hope
➤ Acceptance and Understanding versus Being Judged
➤ Recharging and Lessening of Stress versus Living in Crisis
➤ Acquiring Information and Tools versus Lack of Safety Nets and Supports
➤ Planting Seeds
➤ Ongoing Commitment and Connection

Jevne and Miller (1999) define hope as “looking forward with both confidence and unsureness to something good” (p. 10). Edey, Jevne, and Westra (1998) outline four paradigms that characterize the lives of those who lose hope: (1) The skidding effect—“I’m trying to make a difference but circumstances are out of my control!” (2) The bruising effect—“So many bad things have happened that now I don’t seem to be able to cope with anything;”(3) The boomerang effect—“No matter what I try, I always end up at the same place;” and (4) The alien effect—“Nobody understands me.” Whitecrow

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Village Camp addressed many of these paradigms. Caregivers spoke passionately about the need for community connection and engagement as a way to give their children important life and social skills and as necessary in sustaining the parenting skills learned at camp. Such contact, according to participants, allows self-confidence to build as their children are viewed as more than just a label. *“When opportunities are provided to utilize their strengths, there is an increase in their positive self-image – and mine too”* (P-WC-06). Such experiences make it more likely that the caregiver and the child will overcome the stigma attached to having FASD.

The information and strategies acquired by caregivers gave them assurance and a sense of security. Many caregivers felt a lack of safety nets and supports in their daily life. Whitecrow Village Camp was a place where they found common understanding as well as an opportunity to talk about these challenges with professionals who attended the camp as volunteers. According to Lave and Wenger (2005) through engaging in practice as a legitimate participant, a person moves from peripheral to more central and responsible participation. An important support for this movement is the understanding and appreciation by guides (or camp volunteers and staff) for what the learner is experiencing. The guide can then fine tune the type of support provided to advance learning in the context of this experience.

This process is similar to the experiential approach used at Whitecrow Village Camp that fosters transfer of knowledge about FASD into practical and meaningful ways to support individuals, families, and communities. For example, education was provided in the form of two morning workshops for caregivers and volunteers directed at the effects of prenatal alcohol and drug exposures and explaining how behavior and learning

is impacted. The goal was to empower caregivers by improving their knowledge of their children's development and by illustrating how to be positive partners with professionals and other agencies in their efforts to obtain needed resources for their children's wellbeing. The second workshop provided education and practice in managing children's behaviour and explained the importance of age-appropriate behavioural regulation skills needed to optimize learning experiences.

Parenting a child with FASD presents a unique set of challenges making access to appropriate services and supports throughout the life cycle crucial. Yet caregivers consistently noted the lack of services available to them. Parents identified the need for inclusive activities for children with FASD, suggesting that "because FASD is an invisible disability that manifests in diverse ways, children's non-normative behaviours may well draw attention from others," often negative attention (Brown et al., 2005, p. 317).

Participants also noted that professionals often treated them as clients rather than as members of the team. Instead of valuing and respecting their expertise and knowledge participants believed that their contributions were minimized. "*I am the one who knows my child as a special person with unique needs – why not ask me?*" Brown et al. (2005) found that access to responsive professionals who were willing to work with caregivers in a respectful manner was demanded by participants in their study.

Participants did not see the Whitecrow Village Camps as an endpoint but rather as a new beginning. "*It's about planting seeds...I didn't realize...down the road...ten years down the road...the implications of this camp...they're going to be enormous*" (P-WC-05). Caregivers left the camp with a commitment to continue learning and improving as

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parents of children with FASD. *“I feel renewed and ready to carry out my responsibilities as a foster parent... and to reach out to other parents and professionals in my community”* (F-WC-03).

A thread running through the four themes was the impact of a positive relationship with professionals on the caregivers and their children. For most participants, this was the first time that they viewed professionals as on their side. Their interactions with professionals at the camp were based on mutual concerns. Both parties aimed to understand each child’s learning strengths and difficulties and to find ways for families, children, organizations, and school systems to effectively work together.

I just hope that he remembers the joy of being himself without anybody saying don’t do that, sit down, be quiet, all those kinds of things. I guess he’s having the opportunity to take the blanket off his light and nobody’s saying that it’s wrong. So this is like his first experience and I hope I can provide other ones. (P-WC-06)

According to caregivers in this study, professionals who work with alcohol-affected children and their families need to become advocates. Until recently, parents, families, service providers and the wider community have been largely unaware of the serious impact maternal alcohol consumption during pregnancy may have on the unborn child. FASD is a national public health, education, economic, and social concern as those affected suffer a lifelong disability. Professionals who work in the area of FASD have a responsibility to raise awareness about the serious issue of FASD in our communities and to help change community attitudes and behaviours regarding FASD.

As Olson and colleagues (2009) note, caregivers are required to be lifelong primary advocates and are pivotal to their children’s adaptation and developmental outcomes. However, families require the support of the community in order help their

child succeed day-to-day (Olson et al.,2009; Rutman & Bibber, 2009). Informal networks such as sharing at conferences, websites, online forums, family support groups and therapeutic camps such as Whitecrow provide education and opportunities for sharing stories about the rewards and barriers of raising a child with FASD. *“I think that um the benefits to the camp I can't even begin to tell you. The benefits for me, for his mom and for (my child), it was a life-changing experience for (him)”* (Pre-WC-03).

Conclusion

Formal networks involve being part of the health care team and being someone who is an educator to professionals (Olson et al.,2009). However, before formal networks can be effective, relational trust must be built (Bryk & Schneider, 2002). Relational trust is defined as the interpersonal social exchanges that take place in the community built on four criteria: respect, competence, personal regard for others, and integrity. Respect involves the recognition of the role each person plays in a child's life. Competence is the ability one has to achieve the desired outcomes. This research suggests that the positive outcomes from caregivers' experiences of Whitecrow Camp results from the respect, integrity, and personal regard modeled by camp staff and volunteer professionals towards both the children with FASD and their caregivers.

Often parents of children with FASD receive a great deal of blame when things go wrong, yet there is very little support available to help them in what is the most important and responsible job most people ever take on in their lives. What is new is the growing recognition that parents need help and informal and formal support in the increasingly complex responsibilities of bringing up children with disabilities such as FASD in the

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21st century. Understanding the concerns and perspectives of these parents is fundamental to working with them effectively as partners in their children's education and overall well-being. Parents in this study viewed their increased confidence after attending Whitecrow Village Camp as planting a seed of hope for a positive future.

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References

- Agate, S.T., & Covey, C.D. (2007). Family camps: an overview of benefits and issues of camps and programs for families. *Child and Adolescent Psychiatric Clinics of North America*, 16(4), 921-937. [doi:10.1016/j.chc.2007.05.007](https://doi.org/10.1016/j.chc.2007.05.007)
- Beckman, P. J. (2002). Providing family-centered services. In M. Batshaw (Ed.), *A medical primer* (pp. 683-691). Baltimore, MD: Paul H. Brookes Publishing Company.
- Boland, F., Chudley, A., & Grant, B. (2009). *Forum on corrections research*. *Correctional Services Canada*. Retrieved December 4, 2010 from www.csc-scc.gc.ca.

- Bromer, J., & Henley, J. R. (2004). Child care as family support: caregiving practices across child care providers. *Children and Youth Services Review, 26*(10), 941-964. doi:10.1016/j.chilyouth.2004.04.003
- Brown, J., Sigvaldason, N., & Bednar, L. (2005). Foster parent perceptions of placement needs for children with fetal alcohol spectrum disorder. *Children and Youth Service Review, 27*, 309-327.
- Bryan, J. (2005). Fostering educational resilience and academic achievement in urban schools through school-family-community partnerships. *Professional School Counseling, 8*, 219-227.
- Bryk, A.S., & Schneider, B. (2002). *Trust in schools: A core resource for improvement*. New York: Russell Sage Foundation.
- Caley, L. M., Winkelman, T., & Mariano, K. (2009). Problems expressed by caregivers of children with fetal alcohol spectrum disorder. *International Journal of Nursing Terminologies and Classifications: The Official Journal of NANDA International, 20*(4), 181-188.
- Chamberlain, P. (1999). Residential care for children and adolescents with oppositional defiant disorder and conduct disorder. In H.C. Quay and A.E. Hogan (Eds.), *Handbook of Disruptive Behaviour Disorders* (pp. 495-506). New York: Kluwer Academic/Plenum Publishers.
- Chudley, A., Conry, J., Cook, J., Looock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorders: Canadian guidelines for diagnosis. *CMAJ, 172* (5 supplement), 1-21. doi:10.1503/cmaj.1040302

Intervention of Hope

- Doig, J. L., McLennan, J. D., & Urichuk, L. (2009). 'Jumping through hoops': Parents' experiences with seeking respite care for children with special needs. *Child: care, health and development*, 35(2), 234-242. doi:10.1111/j.1365-2214.2008.00922.x
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006a). Persistence in high school: Experiences of adolescents and young adults with Fetal Alcohol Spectrum Disorder. *Journal of Intellectual & Developmental Disability*, 31(4), 219-231. doi:10.1080/13668250601031930
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006b). Teaching students with developmental disabilities: Tips from teens and young adults with Fetal Alcohol Spectrum Disorder. *Teaching Exceptional Children*, 39(2), 28-31.
- Edey, W., Jevne, R. F., & Westra, K. (1998). *Hope-focused counselling*. Edmonton, AB: The Hope Foundation of Alberta.
- Edmonds, K., & Crichton, S. (2008). Finding ways to teach to students with FASD: A research study. *International Journal of Special Education*, 23(1), 54-73.
- Galassi, J., & Akos, P. (2007). *Strengths-Based School Counseling: Promoting student development and achievement*. Mahwah, NJ: Lawrence Erlbaum.
- Giunta, C., & Streissguth, A. (1988). Patients with fetal alcohol syndrome and their caretakers. *Social Casework*, 69(7), 453-459.
- Granitsas, J. (2004). Experiences of adoptive parents of children with fetal alcohol Syndrome. *Clinical Excellence for Nurse Practitioners*, 8(1), 22-28.
- Green, S. A. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64, 150-163. doi:10.1016/j.socscimed.2006.08.033

Heflinger, C.A., Bickman, L., Northrup, D., & Sonnichsen, S. (1997). A theory-driven intervention and evaluation to explore family caregiver empowerment. *Journal of Emotional and Behavioral Disorders*, 5(3), 184-91.

doi:10.1177/106342669700500306

Hooper, S. R., Murphy, J., Devaney, A., & Hultman, T. (2000). Ecological outcomes of adolescents in a psychoeducational residential treatment facility. *American Journal of Orthopsychiatry*, 70(4), 491-500. doi:10.1037/h0087807

Jenson, J. M., & Whittaker, J. K. (1987). Parental involvement in children's residential treatment: From preplacement to aftercare. *Children and Youth Services Review*, 9(2), 81-100.

Jevne, R. F., & Miller, J. E. (1999). *Finding hope: Ways to see life in a brighter hope*. Fort Wayne, Indiana: Willowgreen Publishing.

Lave, J., & Wenger, E. (1991). *Situated Learning: Legitimate peripheral participation*. Cambridge, UK: Cambridge University Press.

McDonald T., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress: An ecological perspective. *American Journal of Orthopsychiatry*, 69 (1), 100-109. doi:10.1037/h0080385

McLennan, J. D. (2010) Critical considerations for intervention planning for children with FASD. In E. P. Riley, S. Clarren, J. Weinberg and E. Jonsson (Eds.), *Fetal Alcohol Spectrum Disorder: Management and policy perspectives of FASD*. Weinheim, Germany: Wiley-VCH Verlag GmbH & Co. KGaA. doi: 10.1002/9783527632510.ch22

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ISSN 1718-9748 © University of Alberta

<http://ejournals.library.ualberta.ca/index/php/cjfy>

Michalski, J., Mishna, F., Worthington, C., & Cummings, R. (2003). A multi-method

impact evaluation of a therapeutic summer camp program. *Child and Adolescent*

Social Work Journal, 20(1), 53-76. doi:10.1023/A:1021467503588

Morse, J. M., & Richards, L. (2002). *Read me first for a user's guide to qualitative*

methods. Thousand Oaks, CA: Sage.

Olson, H. C., Oti, R., Gelo, J., & Beck S. (2009). Family matters: Fetal Alcohol

Spectrum Disorders and the family. *Developmental Disabilities Research*

Reviews, 15, 235-249.

Pearson, M. (2004). Building resilient lives: Including families in residential intervention.

Social Work Now, 26, 15-20.

Pridham, K., Limbo, R., & Schroeder, M. (1998). *Support of family caregiving for*

children with special needs. Parenthood in America: University of Wisconsin-

Madison. Retrieved November 20, 2009, from <http://parenthood.library.wisc.edu/>

Pridham/Pridham.html

Rutman, D., & Van Bibber, M. (2009). Parenting with Fetal Alcohol Spectrum Disorder.

International Journal of Mental Health Addiction, 8, 351–361. Retrieved from

<http://www.fasd-cmc.alberta.ca/uploads/1006/parentingwithfasd77205.pdf>

Singer, G. H. S, Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of

parenting and stress management interventions for parents of children with

developmental disabilities. *Mental Retardation and Developmental Disabilities*,

13, 357-269.

Smith, E. J. (2006). The strength-based counseling model. *The Counseling Psychologist*,

34, 13-79. doi:10.1177/0011000005277018

- Sokol, R. J., Delaney-Black, V., & Nordstrom, B. (2003). Fetal Alcohol Spectrum Disorder. *JAMA: Journal of the American Medical Association*, 290(22), 2996-2999. doi:10.1001/jama.290.22.2996
- Strauss, A., & Corbin, J. (1994). Grounded Theory Methodology: An Overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 273-285). Newbury Park, CA: Sage Publications Ltd.
- Whitecrow Village FASD Society. *Live In FASD Education (L.I.F.E.) Sessions*. Retrieved November 15, 2009 from <http://www.whitecrowvillage.org/>
- Wilson, S., & Martell, R. (2003). The story of fetal alcohol syndrome. *Women & Environments International Magazine*, 60, 35/37.
- Worcester, J. A., Nesman, T. M., Raffaele Mendez, L. M., & Keller, H. R. (2008). Giving voice to parents of young children with challenging behavior. *Exceptional Children*, 74, 509-525.