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Supporting Adults Living with Fetal Alcohol Spectrum Disorders in Achieving

Community Integration: A Complex Task

By

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
Saint Catherine University and the University of Saint Thomas
Saint Paul, Minnesota

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Abstract

Fetal alcohol spectrum disorders (FASD) is an all-encompassing term that refers to specific diagnoses resulting from prenatal alcohol exposure which cause a multitude of social and adaptive deficits for children that will typically become more pronounced as they age. These probable, lifelong deficits suggest that adults are likely to need unique supports throughout their lives for successful community integration. The purpose of this study was to explore the complex aspects of community integration for adults living with FASD. Using a qualitative design, four participants, who identified as a caregiver to an adult child with FASD, were interviewed regarding what types of services and supports are utilized, what barriers have been faced, and what still may be needed by adults living with FASD to enhance community integration. Data were analyzed using both inductive and deductive approaches in which reoccurring concepts present in the data were identified. These concepts were then organized into themes and subthemes and then linked to previous literature. The findings indicate that adults living with FASD had a very active caregiver in their life to help with service coordination, organizing and planning, and to act as a safety net. All of the caregivers reported that their adult children have utilized both formal and informal supports to supplement community integration and all had also faced systemic barriers to access supports. In addition, all participants were able to identify both struggles and successes that their adult children experienced with autonomy in community integration. These findings indicate that adults living with FASD do need supports and are likely in need of unique supports and services for optimal community integration which points to the need for continued research into the complex aspects of community integration for adults living with fetal alcohol spectrum disorders.

Acknowledgement

First, and foremost, I would like to extend gratitude to David Roseborough, my research chair. Thank you for you constant encouragement, your support throughout this entire year, and your patience with me. You made this processes enjoyable; you never stopped pushing me to meet my expectations; you really made this experience a gift that I will never forget. Thank you David! I would also like to thank the seven other students that went through this research project with me in David's presence. You are all fantastic individuals and are going to be amazing social workers. Thank you!

I would like to thank my parents for encouraging me throughout my life to reach for my goals—no matter how small or big. Your encouragement will never be forgotten. Thank you Mom, for instilling social work values in me at such a young age. I do not think that there is any other profession for me. Dad, thank you for letting me be forever your little girl. I look up to you; I hope to have the dedication and work ethic that I have always seen in you.

Next, I would like to thank my wonderful husband. Thank you for taking care of me for the past four years. Without your support and love, I do not think I could have come this far. I am truly blessed to have you in my life and cannot wait to see what life brings us next. Thank you for everything, Amin.

Finally, I would like to thank my sponsoring organization for helping me with recruitment. I would like to thank the wonderful caregivers I had the honor of interviewing. Thank you for candidly sharing your stories and experiences. I dedicate this paper to all individuals living with fetal alcohol spectrum disorders and all caregivers out there who are supporting children living with FASD.

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According to the Centers for Disease Control and Prevention (CDC) approximately four million births occur each year nationally (CDC, 2012). During pregnancy there are various teratogens—drugs or other substances capable of interfering with the development of a fetus that may lead to birth defects, developmental malformations or outright halt a pregnancy—that women can encounter. Alcohol is the most frequently and socially acceptable teratogen pregnant women in the United States encounter. In a study conducted by the CDC from 1991-2005, approximately one in eight pregnant women (12.2%) reported alcohol use within the past 30 days over the 15 year period of the study. Prenatal alcohol exposure (PAE) has been associated with a wide range of deficits that adversely influence the development of some children and can cause lifelong defects in virtually every part of the body, including the brain, face, eyes, ears, heart, kidneys, and bones (Schonfeld, Paley, Frankel & O'Connor, 2006).

Fetal alcohol spectrum disorders (FASD) is an all-encompassing term that refers to three specific diagnoses resulting from PAE that exists on a continuum—fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) and alcohol related neurodevelopmental disorder (ARND) and it is one of the leading causes of intellectual disabilities in the United States even though it is completely preventable (Rasmussen, Beckert, McLennan, Urichuk & Andrew, 2010). The estimated rate of FAS is approximately 1 in 1000 births, pFAS is 5 in 1000 births and ARND is 1 in 100 births (O'Connor, et al., 2007; Rasmussen, Beckert, McLennan, Urichuk & Andrew, 2010). FASD are known to be the only preventable cause of intellectual and developmental disabilities; however, the rate of PAE with no confirmed diagnosis is likely to be higher and still contributes to substantial life-long impairments (O'Connor, et al., 2007; Rasmussen, Beckert, McLennan, Urichuk & Andrew, 2010). The effects of PAE may be immeasurable and effect more people than research can even suggest.

Among the most prominent consequences for individuals with FASD are the central nervous system damages that can include many permanent, structural abnormalities in the brain. As a consequence of the brain abnormalities, children with FASD exhibit considerable social impairment (O'Connor et., al., 2007) and are at high risk of problematic behavior which will usually last a life time (Rasmussen, Becker, McLennan, Urichuk, Andrews, 2010). Adaptive and social skills deficits are clearly a primary concern for this population due to lower cognitive functioning of individuals. Studies have demonstrated children with PAE have problems with understanding social cues, displaying inappropriate social behavior, communicating within social context (Jirikowic, Kartin, Olson, 2008), having consideration for others, and are resistant to limits and authority figures (O'Connor, et al., 2007). The multitude of social and adaptive deficits cited for children with FASD will typically become more pronounced as they age resulting in lifelong deficits. (Rasmussen, et al., 2010; Jirikowic, et al., 2008; O'Connor, et al., (2007). These lifelong problems suggest that not only will children, but adults are likely to need unique supports throughout their lives.

Given the high prevalence of significant social impairment, early intervention supports are essential for children with FASD so that specialized professionals and services can target these deficits and begin promoting adaptive social functioning before adulthood. Research by O'Connor et al., (2006) has explored the effectiveness of Parent Assisted Children Friendship Training in children with FASD. CFT is an established curriculum that focuses on social skills modules that are based on social learning theory. It has been found to be empirically valid and has been successfully implemented for children with attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and FASD between the ages of six and twelve in a variety of clinical settings (O'Connor, et al., 2006). The research by O'Connor et al., (2006)

suggested that children in the CFT group improved knowledge and appropriate social skills, and decreased problem behaviors compared to children in the delayed treatment group. A three-month follow up examined maintenance of social skills knowledge and gains as well as reduction in problem behavior. The results demonstrated that a significant improvement in social skills knowledge and appropriate social skills was maintained over the follow up period. Problem behaviors did not decrease significantly but remained lower than initial results before CFT was initiated (O'Connor, et al., 2006). Although this study suggested improvement in the areas of social knowledge and skills in children, problem behaviors had no significant change. Since these social and behavioral issues are likely lifelong, adults living with FASD will need additional supports for successful community integration.

Community integration is defined as the desire to belong to a community in a variety of aspects including: having meaningful things to do (such as school or work), having a social network, access to medical or social services, and living independently, which are all important aspects of any persons' quality of life (Clark et al., 2007). We all require some degree of support in our lives; however for individuals living with disabilities like FASD support may be needed more frequently and at more intense levels to accomplish community integration. Clark et al. (2007) suggested that adults living with FASD did require support to achieve community integration and that much of this support was from family and friends. Although their findings suggested certain aspects of community integration were achieved (e.g. medical, housing) a large number of the participants were marginalized in other areas (e.g. social, community involvement) (Clark et al., 2007). Only adults with FASD who had support from a caregiver were included in this study which leaves the question of what happens to adults with FASD who do not have access to informal supports from family and friends.

Although literature thoroughly addresses the life-long neurobehavioral deficits that PAE has on children and the unique supports that are needed for quality of life and community integration, the significant implications that carry on into adulthood and the supports needed have yet to be adequately explored. Since literature strongly suggest that the neurobehavioral deficits of PAE are life-long, additional supports may be needed in adulthood. However, there is a lack of research done in the adult population. The focus of this study was to explore the supports and services that are utilized and those that may still be needed by adults living with FASD. To achieve this goal, interviews were be conducted with caregivers who have adult children living with FASD by addressing the primary research question: what types of services and supports are utilized, what barriers are faced, and still may be needed by adults living with FASD to enhance community integration?

Literature Review

Clinical Diagnosis of FASD

For over four decades research has been published aiming to gain more knowledge regarding the effects of prenatal alcohol exposure (PAE). Jones and Smith (1973, 1974) published the first articles depicting identifiable birth defects in infants of women who heavily consumed alcohol during their pregnancies and the amount of research dedicated to Fetal Alcohol Syndrome (FAS) since their first publications has been significant (as cited in Goodlett, 2010). Despite the amount of research and publications that have emerged over the past several decades, there continues to be difficulty in the area of diagnosing Fetal Alcohol Spectrum Disorders (FASD). Among the most difficult problems in PAE research is the wide range effects that alcohol has on the growing fetus as well as to the individual after birth (Goodlett, 2010). Since the fetus is constantly developing throughout pregnancy the effects of PAE can occur at

any time and the level of exposure can influence the severity of the primary characteristics for individuals with FASD (Davis, Desrocher, & Moore, 2010; Goodlett, 2010).

Since prenatal alcohol effects can affect the fetus throughout the pregnancy there is no known gestational time or amount of alcohol that is linked to FASD. Due to the variants of exposure, research presents the range of effects caused by prenatal alcohol exposure on a continuum with FAS reflecting the most severe end of FASD, followed by partial fetal alcohol syndrome (pFAS) and alcohol related neurodevelopmental disorder (ARND) (Connor & Streissguth, 1996; Davis, Desrocher, & Moore, 2010; Gibbard, Wass, Clarke, 2003; Goodlett, 2010). Individuals with FASD can experience primary characteristics such as distinct physical and facial features, and central nervous system damage resulting in permanent brain deficits (Davis, Desrocher, & Moore, 2010; Gibbard, Wass, & Clarke, 2003; Goodlett, 2010; Streissguth, 1996). Since there is no clear, comprehensive consensus about the diagnostic features of FASD across the continuum it is important to understand the range of primary characteristics that can be present.

Primary characteristics. Among the most significant primary characteristic for an individual with FASD is permanent brain damage that occurs across a continuum (FAS, pFAS and ARND) and the life-long effects that it has on a person's adaptive functioning. PAE is known to be detrimental to development in many areas of the brain including the cerebellum, hippocampus, basal ganglia, corpus callosum and the frontal lobes (Connor & Streissguth, 1996; Gibbard, Wass, & Clarke, 2003; Schonfeld, Paley, Frankel, & O'Connor, 2006). To date, no research on FASD has identified a specific cognitive profile and it is very unlikely that a standard cognitive profile will ever arise due to the variation of exposure that can be present across individuals affected (Gibbard, Wass, & Clarke, 2003).

Individuals who are exposed to high levels of PAE will often display a distinct set of discriminating facial features including; "microcephaly, short palpebral fissure, a smooth philtrum and a thin upper lip" (Davis, Desrocher, & Moore, p. 146, 2010) as well as growth deficiencies impacting height and weight; however, these facial and physical features are not present across the FASD continuum and only a those who meet criteria for FAS and pFAS will typically have some of these features (Davis, Desrocher, & Moore, 2010; Goodlett, 2010). Due to the variation in a specific cognitive profile and the presence of discriminating facial and physical features and for individuals with FASD, difficulties can arise in assessing for diagnosis. Since the fundamental, primary characteristic in individuals with FASD is permanent brain damage that occurs; this area is worth further exploration because significant deficits are present across the FASD continuum in many ways.

Life-long effects. Although variations occur in the development of the brain, there are common difficulties that arise due to the many permanent, structural abnormalities that can occur due to prenatal alcohol exposure. Some of the most common neurobehavioral deficits that occur can include difficulty in the areas of: attention, learning and memory, complex problem solving, abstract thinking, poor response inhibition, impulsivity, motor function, language, executive functioning and behavior (Connor & Streissguth, 1996; Davis, Desrocher, & Moore, 2010; Gibbard, Wass, & Clarke, 2003). As a consequence of these neurobehavioral deficits, research has shown that children with FASD exhibit considerable social impairment (O'Connor et., al., 2007) and are at high risk of problematic behavior which will usually last a life time (Rasmussen, Becker, McLennan, Urichuk, Andrews, 2010).

Studies have demonstrated children with such prenatal exposure have problems with understanding social cues, displaying inappropriate social behavior, communicating within social

context (Jirikowic, Kartin, Olson, 2008), lack consideration for others, are resistant to limits and authority figures, and have early problem behavior (O'Connor, et al., 2007). The multitude of social and adaptive deficits cited for children with FASD will typically become more pronounced as they age and move onto adolescence and even into adulthood (Rasmussen, Becker, McLennan, Urichuk, Andrews, 2010; Jirikowic, Kartin, Olson, 2008; O'Connor, et al., 2007). Streissguth, et al. (1997) established a group of 'secondary disabilities including (percentage of individuals who reported concerns in brackets): mental health problems (90%), disruptive school experience (60%), trouble with the law (30%), confinement for inpatient treatment or incarceration (50%), inappropriate sexual behavior (50%), and alcohol/drug problems (30%) (as cited in Davis, Desrocher, & Moore, p. 153, 2010).

Research findings have also established that individuals affected by PAE are at high risk of detrimental effects on intellectual functioning across the fetal alcohol spectrum disorder continuum. Early work in the field indicates that many individuals with FASD, but not all, fell in the range of having an intellectual disability. Streissguth, Barr, Kogan, and Bookstein (1996) found that 25% of individuals with FAS and less than 10% of individuals with Fetal Alcohol Effects (now referred to as ARND) qualified for an intellectual disability and additional supports associated with that diagnosis. This indicates that although individuals with fetal alcohol spectrum disorders have significant behavioral and social impairment due to permanent brain damage, they may not receive additional supports in areas where they have significant needs. For an individual living with FASD to receive additional supports or even recognize that serious impairment is present, research urgently needs to address appropriate interventions and supports that can positively impact an individual's adaptive functioning and quality of life in hopes to alleviate the behavioral and secondary diagnoses that can develop across the life-time.

Community Integration

Community integration is the basic idea that all people, including those who have disabilities, have a right to community involvement and connectedness. Community integration is defined as the desire to belong to a community in a variety of aspects including: having meaningful things to do (such as school or work), having a social network, access to medical or social services, and living independently, which are all important aspects of any persons' quality of life (Clark et al., 2007, Minnes, Buell, Feldman, McColl & McCreary, 2002). Within the context of community integration is the idea that integration is achieved with some degree of support that can be considered on a continuum. It can be looked at as an outcome from a combination of self-help, peer support and professional services and is essentially the goal of rehabilitation services for individuals that have disabilities (Yasui & Berven, 2008).

Individuals with intellectual disabilities. Historically, society has treated individuals with intellectual disabilities as inferior to the general population, and they have not always had the opportunity to meaningfully participate in society. This population has been institutionalized, sterilized, restricted in many ways and often only had socialization with others who had intellectual disabilities, family or paid staff (Kampert & Goreczny, 2005). Because of this, individuals with intellectual disability had little community involvement, felt lonely and isolated, had few social relationships, and spent a great deal of time homebound (Kampert & Goreczny, 2005). Bramston, Bruggerman, and Perry (2002) found that individuals with intellectual disabilities more commonly took part in solitary leisure activities (playing video games, watching television and listening to the radio) that offer no aspects of community involvement (as cited in Kampert & Greczny, 2005). This study also found that typically developed peers reported shopping at malls, supermarkets, and other stores; going to the movies, sporting event

and friend's house—all involving socializing or being in the community—more often than the individuals with intellectual disabilities. Kampert and Goreczny argue that it is essential for individuals with intellectual disability to have meaningful social relationships as well as community membership to foster participation in typical social situations, to increase social skills and to decrease the stigma some of our society hold against individuals with intellectual disabilities (2005).

Although there is an aspect of support in the basic context of community integration, individuals with intellectual disabilities likely need a higher degree of support for success. This can be conceptualized well through Berry's (1989) acculturation perspective that suggests "integration involves retaining unique aspects of cultural identity as an ethno-cultural group (or minority group), while maintaining contact with the larger society" (as cited by Minnes, et al., p. 378, 2002). Essentially, individuals with intellectual disabilities are a minority group that has unique needs that need to be identified and supported by larger society which will ultimately promote interaction with others in the community. Berry's stress on the role of individualized supports as a major factor to community adjustment makes this a unique perspective that can help individuals with intellectual disabilities successfully be integrated in the community. Minnes et al., (2002) suggest that individuals with intellectual disabilities have had some success in community integration in the aspects of medical and dental services, housing, social activity and community involvement; however the highest percentage of community integration did not exceed 53% which suggest improvements can still be made. Unfortunately, Minnes et al., (2002) also indicated that individuals were rated marginalized—needs are identified and supported but not in way that promote community integration—in activities like education, employment, and volunteerism. Although there has been a focus and some success to promote community

integration for individuals with intellectual disabilities further gains in this area will promote a

better quality of life for this population.

Aspects of Community Integration for Individuals Living with FASD

Due to the multitude of neurobehavioral deficits that occur due to prenatal alcohol

exposure, community integration needs of these individuals is likely unique. It is proposed that

the acculturation perspective for individuals with intellectual disabilities is likely to be effective

for individuals living with FASD. Assessing an individual's unique needs and supports seems to

be an important aspect of community integration for those affected by FASD. There are likely

additional aspects of successful community integration to consider due to the significant impacts

from the neurobehavioral deficits individuals with FASD are affected by.

Foster parents of children with FASD reported that placement would end if the child's

behavior became unmanageable, or if the child posed a threat of harm to the others living in the

home (Brown, Bednar, Sigvaldason, 2007). Since children with FASD exhibit social and

behavioral difficulties, these aspects are important targets of intervention and can significantly

play a role in community integration in adulthood. The research by O'Connor et al., (2006)

suggested that children in the CFT group improved knowledge and appropriate social skills, and

decreased problem behaviors compared to children in the delayed treatment group. A three-

month follow up examined maintenance of social skills knowledge and gains as well as reduction

in problem behavior. The results demonstrated that a significant improvement in social skills

knowledge and appropriate social skills was maintained over the follow up period. Problem

behaviors did not decrease significantly but remained lower than initial results before CFT was

initiated (O'Connor, et al. 2006). Since there are known deficits in learning and memory for

individuals with FASD, continued training in these areas throughout the lifespan may help to

increase a variety of aspect in community integration in adulthood.

Due to the fact that individuals with FASD are at a higher risk for disruptive behavior,

mood disorders, substance abuse problems and psychiatric confinement, it is not surprising that

individuals often receive pharmacological interventions. Despite the frequency that individuals

with FASD are prescribed medications there are many factors that can complicate their response

to these medications (Paley & O'Connor, 2009). Some research has resulted in evidence that

stimulant medications can be helpful for individuals who also have an ADHD diagnosis;

however, a number of trials stopped due to negative side effects (Paley & O'Connor, 2009).

Because of this, there needs to be more research that can support the efficacy of pharmalogical

interventions for individuals with co-occurring mental health issues.

Environmental factors can play a large role in the success of individuals living with

FASD. Visual structure can make an environment and tasks more easily predictable and clear;

through the use of visual schedules, instruction, and lists an individual with FASD is offered

support and given information to anticipate and predict what will happen next or what needs to

be done—an area of difficulty due to the permanent brain damage (Kalberg and Buckley, 2007).

These types of environmental supports may prove to be effective in areas of daily living, job

performance and meeting personal needs in adulthood. An effective teaching strategy for

children with FASD is breaking down verbal instructions into smaller steps to effectively address

problems with receptive communication that is often present in FASD. Kalberg and Buckley

(2007) suggest that this strategy can aid in language comprehension and increase performance of

multiple tasks. Adapting the way information is presented to an individual with FASD is

important and is likely something that will be effective throughout the life span to increase

community integration.

          Pilot Study. In a pilot study done with 19 young women living with FASD, the standard

Parent-Child Assistance Program (PCAP) model was modified to accommodate individuals with

FASD (Grant, Huggins, Connor, Pedersen, Whitney, & Streissguth, 2004). PCAP advocates

were educated in all aspects of FASD, meet weekly for consultation, addressed barrier to service,

and discovered that the neurobehavioral deficits were obvious among these women that signified

a modification in their approach was needed (Grant, et al., 2004). Through this study, it was

found that a majority of these women's needs in the areas of medical and mental health care

were unmet at the program initiation. A typical skill in PCAP is to teach clients how to access

needed services. Grant et al., (2004) found that many of the clients were simply unable to learn

theses skills or they learned at a very slow pace with assistance from their advocate; although

these skills were not necessarily fostered, assistance from the advocate ultimately increased the

clients' use of services during the program time. Another significant finding was that although a

client had very poor adaptive skills which prevented successfully independent living, the

stringent criteria enabling access to specialized services prevented access to these services or

made them unaffordable because intellectual functioning was above the criteria for

developmental disabilities and/or financial support (Grant et al., 2004). Through the help of a

highly trained advocate the women in this pilot study were able to work collaboratively to work

on the following: securing stable housing, obtaining chemical health services when needed,

evaluating family planning needs and long term contraceptive use, establishing a network of

service providers who understood FASD, obtaining developmental disabilities services to those

who qualified, and identifying mentors for long term supports (Grant et al., 2004). This study

suggests that individuals with FASD will need coordinated assistance across the lifespan and

offers hope that with appropriate assistance and support individuals with FASD can improve

their quality of life and increase community integration.

      Protective Factors. Striessguth, Barr, Kogan, and Bookstein (1996) found eight factors

that were found to decrease the secondary factors discussed earlier in this literature review.

These factors would likely increase successful community integration later in life, and include:

"living in a stable and nurturing home for over 72% of life, being diagnosed before the age of 6

years, never having experienced violence against oneself, staying in each living situation for an

average of more than 2.8 years, experiencing a good quality home from age 8-12 years, having

applied for and found eligible for supports from the Division of Developmental Disabilities,

having a diagnosis of FAS (rather than [ARND]), and having basic needs met for at least 13% of

life" (as cited by Clark, Lutke, Minnes, Ouellette-Kuntz, p.2, 2004). Their research suggests that

with recognition of a disability and adequate supports in place, a person living with FASD may

not be as likely to experience the secondary disabilities that can affect quality of life and

community integration. Several research studies have found that families report that needed

services include: greater education on FASD for caregivers and the community, collaboration

between support systems (e.g. family and educational), respite care, strong advocates, and

financial supports (Leenaars, Denys, Henneveld, & Rasmussen, 2012). Leenaars et al., (2012)

also suggest that families that have fewer resources and the presences of the common secondary

problems that come with FASD were associated with higher familial stress that extended beyond

the individual with FASD to their families and caregivers.

Caregivers' Perspective

Due to the multitude of effects that can result from having an FASD, having a clear understanding of the lifelong implications is essential. Literature suggests that foster parent perceptions of placement needs for children with FASD indicate that knowledge and training specifically about FASD is a key element for an increased likelihood of success. Brown, Sigvaldason and Bednar (2004), found that foster parents specifically indicated that having experience with children who have a FASD, understanding multiple disabilities, and understanding how alcohol affects the brain is necessary to have appropriate expectations and offer the supports needed for long-term placement. Similarly, other literature indicates that providing education to parents and caregivers regarding the nature of the disability due to prenatal alcohol exposure, including the deficits that will be present in daily life, can help increase understanding challenging behavior in terms of the neurocognitive deficits, rather than willful misbehavior (Paley & O'Connor, 2009). This knowledge and understanding of FASD can help parents and caregivers respond in more supportive and effective way. In turn, it is important for them to educate others living with individuals affected and professionals who are working with them (Brown, et al., 2004). Often times, medical, mental health, and educational professionals may lack training specific to FASD and may not understand the extent or nature of the impairments so it is important for the parent or caregiver to advocate by sharing their own knowledge (Brown, et al., 2004; Paley & O'Connor, 2009).

Several studies have indicated both natural and professional supports can impact quality of life and aspects of community integration for individuals living with FASD (Brown, et al., 2004; Clark, Minnes, Lutke, Ouellette-Kuntz, 2007; Paley & O'Connor, 2009). Foster parents indicate the following supports increase the likelihood of successful placement for children:

mentors, advocates, professional counseling and the opportunity for some respite care (Brown et al., 2004). Similarly, Clark et, al. (2007) suggest that paid caregivers play a significant role in supporting individuals living with FASD and their families; however, they also note that despite having significant deficits, individuals often have an IQ higher than 70 which disqualifies them from receiving formal services. Family and friends often end up being the sole source of supports in the following aspects of community integration: medical and dental care, productive activity (education, employment, volunteering, housing, social/recreational activity, community involvement, and spirituality (Brown et al., 2004). Studies have also demonstrated high levels of stress experienced by biological and foster/adoptive parents of children living with FASD further supporting the need for social, instrumental, and professional supports and services (Clark et, al. (2007); Paley & O'Connor, 2009).

Since literature strongly suggests that the neurobehavioral deficits of prenatal alcohol exposure are life-long, additional supports are likely needed in adulthood to foster community integration. However, there is a lack of research done in the adult population. The focus of this study was to explore the supports and services that are utilized and those that may still be needed by adults living with FASD. To achieve this goal, interviews were conducted with caregivers who have adult children living with FASD by addressing the primary research question: what types of services and supports are utilized, what barriers have been faced, and what still may be needed by adults living with FASD to enhance community integration?

Conceptual Framework

The researcher conducted a data analysis using acculturation as a framework to understand that data that will be obtained through qualitative interviews. Acculturation is a frame work that essentially explains the variety of ways that a smaller group can interact, or

integrate with a larger, dominant group (Buell & Minnes, 2006). The acculturation framework

was created by Berry (1993), a cross-cultural psychologist, who more specifically explains that

"integration involves, retaining unique aspects of cultural identity as an ethno-cultural group (or

minority group), while maintaining contact with larger society" (as cited in Minnes, Buell,

Feldman, McColl, McCreary, p. 378, 2002).

Berry questions two main issues in addressing acculturation: what is the importance and

value of maintaining the cultural uniqueness of the minority group apart from the dominant

group, and what is the value of the minority group seeking and maintaining positive relationships

with the dominant group (Buell & Minnes, 2006). When assessed, the two issues questioned will

form one of four categories between the two groups: 1) integration (minority group maintains

cultural value and positive relationship with dominant group); 2) assimilation (maintaining

cultural value of the minority group is not met but a positive relationship with the dominant

group is maintained); 3) segregation/separation (maintaining cultural value of the minority group

is met but a positive relationship with the dominant group is not); 4) marginalization (cultural

value of the minority group and a positive relationship with the dominant group is not

maintained) as shown in Table 1 (Buell & Minnes, 2006). According to Berry's framework,

minority groups that are categorized as integrated experience less identity confusion,

marginalized feelings, depression and anxiety than those in other categories (Minnes, et al.,

2002).

Table 1: Options in Acculturation Framework		1) Is it important and valuable to maintain the cultural uniqueness of the minority group apart from the dominant group?	
		Yes	No
2) Is it valuable for the minority group to maintain positive relationships with the dominant group?	Yes	**Integration** *Minority group maintains cultural value and positive relationship with dominant group*	**Assimilation** *Minority group does not maintain cultural value but has a positive relationship with dominant group*
	No	**Separation** *Minority group maintains cultural value but does not maintain a positive relationship with dominant group*	**Marginalized** *Minority group does not maintain cultural value or a positive relationship with dominant group*

There is an adequate amount of research that describes individuals with developmental disabilities as a smaller (minority) group and Buell and Minnes (2002), revised the original acculturation framework to incorporate the perception of developmental disabilities—the adaptive acculturation framework. In this adaptation the issue of maintaining cultural value and identity is revised instead to be an issue that looks at whether the unique needs and characteristics of persons with developmental disabilities are recognized and supported by the dominant group or individuals without developmental disabilities (Buell and Minnes, 2002). The second issue, maintaining relationships with the dominant group remains a part of this adaptation. In the same way, individuals with developmental disabilities fall into one of the four categories: integration (disability related needs are identified and supported and the person is involved in the community); assimilation (disability related needs are not identified and supported but the person is involved in the community); segregation/separation (disability related needs are identified and supported but the person is not involved in the community); or marginalization (disability related needs are not identified and supported and the person is not involved in the community). See table 2 for the four categories formed between individuals with disabilities and those without.

	1) Is it important and valuable to recognize and support the unique needs and characteristics of persons with developmental disabilities?	
Table 2: Options in Adapted Acculturation Framework	**Yes**	**No**
2) Is it valuable for persons with disabilities to maintain positive relationships with the dominant group? **Yes**	**Integration** *Disability related needs are identified and supported and the person is involved in the community*	**Assimilation** *Disability related needs are not identified and supported but the person is involved in the community*
No	**Separation** *Disability related needs are identified and supported but the person is not involved in the community*	**Marginalized** *Disability related needs are not identified and supported and the person is not involved in the community*

To further explore the aspects of acculturation for individuals with developmental disabilities, Buell and Minnes (2002) developed the Acculturation, Integration, Marginalization, Segregation (AIMS) Interview which assessed ten specific categories to evaluate whether or not unique needs were met and supported in the categories and whether or not they were involved in the community. The ten categories assessed were: medical services, special medical, dental services, education, employment, volunteer activity, housing, social activity, community involvement, spiritual activity—all areas that have been identified by service providers, professionals, and policy makers as areas requiring evaluation and support in regards to community integration for individuals with a developmental disability (Buell and Minnes, 2002). Their research suggests that attempts for community integration in the developmental disability population have been relatively successful, but there continues to be a need to further assess this concept. The largest percent of individuals in their study were found to be integrated in six of the ten categories: medical, special medical, dental services, housing, social activity, and community involvement; however, it should be noted that no category exceeded 53% except for medical at 82% (Buell and Minnes, 2002).

The adapted acculturation framework is a logical framework for a few reasons. First, the categories in the AIMS interview are encompassing of what community integration is at its essence and providing a more thorough look at what community integration may mean for an individual living with fetal alcohol spectrum disorders. Second, the adapted acculturation framework seems to fit well with what literature has found to be necessary for children and adults living with fetal alcohol spectrum disorder—specialized needs have to be recognized and supports and services need to be adapted for successful community integration. Lastly, the acculturation theory fits within the foundation of social work—meeting a client where they are at, self-determination, dignity and worth of the person, etc.

Methodology

Research Design

The purpose of this study was to complete a needs assessment regarding adults living with FASD and what supports and services are needed, or may be needed, for successful community integration by interviewing caregivers. Caregivers were operationalized as any adult individual who supports an individual living with FASD (e.g. parent, adoptive parent, foster parent, grandparent, adult sibling, friend who is involved with supporting an adult living with FASD). The literature discussed addresses many life-long implications due to neurobehavioral deficits, various secondary problems that can arise, hopeful interventions that can aid in successful community integration, and the fact that further research is necessary in order to determine what is needed for community integration to be successful for this population. This study utilized a qualitative research design to better understand what supports and services are utilized and what supports may still be needed for adults living with FASD to achieve successful community integration.

Population and Sample

Participants were selected through purposive sampling. The sponsoring organization emailed their agency participants and told them about the current research project and provided individuals with contact information if interested in the study (Appendix A). The researcher has chosen this type of sampling because it is important for the purpose of the research to have collected data from people who intimately know an adult who is impacted by FASD and who have witnessed firsthand the variety of aspects that impact community integration for adults living with FASD. All eligible participants were selected on the basis of being a caregiver for and adult living with FASD and all participants were able to provide information regarding the complex supports and needs that are needed for community integration. For the purpose of this study an adult child with FASD was operationalized to be 21 years of age and older; all participants were from Minnesota's seven metro county areas including: Anoka, Carver, Dakota, Hennepin, Ramsey, Scott and Washington counties.

Data Collection

A qualitative research design was used to obtain data from the participants through interviews using a semi-structured interview format guided by a set of questions that were pre-approved by the research committee and the University of Saint Thomas Institutional Review Board. Questions were developed based on the current research outlined in the literature review regarding FASD and community integration, and also to provide further knowledge surrounding the best ways to support adults living with FASD in the community (Appendix B). The questions attempted to elicit open and honest feedback from the interviewees, and used descriptive wording and open-ended questions to reduce interviewer bias.

The questions were designed to look at a wide variety of aspects of community integration for adults living with FASD to gather caregiver perspectives on what supports are utilized, helpful, unhelpful and what is possibly still needed for successful community integration. Questions explored a variety of aspects of community integration including: having meaningful things to do (such as school or work), having a social network, access to medical or social services, and living independently, which are all important aspects of any persons' quality of life. Following the interviews, electronic recordings were transcribed by the researcher to produce transcripts of the interviews which were used for data analysis.

Data Analysis

This study used both inductive and deductive approaches to review the data and drew on information explored in the literature reviewed. In order to uncover themes, transcriptions were initially reviewed to identify recurring concepts present in the data set. To ensure reliability of the established concepts a secondary review of the transcriptions determined if any prevalent concepts were missed during the initial coding. The recurring concepts were then organized into themes which were then studied for sub-themes as well as to ensure no themes were missed upon the initial review. The validity of this study depended in part on the caregivers who completed the interviews as well as the researcher's ability to uncover concepts that created significant themes.

Protection of Human Participants

In order to ensure the protection of human participants, an informed consent form was developed, and reviewed by the research chair and committee members (Appendix C). This consent form was reviewed with each participant prior to beginning the interview and the researcher further explained the purpose of the study, the voluntary nature, and the measures that

will be utilized to ensure confidentiality, such as: removing any identifiable information from interview transcripts, never disclosing the city participants live in, never asking who or how they heard about the present research study, etc. The informed consent was developed from a template approved by the University of Saint Thomas Institutional Review Board (IRB) for a full-board review and also approved by the research committee– Karen van Rooyen, Sierra Asamoa-Tutu, and David Roseborough–and the IRB prior to administering to participants. Participants were given the opportunity to ask question after the form was reviewed, and then agreed to the information laid out in the informed consent. All participants were given a copy of the informed consent as well as given the names of counseling services that they could be connected with if the need arises following the interview. All participants were told that they could end participation in the study at any point in time, without consequence. If a participants chose to end their participation in the study, none of their data would be used for the study– no participant opted to end their involvement in this study. Participants were told that their involvement in this study would not affect current or future relations with St. Catherine University, the University of St. Thomas, the School of Social Work or the sponsoring organization. The names of the respondents have been kept confidential by omitting them from the transcripts and in other sources that may contain identifying information.

The records of this study have been be kept confidential by storing all records (i.e. digital recording of interviews and hard copies of interview notes, interview consent forms, and all other documents containing potentially identifying information) in a locked closet in the researcher's home. Electronic copies of the interview transcripts will be kept in password protected files on the researcher's personal computer indefinitely as original data. Research participants have been identified by a respondent number, not by name. Any highly identifying information from the

interviews was entirely omitted from the study (e.g. name of participant or name of agencies that

provide services, name of adult child with FASD, etc.). All interview recordings from the present

study will be deleted and/or destroyed by June 2015. The signed consent for each participant

will be kept for one year before being destroyed. Written transcripts will be kept indefinitely as

original data, however; any identifiable information is not present on the transcripts.

Precautions were used to minimize risk for participants. Participants were told that they

did not have to answer any question they did not feel comfortable with, and that they could

withdraw from the research process at any time. Participants were given a list of resources to

seek support for themselves if needed following the interview including contacting their own

employment assistant programs (Appendix D). The participants were also given a thank you card

to validate the importance of their participation and as a way for closure to be fulfilled following

the interviews. The study had no direct benefits other than contributing to the overall effort to

improve community integration for adults living with FASD by sharing personal experiences.

Findings

The current study had the following research questions: what types of services and

supports are utilized and still may be needed by adults living with FASD to enhance community

integration? What are informal and formal supports utilized? What supports are utilized to

enhance living and working in the community? What are barriers faced? And finally, what role

does the adult have in their community integration? By using the adapted acculturation

framework, the hope of this study is to provide a more thorough look at what community

integration may mean for adults living with FASD and also to better understand how specialized

needs may have to be recognized and how supports and services may need to be adapted for

successful community integration. The method used for recruiting caregivers used purposive

sampling; the sponsoring organization sent recruitment emails to caregivers who were currently connected to their organization and were willing to receive emails. Four caregivers responded to the recruitment email and agreed to an interview ranging from one hour to one hour and thirty minutes.

The sample included four female participants (N = 4). Two participants were the adoptive mother of an adult who was diagnosed with FASD; two participants were the adoptive mother of one adult with FASD and one adult living with suspected FASD—six adult children were the topics of the four interviews. The ages of their adult children ranged from 40-21, with a mean age of 29. All of the children were adopted by their caregivers by the age of two or younger. Three of the participants had an adult child still living with them in the family home, one of the participants had a child living in a residential group home, and two of the participants had an adult child living independently in the community. Of the six children discussed during the interviews, four of them were working in the community independently, one was working in the community and volunteering, and one was working through the support of a day treatment and habilitation agency. Complete demographics of the participants and their children can be seen in Table 3.

Table 3: Participant and adult child(ren) demographics						
Participant	1		2		3	4
Age of adult child(ren)	38	40	22	21	23	27
Gender of child(ren)	F	F	F	M	M	F
Housing	Group Home	Independent	Independent	Family Home	Family Home	Family Home
Vocational	DT&H	Community	Community	Community	Community	Com./Volun.

Data were gathered through transcribed audio recorded interviews. Themes were discovered using both inductive and deductive methods. The transcripts were first explored in an inductive manner, allowing themes to develop on their own through coding. Once this was complete, the data were further explored in a deductive manner to further determine actual themes found supporting the inductive coding and theme emergence.

When explored inductively, themes emerged within three main areas: caregivers' active role in successful community integration for their adult child, Informal and formal supports that supplement or hinder community living, and their adult child's struggles and successes with autonomy in community integration. Within the area of caregivers' active role in successful community integration three main subthemes emerged: the role of service coordinator, the role of organizer/planner, and the role of safety net. Within the area of informal and formal supports to supplement community living two main subthemes emerged: formal and informal supports, and barriers to supports. Within the area of struggles with autonomy in community integration, two main subthemes emerged: struggles with autonomy vocationally and struggles with autonomy in community living. Within the area of successes with autonomy in community integration, two main subthemes emerged: success with autonomy vocationally and successes with autonomy in community living Figure 1, Figure 2, Figure 3, and Figure 4 display the four main themes along with their subthemes that were found through the exploring the transcriptions in both inductive and deductive manners.

Figure 1: Subthemes of caregiver's active role

```
          ┌─────────────────────┐
          │  Caregivers' active  │
          │  role in community   │
          │     integration      │
          └──────────┬──────────┘
        ┌────────────┼────────────┐
┌───────┴──────┐ ┌───┴──────┐ ┌───┴─────────┐
│ The role of  │ │ The role │ │ The role of │
│   service    │ │    of    │ │ safety net  │
│ coordinator  │ │organizer/│ │             │
│              │ │ planner  │ │             │
└──────────────┘ └──────────┘ └─────────────┘
```
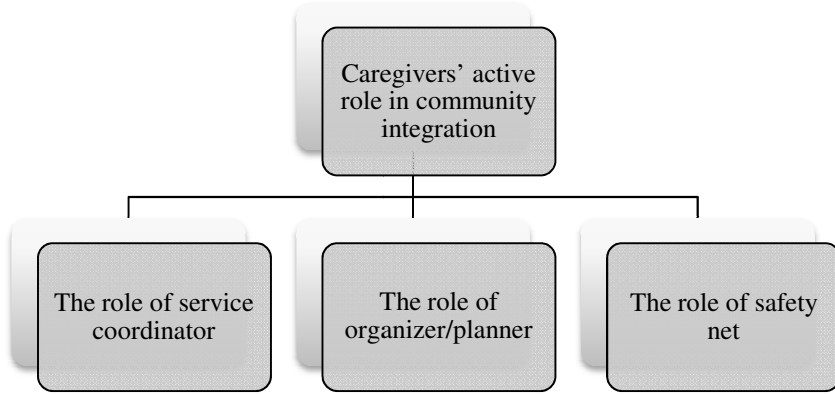
Figure 2: Subthemes of informal and formal supports to supplement community integration

```
          ┌─────────────────────┐
          │ Informal and formal  │
          │ supports to supplement│
          │ community integration │
          └──────────┬──────────┘
          ┌───────────┴───────────┐
  ┌───────┴────────┐     ┌────────┴────────┐
  │ What works and │     │ Barriers to     │
  │  what has not  │     │   supports      │
  └────────────────┘     └─────────────────┘
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Figure 3: Struggles with Autonomy in Community Integration

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          ┌─────────────────────┐
          │   Struggles with     │
          │    Autonomy in       │
          │     Community        │
          │    Integration       │
          └──────────┬──────────┘
          ┌───────────┴───────────┐
  ┌───────┴────────┐     ┌────────┴────────┐
  │ Struggles with │     │  Struggles with │
  │   autonomy     │     │   autonomy in   │
  │  vocationally  │     │   independent   │
  │                │     │  living skills  │
  └────────────────┘     └─────────────────┘
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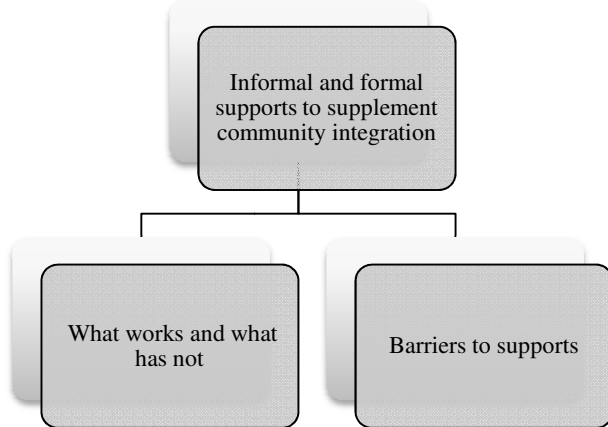
Figure 4: Successes with Autonomy in Community Integration
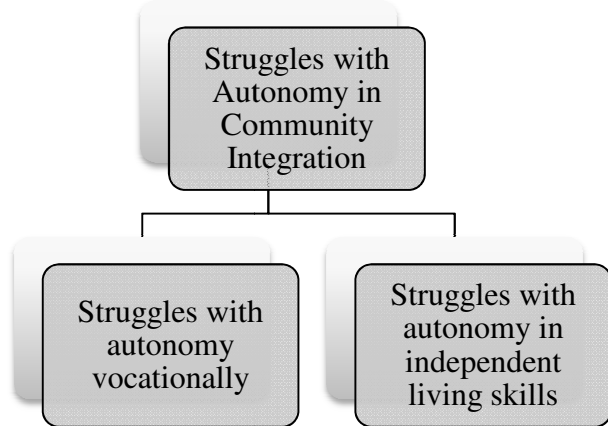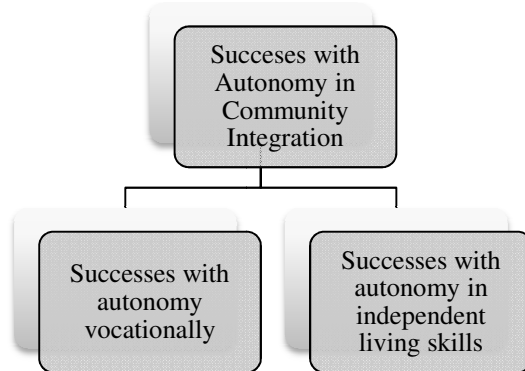

Themes of Community Integration for Adults Living with FASD

Theme #1: The caregivers' active role in community integration

Participants were asked to reflect on both formal and informal supports in their adult

child's life that helped with various aspects of community integration. The first, most frequently

identified theme by participants was their own active role in the life of their adult child to help

with community integration. There were three subthemes related to this theme: the role of

service coordinator, the role of organizer/planner, and the role of safety net. Participants'

responses included topics like organizing formal services and navigating through systems, post-

secondary education/work, keeping their adult child busy, helping to organize their schedules,

helping to ensure that their adult child had emotional support and to ensure that safety was

maintained throughout various aspects of community integration. All four participants endorsed

their own active role in their adult child's life.

Subtheme #1: The caregivers' role of service coordinator

Coordinating through various types of systems and services was identified by several

participants. Participants shared concerns regarding the ability of their adult children to access

services on their own and to navigate through the social service and the criminal justice systems.

Participants also shared how their active role in assisting the coordination of services can be

overwhelming and exhausting. One participant shared her concerns regarding her adult child's

ability to access services if she was not there to assist him:

> *Like I say, it's just, I think about what if I weren't there. What if, what would he be doing? Would he figure out a way to scratch out a living? He would, you know, would he know to go apply for some services? Some energy assistance or SNAP benefits or that his health insurance just got cancelled. Would he know?*

Another participant shared her experience assisting her son through the expungement

process and how he would likely not be able to navigate through this process on his own due to

the complexity of what needs to be done just to begin:

> *Somebody should be able to help him with this expungement process. Well, you know who's gonna be doing it? Me. And so I found the B.C.A form. Got that all filled out for him. I write the check. I said, you have to go, because it has to be his signature. Get it notarized. I said, you have to do this part. Go to the bank and get this form notarized. I had the envelope all made out…Because I said, that's the starting point. We have to have all of the sealed and unsealed records in front of us before you can even go sit down in front of the legal aid people. So I said that's what we're doing. But he would never be able to do this on his own.*

Due to the complexity of these systems, participants deemed their active role was a

necessary support. Because of this, caregivers can become overwhelmed and exhausted by the

amount of effort they have to put into their child's life as a service coordinator of sorts. One

participant explained how taking such an active role within various systems has taken away from

feeling like a parent and that this assistance will likely be needed for a lifetime:

> *And for me for the last eight years it doesn't feel like I've been the parent because I've been the warden, the teacher, the parole officer, the, you know, the scheduler, the everything. To me, there should be [something]. And so now as an adult, even more so and I think some of those things I listed are less critical to him particularly now but some of those things still exist and will exist for a lifetime.*

And finally, one participant expressed the toll it takes to have such an active role in helping to

coordinate services in different systems for their adult child's life:

> *Oh, it's just amazing how many hours I've spent trying to advocate in so many different systems for him. It gets tiring.*

Overall, participants clearly identified the active role that they have in helping to coordinate services and navigate through the complex social service and criminal justice systems. Participants have also identified that assistance with service coordination is likely a necessary, lifelong support needed for their adult child's success in navigating through systems and accessing appropriate services.

Subtheme #2: The caregiver's role of organizer and planner

A second subtheme within the active role of the caregiver in community integration is the role of organizer and planner. Many participants described how they help their adult child in various aspects of organizing: keeping track of items, making schedules to detail work, school, and volunteer time, when to complete hygiene cares, and how long it will take to complete a post-secondary certificate program. Several participants endorsed playing a pivotal role in guiding the process of planning for their adult child's post-secondary future. One caregiver explains how she approached the challenge of her son losing important documents:

> *I keep track of his medical assistance card because he loses things. We've been trying for a long time to tell him to get a wallet. He, he's lost his wallet too, but he loses his driver's license more because it slips out of his pocket. And we told him, "Get a wallet, get a wallet." We wanted to get him one for Christmas. No, [he said] I'm gonna get one from [his girlfriend] and so we didn't get him one and he didn't have a wallet. And the other day I found his driver's license. Luckily I found it on the floor by the garage door. So, I went to TJ Max and I found a wallet that I thought he would like and I brought it home and put his license in it. And he thanked me. He's really good at thanking me.*

Another participant explains how over time she created a plan that simply helped her adult child keep track of matching gloves and socks:

> *He loses things. Like it's kind of a running joke. The other day I said, don't you have any gloves? No. Like we start the winter out, like right now, I'm on the hunt for gloves for next year. And I try to buy identical, like ten pairs of identical ones.*

> *So, if one's lost you can just…we still have a right one we just don't throw that away. Keep it because next time you'll lose the other hand. Socks are all identical. Same color. Same whatever because, these are just lessons learned.*

Two participants explained how they help their adult child with scheduling and structuring out the week/month to help manage the various activities and tasks that need to be completed by their children:

> *Ah, well she has a calendar. So I help her fill out the calendar. So I help her fill out the calendar every week. So we talk about, Okay, you work Tuesday, Wednesday, and Thursday. Here is your schedule, what time do you need to be out of the house? She takes the bus back and forth. If you work these hours when do you need to schedule your bath and was your hair, um, so my role is to kind of structure the week for her.*

Another participant talks about the importance of helping with scheduling:

> *I don't want him overwhelmed. He'd look at that and go…I print a schedule for him out every month. We'd keep everybody's stuff, I'd segregate it out and print just his [schedule] It's on the kitchen table, you know, it's in his phone too. It's all there. You know, he probably looks at about a week. And he would never look, like, oh, what happens when this class is over? I don't have anything going on. That wouldn't happen.*

Finally, one participant shared about the importance of keeping her son busy and how she will bring vocational/post-secondary learning opportunities to her son because he would have a hard time finding these opportunities on his own:

> *But, you know, like getting him into this green construction [program], I brought it to him. I mean, he would never find it on his own, nor seek it out on his own. But I said, hey there is this thing and it's coming up and it's winter and he doesn't have a whole lot going on and your [job] is gonna be done and [the program is only four weeks. And its inside. I mean, it's just the whole sales pitch; I have to pitch it to him.*

Subtheme 3: The caregiver's role of a safety net

The last subtheme regarding the caregiver's active role in community integration is their role as a safety net for their adult children living with FASD. Participants spoke about both formal and informal ways they acted as a safety net for their adult child. One mother spoke about

how legal guardianship was in place to ensure some safety. She explained how the guardianship

is there if she needs to use it:

> *Fortunately I have guardianship because, with him, he'd go buy a car, he'd go*
> *sign an apartment lease. He'd go buy a cell phone. He'd, you know, so fortunately*
> *I haven't had to exercise that but he knows it's there. He knows it's there but that*
> *a safety net I've put in place myself.*

One mother spoke about a harm reduction approach she utilized with her son to reduce the

likelihood of him getting in trouble with the law:

> *And we used to ban it [cannabis] completely from our house, and, you know,*
> *we're not gonna have it in our house or anywhere on our property, but my*
> *husband felt that it was probably safer for him to get high outside of our house.*
> *We wouldn't let him smoke in the house. Get high outside of our house rather*
> *than on the road because he'd be less likely to get arrested.*

Lastly, one mother explained the legal help that she was able to provide for her child when he

was in trouble with the law:

> *His trouble with the law has been, you know, he certainly went through a streak*
> *where it was, you know, difficult and I hired an attorney who deals with, you*
> *know, has dealt with some folks with disability and some of those things and we*
> *were somewhat successful maybe the first time. Subsequently, you know, that too,*
> *it's like, you know, he was a juvenile and he didn't get a public defender because*
> *I, I mean he has been an extremely expensive kid to raise.*

It is clear through what participants shared that the active role of a caregiver is likely a

necessary support to ensure successful community integration for many adults living with FASD.

The various roles that were shared by participants all seem to play an essential role in helping to

foster success in the community.

Theme 2: Informal and Formal Supports that Supplement Community Integration

The second main theme found in the data was the use of both formal and informal

supports to supplement community integration. While all participants spoke about multiple

informal supports, the main informal support found was the active role of the caregiver which

resulted in it being its own theme. However, participants shared ways in which other informal

supports–family, friends, and significant others–played a role in community integration for their

adult children. Another informal support that was found was the use of cell phones as a way to

connect with others and to problem solve when their adult child needed support. While all

participants spoke about informal supports, only a few participants mention formal supports that

were in place to help with community integration. One of the adult children was living in a group

home and attending a day treatment and rehabilitation program. Two of the other participants

mentioned independent living skills workers, being connected to case management services and

the help of therapeutic services. All participant spoke about barriers that their adult children have

faced in regards to both informal and formal supports to help with community integration.

Subtheme 1: What has worked and what has not

A few participants talked about the formal supports that are in place in their adult child's

life that supplement community integration in a positive way. The formal supports discussed

help with vocational opportunities, accessing the community, and with independent living skills.

One participant talked about how living in a group home and having day treatment program has

been good for her daughter's community integration:

> *[She] is in a group home for couples. She is in a committed relationship and has*
> *been for seven years. And um, and she goes to work every day she has a day*
> *treatment program, and from there they go out in teams and uh, right now, what*
> *she loves is that she has a paid job that is paid by the hour and she works for a*
> *toy company.*

She later went on to explain that he daughter receives county services and that her group home

program director really understands her daughter:

> *Um, yes, she had case management. We kept that thank God. And um, she's had*
> *wonderful case managers, just wonderful. And the, um, program director at her*
> *house is wonderful. Really, really, gets her.*

Another participant explained that her daughter receives help in the family home from an

independent living skills worker to help with community integration:

> *Right now she has 5 hours a week. Her social worker is willing to up it to 8 hours*
> *a week. They have a kind of routine. The do laundry, grocery shopping,*
> *appointments, and they go through her mail. Um, they go out places. They are*
> *supposed to be every Monday and Wednesday getting some sort of exercise in the*
> *winter, [she] is reluctant to step foot outside unless she has to.*

Another participant speaks about how having an independent skills worker for her son did not

work as well for him:

> *He had an ILS worker for a while. He seemed to get along pretty well with the*
> *people who did the ILS, but it wouldn't stick. Like the ILS person would have him*
> *work on like a calendar or something and that's great. [He] can do that part. He*
> *can't follow through on his own. You know, that would be too much thought*
> *processes or, you know, while I am busy playing right now, why would I want to*
> *clean the bathroom just because it's on the list? And I've offered to have*
> *somebody do that with him again in recent years but he feels he's way too old for*
> *that.*

Another type of formal support shared by participants were therapeutic services that have been

helpful. Participants explained that counseling services, behavioral services, and spiritual

services have benefited their adult children in community integration. One participant explained

how she can collaborate with her son's therapist at times:

> *I find him locked in, well, with his door closed, in his room, watching TV, playing*
> *video games. You know…, it might be a good opportunity to use your time at this*
> *moment to look for jobs, but I don't feel like being snapped at again. Yeah, and I*
> *talked, I feed information to his therapist. But the therapist that he works with,*
> *now, he's eager to go to her and we're willing to pay because he needs to have*
> *some continuity.*

Another participant shared that her daughter has had a psychologist, behavior therapist and a

Native American life coach involved to help with aspects of her daughter's community

integration:

> *[She] has always had, well for years, since she has been back with me, uh,*
> *therapists. And now, well for a while she had two, there was one who was a*

general psychologist therapist and for a while she had one that was more of a behavioral therapist. She would do sometime, four times a month for each of them, sometimes two times a month for each of them. And now she has somebody at a Native American center [in the metro] that is not a therapist, but she is like a life coach and they are working with [her] on her heritage. What they are working with, all this knowledge that she has that is very hard for her to integrate into her life. They are working on helping her to understand how to do that.

Although every participant did not mention formals supports, there seems to be a significant value for some adults living with FASD to have access to formal supports.

Every participant mentioned informal supports that were evident in their adult child's life that helped with various aspects of community integration. The main informal supports shared were, family, friends, and significant others. Two participants mentioned the support that their adult children get from a significant other. One participant explained that her daughter cannot access the community alone, but with her friends and partner, she is able to:

She's made a few friends that she can do stuff with, um, she can go out in the community with [him]. The two of them together. They take busses, they go to the mall, they are able to get a hotel room for a night or two to be together and they help each other take their meds. And um, [He] just works at keeping her safe. And if she thinks he is being too protective she will have him call me. And he will say, [she] wants to do this and this is that okay?

Another participant shared how her son's new girlfriend has helped him on two occasion with activity of daily living at the family home:

And she came to me the other day with a bunch of his clothes draped over her arm, and said, I understand that you soak and you do this and this and this for [his] clothes and I thought, he could ask me. He has in the past but I thought here's the external brain for him. It makes me happy.

And she also shared about how his girlfriend helped to clean his bedroom in the family home:

And one day his girlfriend helped tidy up his room and he has so many ants in his room and just leaves food and wrappers and things all over the place.

Participants also spoke about how technology can be helpful to enhance aspects of community integration for their adult children. They shared how the use of cell phones either for talking or

texting can help when extra support is needed. One participant elaborated on how she can be a

support over the phone when her daughter is having a difficult time:

> *So that was the next step of learning that mom is close, as close as a phone. She
> was talking to me every day three, four, five times a day. Then um, now its where
> usually one a day but sometimes it is two, three days between calls. But I am
> there. What I do is that I guide her through. Well what have you done? What are
> your stressors? Who have you told? What are your resources?*

Another participant explained how texting can help her daughter if she has a question or concern:

> *Um, I also provide a lot of tech support. Where is she has a question or concern,
> she can text me. It is working out pretty well. When she calls me, I can't always
> answer. So having the freedom to text at least let her get whatever she needs to
> get out. And then when I can, I will reply back. But at least she can get it out and
> she knows I will respond when I can.*

Subtheme 2: Barriers to supports

All participants talked about multiple barriers that their adult children living with FASD

faced in various aspects of community integration. One barrier mentioned was due to syestemic

challenges faced in receiving or qualifying for formal supports that would supplement and

enhance community integration vocationally, residentially and socially. Participants explained

how their child may have received school supports but since leaving the education system and

entering adulthood specialized supports did not follow. Another barrier that participants shared

was their adult child's struggle with mental health concerns/chemical dependency issues that

sometimes lead to hospitalizations or expensive services. Participants described how formal

supports did not always fit the unique needs of their adult child. Participants also explained how

legal issues became barriers for supports regarding community integration for their adult

children.

One participant shared her son's experience in the children's mental health system and

juvenile justice system. She explained how frustrating it was when her son was involved in both

systems at the same time, but it seemed no one wanted to help. She also expressed frustration

because once her son turned 18, his mental health services through the county did not continue.

She explained:

> *In the case of my son, there were a couple of hospitalizations of the children's health umbrella in [a local metro county]. At the same time, starting to have some legal issues and then we were just bounced back and forth, back and forth, between the juvenile system and children's mental health. He was a hot potato that nobody wanted to touch and it was hugely frustrating. And looking back, it was a huge waste of time and effort and energy that went into zero benefit. And particularly now—zero benefit. To me he should have transitioned from children's mental health in to adult mental health or something. But instead, he was 18 and he was done.*

Another participant explained how her son's time at residential treatment interfered with him

moving into a supported apartment program through his county funded CADI waiver and how

this resulted in him no longer having that funding:

> *A few years ago he was taken by his county case worker at that time to a, not a subsidized, a supported apartment and he, he had a CADI waiver at the time. He could've lived in an apartment and it turns out he was going to residential treatment at the time…part of it again is that, again, he falls through the cracks…he still has a case manager. The CADI waiver is no longer.*

Another participant comments about falling through the systemic cracks:

> *Falling through the cracks is just it's like a story of our life. And I know that there's a limited budget for both schools and for the state. But that's not an excuse.*

Another participant explained how both the mental health and developmental disability systems

did not fully support her daughter's unique needs:

> *And when she got out [of the psychiatric hospital], there was nothing in [that state] available and she was a ward of the state so they placed her in a home in um, like a transition home in [a metropolitan city]. And that didn't work. And then she went into a home for dual diagnosed women but it was for mental health and alcohol use, and not DD. So the DD was restrictive and the mental health was too informal, too loose.*

Another participant shared how moving from one metro county to another metro county disrupted continuity with the service provider her daughter was receiving support from which resulted in needing to find a better fit in providers:

> *We have been through multiple ILS providers. Yes, um one reason is because we moved from [one metro county] to [another metro county] in the past eight years. So she switched over counties and then each county seems to have a preferred list of providers. The latest switch was because the providers that were working with, it was not a good match and they did not have someone else. Yeah, they did not have any other staff person besides the woman… did not engage with well. So then we had to switch providers to find a better one.*

Finally, two participants explained how the invisibility and lifelong implications of FASD were one of the major barriers faced in regards to their children getting formal supports for community integration:

One thing that jumped into my thoughts was, if you have a kid with cerebral palsy or with, you know some, if they're in a wheel chair. Everybody sees that and they know you have challenges. But as one of [his] therapists said, these kids have the wheelchair within. They have so many challenges and yet the world doesn't see that they do and so they put down the parents. And I don't know how to make that different. I think, you can't really change a whole society. But kind of one of the biggest barriers is just the invisibility of it and not getting support.

And:

You know, do you think we should go through the [metro county's] front door again, and just kind of see what happens and yet, even, I just cringe. Because it's such a painful process and if they just look at you again like, "Why are you here? I mean that's [disappointing]. And it's like well we're here because this is a lifelong disability and there really are some issues here. No, he doesn't need help with employment. No, he doesn't need much help with living skills. He needs help with maintenance kind of.

All participants clearly shared experiences where their adult children faced barriers—mainly systemic—in receiving, or even qualifying for supports to help with community integration.

Theme 3: Struggles with Autonomy in Community Integration

The third theme that emerged from participants' responses were the struggles their adult children had with autonomy in community integration. There were two subthemes to this theme: struggles with autonomy vocationally and struggles with autonomy in independent living. All participants were able to share experiences that fit into at least one of the two subthemes.

Subtheme 1: Struggles with autonomy vocationally

The first subtheme is that participants' adult children experienced struggles with autonomy vocationally. Participants described how starting a new job can be difficult and how a promotion within a job can be overwhelming for their child. Participants explained how when their adult child would get a promotion or more responsibility at work, it was difficult for them to manage and keep the position. Participants also shared that sometimes their adult child may lack motivation to find a job. One participant, shared her daughters experience with starting a new job and needing assistance from a job:

> *Anything new she needs almost a one on one. If they change her job at work, um if there is a new bus driver or van driver she has to be fore warned and then somebody to ask about how it is going and if there is anything that can be done. If it doesn't happen, things build up and then it explodes. Like for a job and she has like a 2 hour job, she would need 1 hour written down and then another hour written down because 2 hours would be too much for her. Or she has to have someone with her to help prompt her and then she can learn that if she gets stressed um she can't function, she can't think about it. So if she thinks she has made a mistake all of the ability to control herself goes out the window, and so that's why she has to have at least a job coach around that she can go to and say help me I am feeling stressed.*

Two participants shared how their adult child received a promotion or had more responsibilities at work which made it difficult for them to manage and keep their positions:

> *They would, they would promote her and they might train her for a half a day but they wouldn't give her the support to learn the new position because she presents so well that they thought she could just handle it. So within a short time they would be dissatisfied, or she would, and then she would get fired.*

Another participant shared a similar experience that her son went through:

> *Yeah, so he was working at [a sandwich shop]. He was offered an opportunity to become a manager and he go overwhelmed apparently and started acting up and not only did he not get the promotion, he had to quit.*

Participants also shared circumstances where their adult child's vulnerabilities create a struggle vocationally. One participant explained how her son is vulnerable in situations where understanding concepts of money are involved and that he could easily be taken advantage of:

> *You would never know that he has an invisible disability but it also puts him in a situation where he is kind of vulnerable. Especially in that case, where it is splitting up tips and this and that; it's easy for him to be taken advantage of. You could talk him into, "well this is a good deal. I'll give you this $10 for your $20," or you know, whatever.*

Finally, one participant shared her perspective regarding her adult daughter's ability to complete a nursing degree after getting her associates in child development:

> *She got through a child development program. She was going to go into nursing and I don't think she could complete the science courses. I think it is just too much rigor and difficult reading and such.*

It is clear through what participants shared that adults living with FASD will likely experience some kind of vocational struggle, which is a major concern because vocational stability and success is a major, contributing factor for living independently in the community.

Subtheme 2: Struggles with autonomy in independent living skills

The second subtheme found was the struggles that participants' adult children faced with autonomy in independently living. All participants described a wide range of struggles that their adult children have gone through like: having the desire to move out, lacking financial skills, realizing that their parent will not always be there for them, struggles with adaptive coping skills and maintaining safety in the community setting.

One participant described her daughter's feelings about talking to her social worker

regarding alternative living situations that she could pursue to benefit her independent living

opportunities:

> *She is very scared about us talking with her social worker about other living situations. Maybe not scared, but reluctant, because she likes the safety and security [of living at home] but she also spends too much time alone. So that's the concern. She needs perhaps a different environment for more socialization.*

Another participant shared her son's desire to move out of the family home, and that he struggles

with putting effort into saving money so that he could move out of the family home:

> *He wants so badly to move out. He's wanted to for years. He wouldn't have as great of an opportunity to find a roommate but he could conceivably more in with his girlfriend, but he needs to have as steady job. And he thinks more, you know, the typical, I'll think about this and therefore, it feels real but I don't actually want to put the effort into it. Saving, earning the money and saving.*

Similarly, another participant described how her son's impulsivity contributes to his

struggle with money management and his potential to pay bills:

> *I mean he can count money and make change and stuff like that. It's not that. It's just, you know, you have a bill due next week. You know, so the impulsivity. And the lack of consequences and just the concept of you know, time, "Oh, next week. I get paid today but next week I gotta pay this bill. I need that $150." But no, I want to spend it right now. That's what impulsive people do.*

This same participant shared a situation in which her son wanted all of his money out of the bank

which supported her concern regarding her sons struggle with money management:

> *You know, it's like "I want all my money out of the bank". And there have been times I've given in to him and then he'll go to the casino and spend it. It's all gone. Anyway, it's just it just reinforces to me that he cannot handle money.*

Participants also shared that interpersonal skills and maintaining safety while in the community

were areas that their adult children struggled in. One participant explained how her son handles

situations when he gets overwhelmed. He struggles with the ability to cope in an appropriate

way, she explained:

There have been moments when he gets overwhelmed with what is going on. And the hard thing is that you can't tell. Until it was like…he would disappear. He would steal a car. It wasn't about stealing the car; it was about escaping being overwhelmed. Then you have this legal issue to deal with.

Finally, one participant explained how her daughter is very vulnerable in social situations when she does not have somebody with her ensuring her safety. She described two unfortunate situations where her daughter was sexually assaulted:

Oh yeah, she wouldn't make it. You know in the beginning when she was in [a metropolitan city] she would leave my house, she would run away, put herself in harmful situations. She go out to a party with all guys and they would gang rape her. They would get her drunk on 100 proof alcohol. She was gang raped in [a metropolitain city] when she was at a group home and they went to a gym where all these groups of people were there and they were playing basketball and stuff and I am sure she was flirting, and she went out back to have a cigarette and no one went with her and three guys followed her out and gang raped her.

For this young woman living with FASD, having support with her while she is in the community is essentail to her perosnal safety and likely a support she will need whilea accessing the community for the rest of her life.

Theme 4: Successes with Autonomy in Community Integration

The final theme that emerged from participants' responses was successes with autonomy in community integration. There were two subthemes to this theme: successes with autonomy vocationally and success with autonomy in independent living skills. Although all participants were able to describe the multitude of struggles their adult children have experienced, they were also able to share the many successes their children have accomplished in the various aspects of community integration.

Subtheme 1: Successes with autonomy vocationally

Participants shared various successes their adult children have experienced vocationally. The successes discussed mainly focused on interpersonal growth related to jobs skills and the

pride participants' adult children received from having a job of importance. One participant

shared her daughter's ability to recognize a problem at work and advocate on her own to resolve

the problem:

> *And for the first time ever she started to have some problems with coworkers and [the pizza place] promoted her again and gave her too much responsibility. It's a very hectic place. Busy, busy, busy. So, she, on her own, instead of complaining to higher ups, went to another store and asked if they needed her and if she could transfer there. And this is the first time she has done something like that. To find, to reason out what she needed to do, and articulate it and ask for it on her own.*

Similarly, another participant shared how her adult son is self-aware when he may need

assistance from her to complete homework for his vocational certificate program and that he has

always been employed. She explained:

> *And, yes, he was like "We got out a little early today but I got 80 pages to read by Monday. Can you help me?" Yeah, we can sit down and whatever. So he knows at some level he needs some assistance but doesn't like to hear that and he certainly doesn't want his friends to know that. So anyway, that is going really well. And that is what his vocational trail has mainly been. He has always been employed.*

One participant explained how her son was able to take the initiative to search for and inquire

about jobs on his own:

> *He's been looking at jobs through Craigslist and other places and we have no way to really know [that he is searching for jobs]. He said he had an interview on Friday and that he had an interview with the owners of this place doing landscaping on Monday, yesterday. So half the day came and went and we asked him about it. He said, "Oh well they're supposed to call me". And I thought, we'll that's not exactly what you said on Friday, but good for him. He actually placed the call and it turns out [the landscaping company] was so busy because it had snowed a little bit that they hadn't had a chance to call.*

Finally, two participants were able to describe the pride their children received from

having a job that was important to them:

> *And so I think that, that was, to be able to say, "Yeah I have this job," and then to be able to say that you have a job for the city and you were teaching swimming lessons, I think they he learned pretty quickly that those things were something to be proud of.*

And:

> *Yeah. She um, works at a book store and she gets 3-4 shifts a week and she also volunteers at a cat rescue place. Ah, she is a cat lover, but we do not necessarily want a cat in the house so that is where she gets her cat fix. She is proud of it and enjoys it.*

Subtheme 2: Successes with autonomy in independent living skills

The last subtheme found was successes with autonomy in independent living skills that participants' adult children have experienced. Although most participants still lived at home, other successes were found in multiple aspects of independent living. One participant explained how her son has very good social skills:

> *He is really social; he is really a people person and just really social and likes to be around new people and new things. He takes in so much that goes on around him.*

On a similar note, another participant shared about how others in her son's life notice that he is well mannered and a good person:

> *And the counselor [at a treatment program] said, he couldn't believe how [he] stood out from his peers there because he could tell that [he] was raised really well. He has manners. He knows, you know, interactions and stuff. And even the boyfriend of [his girlfriend's] mom told me the other night at bowling, he said, "[he] is a really good kid. He is really nice"*

Another participant explained how her daughter was able to utilize skills to problem solve which is something that she has struggled with in the past. She shared:

> *So probably a year ago, first time ever, she called me, and said, "Mom I am having trouble with staff. And I said to tell me about it and she was like "Well, I really thought about it, Mom, and I decided that to act out really wouldn't be beneficial…She processed, and was able to put the tools together and use impulse control, first time ever.*

Lastly, one participant shared her daughter's success with living in an apartment on her own:

> *My daughter lives nearby in an apartment by herself. She is employed fulltime and we see her almost every day because she is pretty close by. Yeah, she went to technical college and lived at home and then she went to [a state college] to finish*

her two year degree in child development. She moved home for the summer and
after that has moved just a few months ago. She has some money management
issues. She has a lot better handle of time and keeping a calendar and those kinds
of things. She knows her calendar and knows where she needs to be…things like
that.

The aspects of community integration for adults living with FASD are truly unique and

multi-faceted. The experiences shared by caregivers who are directly involved in the lives of

their adult children living with FASD offer insight into what other adults living with FASD may

face while trying to achieve community integration.

Discussion

The purpose of this study was to explore with caregivers what types of services and

supports are utilized and still may be needed by their adult children living with FASD to enhance

community integration. Since there is a limited amount of research done in the area of adulthood

for individuals living with FASD, the results of this study are compelling in many ways. The

data revealed information that is consistent with research that has already been done in the area

of FASD and it also revealed new, valuable information to consider for adults living with FASD.

Overall, the caregiver participants were very forthcoming in sharing their adult child's and even

their own experience regarding the aspects of community integration. Each caregiver was able to

identify elements that contributed to the most successful community integration for their adult

child including: their active role, formal supports, and other informal supports. Each caregiver

was also able to identify various barriers that prevented successful community integration and

various aspects of what contributed to successful integration.

Caregiver's active role

One of the most outstanding findings in this study was the caregiver's active role in their

adult child's community integration. Caregivers spoke often about assisting their adult child in a

variety of ways to get the services and supports that they needed to function well in the community. They discussed helping their children within complex systems and helping to connect them to services that were available. Similarly, Grant et., al. (2004) found that young women living with FASD were unable to learn the skills needed to access services or they learned at a very slow pace with assistance from an advocate. Although these skills were not necessarily fostered by the young women, assistance from an advocate ultimately increased the women's use of services. This similar finding may suggest that adults living with FASD will need extra support, either from a caregiver or an advocate, to ensure services that would benefit integration and that are available to them would be utilized in adulthood. Without this additional support accessing services, it is likely that adults living with FASD, as represented in this sample, may struggle within countless aspects of community integration.

Another important finding in this research regarding the caregiver's role was that of organizer and planner. Many caregivers spoke about the importance in helping their adult child plan and organize their weekly/monthly schedules to help them navigate through the week. This is consistent with research suggesting that visual structure can make an environment and tasks more easily predictable and clear through the use of visual schedules, instruction, and lists (Kalberg and Buckley, 2007). An important aspect of community integration is having meaningful things to do such as school and work (Clark et al., 2007, Minnes, et al., 2002) and many caregivers share how they were instrumental in helping to plan for post-secondary education and vocational opportunities. Although the research reviewed did not address planning for post-secondary school or work, research does address the lifelong difficulties with in the areas of: attention, learning and memory, complex problem solving, abstract thinking, poor response inhibition, impulsivity, motor function, language, and executive functioning (Connor &

Streissguth, 1996; Davis, Desrocher, & Moore, 2010; Gibbard, Wass, & Clarke, 2003). These lifelong difficulties will likely inhibit many adults living with FASD in planning their schedules and futures hence supporting the need for the caregiver's active role in planning and organizing found in this study.

The last active role of the caregiver found in this study was the variety of ways caregivers act as a safety net for their adult child. Research suggests that the multitude of social and adaptive deficits cited for children with FASD will typically become more pronounced as they age and move onto adolescence and even into adulthood (Rasmussen et. al., 2010; Jirikowic, Kartin, & Olson, 2008; O'Connor, et al., 2007). A caregiver made note of a variety of reasons why she obtained guardianship as a formal safety net for her adult son with has difficulty with money management, impulse control and executive functioning: "Fortunately, I have guardianship because, with him, he'd go by a car, he'd go sign an apartment lease. He'd go buy a cell phone". Although her son is an adult, he continues to be affected by the lifelong implications of FASD and needs continued formal support from her as a guardian to ensure sound, safe decisions are being made.

The findings of this study also lend support to the notion that individuals living with FASD are at risk of developing 'secondary disabilities' (Streissguth, et al., 1997). The research done by Streissguth, et al., (1997), suggests that 60% of individuals living with FASD will experience trouble with the law and 30% will experience trouble with drug and alcohol use. The findings of this study further support the idea of the caregiver at a safety net when a 'secondary disability' is faced. One caregiver reported a harm reduction approach that was utilized due to her son's cannabis use to keep him out of getting in trouble with the law and another reported hiring an attorney after her son had already been in trouble with the law. These findings further

support the idea that the caregiver of an adult child living with FASD will likely play an active

role in their child's life to ensure that community integration is successful. Similar to findings

from Brown et al., (2004) this research supports the impression that family and friends often end

up being a sole support in various aspects of community integration.

Formal and other Informal Supports

Caregivers in this current study shared their adult child's experience with both formal and

other informal supports that supplement community integration. Several studies in the literature

indicate that both natural and professional supports can impact quality of life and aspects of

community integration for individuals living with FASD (Brown, et al., 2004; Clark, Minnes,

Lutke, Ouellette-Kuntz, 2007; Paley & O' Connor, 2009). Similarly, caregivers reported formal

supports that have been helpful such as, independent living skills workers, therapeutic services,

case management and supported living services. On the contrary, one participant shared that her

son did not benefit from an independent skills worker because he felt that "he's way too old for

that." Some of the caregivers shared that collaboration among formal supports was very effective

in enhancing community integration for their adult child. Two caregivers shared that

collaboration with a psychologist, behavior therapist, and life coach; although the literature does

not directly speak to collaboration among a variety of formal supports this study seems to

suggest that collaboration is an effective way to increase the likelihood of successful community

integration.

To reiterate, research conducted by Brown et al. (2004) supports the impression that

family and friends often end up being a sole support in various aspects of community integration.

Caregivers in this current study reported additional informal supports like their adult child's

significant other and the use of technology. Although research addresses family and friends often

being a major support for adult living with FASD, the research seems to lack the idea that a

significant other can act as an informal support for an adult living with FASD. One participant

shared that her daughter and her boyfriend "…help each other take their meds, and um, [He] just

works at keeping her safe." Another participant reflected when talking about her son's girlfriend:

"I thought [she is] the external brain for him. It makes me happy." Receiving informal support

from a significant other to supplement community integration for an adult living with FASD is a

unique finding to this current study. The use of technology is also a new finding according to the

literature reviewed. Caregivers shared that they are able to provide support via a phone call or

texting if there is a question, concern, or if emotional support is needed. These additional

informal supports may help to decrease the need for such a significant, active role of the

caregiver's interviewed which were already discussed.

      Barriers. Caregivers reported various barriers–mainly systematic–to formal supports that

were faced by their adult children. Two caregivers detailed the lack of continuity in supports

when dealing within the juvenile justice system and children's mental health system or when

moving from one county to another. Once one child reached adulthood, a caregiver reported that

there was no transition for him within the system, and supports just ended. Another caregiver

reported that her son's stay in residential treatment interfered with him moving into a supportive

apartment program and also resulted in him losing his county support: a CADI waiver. Multiple

caregivers reported that they felt as though their adult child kept "falling through the cracks"

when it came to formal supports. Another participant shared that the mental health system was

too informal for her daughter, but the developmental disability system was too restrictive. These

findings suggest that the multitude of lifelong implication individuals' experience that have

FASD will likely require a unique type of support for adults to be integrated into the community that may not exist within just one system.

Lastly, two participants reported that the invisibility of the diagnosis is a major barrier to receive services. Since individuals with FASD may have few to none of the notable facial features present in FASD the support needed for successful community integration can be overlooked by support providers. This also lends to support current research that suggests despite having significant deficits, individuals with FASD often have an IQ higher than 70 which, from the get go, disqualifies them from receiving formal services. Caregivers reported in this current study that not receiving formal supports because of the invisibility of FASD is 'disappointing' and that their child experiences "so many challenges and yet the world doesn't see that they do and so they put down the parents."

Struggles and Successes with Autonomy in Community Integration

Since there is little research done in the area of community integration for adult living with FASD, there is little to no research available to interpret the findings. Despite that, as a consequence of these neurobehavioral deficits, research does show that children with FASD exhibit considerable social impairment (O'connor et al., 2007) and are at high risk of problematic behavior which will usually last a life time so these deficits are likely present in adulthood (Rasmussen, Becker, McLennan, Urichuck, & Andrews, 2010). Since FASD are one of the leading causes of preventable intellectual disabilities in the United States, these findings can also be interpreted through the aforementioned adapted acculturation framework for individuals living with developmental disabilities.

Vocational struggles. Caregivers reported various struggles that their adult children experienced vocationally. One participant shared that when her daughter starts a new job, she

basically needs one to one support from a job coach and a visual written schedule broken down

hour by hour to succeed; if a mistake is made by her daughter in the vocationally setting, the

ability to control herself decreases. This can be attributed in part to the organic brain damage that

has happened which can result in difficulties with attention, learning and memory, complex

problem solving, abstract thinking, poor response inhibition, impulsivity, motor function,

language, executive functioning and behavior (Connor & Streissguth, 1996; Davis, Desrocher, &

Moore, 2010; Gibbard, Wass, & Clarke, 2003). On a positive note, this adult child is considered

integrated vocationally according to the adapted acculturation framework—her disability needs

are identified and supported vocationally and she is involved in the community. In this current

study, this adult child is the only one who seems to meet the criteria for being vocationally

integrated because of the specialized supports she receives on the job. Allowing flexible

expectations for adults living with FASD seems to be an important aspect for vocational success

The other caregivers reported vocational success, but had some concerns regarding their

adult child getting a promotion and dealing with monetary tips which can be considered an

abstract concept. Two caregivers shared about their adult child's experience in receiving a

promotion but not being able to handle the added responsibility of the promotion. This can again,

likely be contributed to the difficulties adults experience due to the organic brain damage of

FASD. It could also suggest that individuals living with FASD may have a limit to their optimal

function vocationally. For example, an individual may perform well at an entry level position,

but may become overwhelmed or unable to manage in a higher position from what the findings

of this study suggest. Lastly, one participant reported concern regarding her adult son's ability to

manage monetary tips because of his vulnerability with money management which can be an

abstract concept—an area difficult for individuals with FASD. These findings suggest that these

adults living with FASD are likely assimilated vocationally—their disability needs are not completely met but they are involved in the community vocationally. The findings of this current study suggest that FASD adaptive needs that are met vocationally will lead to more vocational success and that employers should be aware that their seems to be an optimal functioning level for adult living with FASD in the vocational setting.

Independent living struggles. Caregivers also reported various struggles that their adult children experienced with independent living. One participant shared that her adult daughter was reluctant to discuss moving out of the family home because she felt safe and secure their. However, because of this she spent much time alone and did not socialize much outside of working and volunteering. This may suggest that adults living with FASD may prosper more socially once they have reached the milestone of moving out of the family home and further down the path of adulthood. Another interesting finding that was shared and has reoccurred across themes is the struggle with money management which is likely a result from the permanent brain damage that is present in individuals with FASD. One participant reported that although her son has an intense desire for autonomy living alone, his lack of money management skills would likely prevent him from paying bills and rent on time. Difficulties with impulse control also seemed to play a role in what participants shared regarding independent living struggles. One participant shared that if her adult son had access to his money, it may all be spent in just one day. Another participant shared that when her adult son gets overwhelmed, he does not have the skills to cope with or deal with the situation appropriately. He will impulsively react and find a way to escape the situation which has resulted in him stealing a car and getting into trouble with the law. Finally, one caregiver shared how her adult daughter's vulnerability in social situations has led to very some dangerous situations. In the past, when her daughter was in

social situations where she was not being supervised, her vulnerabilities exposed to her to being

raped twice. Her inability to assess a dangerous situation and the social skills and knowledge

deficits that are likely experienced, create situations that become unmanageable and dangerous

when she is left to navigate them on her own.

Although research has found that social skills training with children affected by FASD

did improve their social skills and knowledge, problem behavior had no significant changes

(O'Connor, et al., 2006). This likely has implications into adulthood which suggests specialized

services and supports would likely increase success with independent living. These findings

result in determining that these adult children are assimilated such that their FASD related needs

are not completely identified and supported by the community but that the individual is involved

in the community in some aspects of independent living with specialized supports from their

caregivers.

Vocational successes. Caregivers also reported vocational successes with autonomy that

their adult children have experienced. Two caregivers reported interpersonal growth and self-

awareness that their adult child experienced on the job and during a vocational certificate

program. One participant's daughter was able to self-advocate when she had received too much

responsibility on the job. This same daughter experienced a job loss in the past when promoted

because the responsibility was too much for her to manage. This experience could have

contributed to her self-awareness and ability to advocate on her behalf that the responsibility was

too much for her. Again, this brings up the idea that individuals living with FASD may have an

optimal functioning level vocationally, when that optimal functioning level is exceeded, the

individual is unable to manage. Due to the continuum of effects for individuals living with

FASD, not everyone may experience this self-awareness and ability to advocate, but for this

adult child, she was successfully able to voice her needs and maintain employment. Another

caregiver shared about her son's self-awareness in needing help to study for his vocational

certificate program. Although he would never admit to friends that he needed this kind of help

from his mother, he was comfortable and self-aware enough to request this help from his mom.

Lastly, two participants shared the pride their adult children experienced from having a job of

meaning and that was important to them. Having meaningful volunteer work or employment is

one of the ten categories that are assessed in the adapted acculturation framework as being a key

component of successful community integration.

       Independent living successes. Although each caregiver was able to report various

struggles their adult children have experienced with independent living, they were also able to

report successes as well. Two caregivers reported that their adult children had developed good

social skills and manners and how other people in their children's life were able to identify these

developed skills. Although social skills and knowledge have been identified as an area of deficits

for individuals with FASD, research by O'Connor et al., (2006) also indicates that children who

participated in a social skills group demonstrated a significant improvement in social skills

knowledge and appropriate social skills were maintained after a three month follow up period.

This may indicate that with appropriate training and modeling early on and overtime, appropriate

social skills may be maintained into adulthood. Another participant shared how her daughter was

able to use impulse control and problem solving in a challenging situation—something she had

struggled with in the past. Again, this adult daughter had received services from a psychologist,

behavior therapist and a life coach to work on her coping skills. Again, this finding may indicate

that with the proper supports, over time, areas of functioning that were once challenging may

develop into useful skills. Lastly, one participant shared how her daughter is successfully living

on her own in an apartment that is close to her. Although her daughter is living in her own

apartment, she frequently visits the family home for support from her caregivers. According to

the adapted acculturation framework, these finding suggest that with the proper support, over

time, useful independent living skills can be developed to foster more successful community

integration for adults living with FASD.

Strengths and Limitations

        This current study has both strengths and limitations due the qualitative research design,

participants chosen, and how the data were analyzed. Due to the qualitative nature of the study

the sample size was limited to only four participants who spoke about six adult children living

with FASD total. This is a limitation because it only gathered data from a few people among a

larger population of caregivers that have an adult child living with FASD which may make the

findings difficult to generalize to the entire population of adults living with FASD. This study

only recruited participants from one organization which, again, may make the findings not

generalizable to the larger population of caregivers and adults living with FASD. The purposive

sample may be a biased sample because all of the caregivers interviewed are involved in the

supportive, sponsoring organization so their experience may be different from caregivers who

are not involved in such an organization. Another factor that may make the findings difficult to

generalize is the continuum of effects that are experienced by someone who has been exposed to

prenatal alcohol exposure. On the other hand, the in depth interviews offered a voice to the

participants and validated the experiences that they have encountered as important and add

richness and meaning behind the findings of the study. This study also offered participants

opportunity to speak, first-hand, about what has been successful, supportive, and also to what is

lacking in supporting an adult child living with FASD with community integration. The findings

display a glimpse into a true testament to what caregiver may experience with their adult child who is living with a fetal alcohol spectrum disorder.

Suggestions for Future Research

Community integration for adults continues to be an area of research that is understudied within the area of fetal alcohol spectrum disorders. The findings of this study, that recognition of specialized supports—both informal and formal—are essential to successful community integration suggested that further research in this area is essential. Research done with a larger sample size, focused on a specific diagnosis within continuum of effects that prenatal alcohol exposure can cause would likely produce more generalizable results. The fact that the current findings support the lifelong effects of FASD implies that there is room for further research in this area. An intriguing area of further research would be to explore the aspects of community integration directly with adults living with FASD. Their perspective is absent from any literature reviewed and this perspective would be worthy of exploring.

Lastly, this study was looking at the aspects of community integration for adults living with FASD, however; details regarding the caregivers' experience were also very prominent throughout the data. Since family is a prominent source of support for adults living with FASD, it suggests that the unique experience of caregiver and family members with adult children living with FASD is also worth further exploration. Their insight into the aspects of being a caregiver or family member is also absent from the literature reviewed and would likely provide insight and hope to other who are caring for an adult living with FASD.

Implications for Social Work Practice

Although this study describes the complex aspects of community integration for adults living with FASD, it is just a small step toward unearthing the complete reality for adults living

with FASD. Despite that, the implications of this research study can influence social work practice in a variety of ways. First and foremost, more research needs to be conducted in regards to adults living with FASD in multiple ways. More research should be done to explore different types of supports and services that are relevant and effective in enhancing quality of life and community integration for adults living with FASD. Since literature with children suggests that the neurobehavioral deficits are life-long, it would be beneficial to conduct research with adults in order to assess the levels of supports needed for successful community integration. The wide range of successes and barriers to community integration the adults in this study have faced, should certainly be known by social workers who may work with individuals living with FASD and their families. This knowledge can help social workers provide specialized, unique supports for adults living with FASD. Social workers should be interested in adults living with FASD and looking to increase the knowledge base on what interventions and supports are effective and appropriate for adults on enhancing quality of life and community integration. There is little research exploring community integration for adults which offers the opportunity for social workers to be up and coming in the realm of FASD.

Social workers may be working with individuals and their families in a variety of ways; a greater understanding of what FASD are may lead to more effective practices. An important finding from this study is very active, primary role of the caregiver in supporting their adult child with all aspects of community integration. This suggests that FASD may affect the entire family, and the family, as a whole, may likely need to be supported. Social work professionals who are working with families that are supporting an adult living with FASD need to be aware of the support that the primary caregivers and other family members may need.

The systemic gaps and barriers shared by participants suggest that social workers may need to advocate on the macro level to shift policy and possibly expand the categories for individuals who can meet criteria for more formalized services to supplement various aspects of community integration to include adults living with FASD. It is clear that many individuals living with FASD may need unique, specialized supports for successful community integration and the macro level systemic barriers need to be addressed so that these individuals can access supports that are needed.

Conclusion

It is known that fetal alcohol spectrum disorders cause life-long neurobehavioral deficits due to prenatal alcohol exposure that likely last a life time. In spite of literature supporting primary brain damage in children with FASD, there is little research exploring how individuals are affected in adulthood. Because there is a broad range of effects that can occur from prenatal alcohol exposure, adults are likely going to need unique, specialized supports in a variety of aspect for successful community integration. Because of this, it is imperative that more research is conducted looking to the aspects of community integration for adults living with fetal alcohol spectrum disorders.

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Appendix A

Recruitment Email

You are being emailed as an invitation to consider participating in a study I am conducting that focuses on aspects of community integration for adults (21+) living with a fetal alcohol spectrum disorder from the perspective of (current or past) caregivers. This research study is a part of my Masters Degree in Clinical Social Work at Saint Catherine University and the University of St. Thomas and will be conducted under the supervision of David Roseborough, Ph. D., LICSW. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

The purpose of this study is: to learn more about the aspects of community integration for adults living with FASD in the seven metro county area of the Twin Cities. I am interested in hearing about what supports you perceive to be beneficial and successful for adults living with FASD, what barriers have/are faced, and will also explore what services or supports may still be needed from the perspective of caregivers. If you agree to participate, you will be asked to complete an interview with me that will last approximately 1 hour and will be audio recorded at a location we mutually agree upon.

The choice to participate is yours, and MOFAS will not know if you choose to participate or not. I would like to assure you that this study has been reviewed and received approval through the University of Saint Thomas' Institutional Review Board. Again, the final decision about participation is yours.

Thank you in advance for consideration in participating. If you are interested in hearing more about the study or in potentially participating, you can contact me using the contact information below.

Sincerely,

Lyndsay Gomos
Saint Catherine University and the University of St. Thomas School of Social Work
Masters of Clinical Social Work Student
612-296-9715; lekearney@stthomas.edu

Appendix B

Interview Questions

1. How old is the adult living with FASD that you are a caregiver for?

2. How long have you been their caregiver?

3. When was the individual diagnosed with a FASD?

4. What is the individuals living situation right now?

5. Does the individual have any formal services in place to help with community integration? (case management, PCA, employment support)

6. What do you think makes the biggest difference for an adult with FASD to achieve success when living in the community?

7. What do you think makes the biggest difference in an FASD client's success when working in the community?

8. In your experience are there certain areas that FASD client's need more/less support? (i.e. community living, working, health care, etc.)

9. In your experience, what prevents or hinders a FASD client's success in the community?

10. What are the biggest barriers the adult living with FASD experiences?

11. Are there certain interventions, tools, or support you believe an individual with FASD may benefit from to achieve the highest level of community integration?

12. What role does your individual living with FASD have in planning for their services/supports and do you think it increases their ability to be successful?

Appendix C

PARTICIPANT CONSENT FORM
UNIVERSITY OF ST. THOMAS

Supporting Adults Living with FASD in Achieving Community Integration: A Complex Task

I am conducting a study about the complex aspects of community integration for adults living with fetal alcohol spectrum disorder (FASD). I invite you to participate in this research. You were selected as a possible participant because the Minnesota Organization on Fetal Alcohol Syndrome contacted you as a possible participant who met criteria for the study. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Lyndsay Gomos, a graduate student at the School of Social Work, Saint Catherine University/ University of Saint Thomas and supervised by Dr. David Roseborough, Ph. D., LICSW.

Background Information:

The purpose of this study is: to learn more about the aspects of community integration for adults living with FASD in the seven metro county area of the Twin Cities. The study will look at what supports are beneficial in encouraging success for adults you know living with FASD and will also explore what services or supports may still be needed from the perspective of their caregivers.

Procedures:

If you agree to be in this study, I will ask you to do the following:
> Complete a 45-60 minute interview about your experiences/perspectives regarding community integration for the adult living with FASD for whom you are a caregiver.

Risks and Benefits of Being in the Study:

The study has few known risks. The topic at hand may bring up sensitive information about your experiences and there is a possibility that you may have an emotional response to the questions that are being asked. At any time during the interview you can ask to skip questions or to end the interview. A list of resources that may help if you experience an emotional response will be provided to you. If you decide you do not want your interview to be used as data for this study, you have up to one week following the interview to contact us to remove your interview from the research data. You can do this by contacting me by email in order to ask that a portion of the entirety of your interview not be used.

The direct benefits you will receive for participating are: This study has no direct benefits.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. Research records will be kept in a locked closet at my home that only I have access to. These records include: digital recordings of interviews and hard copies of interview notes and transcriptions, interview consent forms, and all other documents containing potentially identifying information. Electronic copies of the interview transcripts will be kept in password protected files on my personal computer. All participants will be identified by a respondent number, not by name. Any highly identifying information from the interviews will be entirely omitted from the study (e.g. name of participant or name of agencies that provide services, name of adult child with FASD, etc). All interview recordings from the present study will be deleted and/or destroyed by June 2014**.** The signed consent for each participant will be kept for three years after the study is terminated before being destroyed. Written transcripts will be kept indefinitely as original data however any identifiable information will not be present on the transcript and they will continue to be stored in the locked closet. I am a mandated reporter and will be required to report any suspicion of abuse of a vulnerable adult that might be revealed in the course of your interview or during my visit to your home if this is where we agree to have the interview.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, the School of Social Work or the Minnesota Organization on Fetal Alcohol Syndrome. If you decide to participate, you are free to withdraw at any time during the interview or up to one week after the initial interview. Should you decide to withdraw data collected will be used to complete my project unless you state otherwise or contact me within one week of your interview to withdraw the data collected. You can contact me at 612-296-9715 or lekearney@stthomas.edu. You are also free to skip any questions I may ask at any point in time, without consequence.

Contacts and Questions

My name is Lyndsay Gomos. You may ask any questions you have now. If you have questions later, you may contact me at 612-296-9715 or lekearney@stthomas.edu or David Roseborough. Ph. D., LICSW, ACT at 651-962-5804. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6038with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audio recorded. I am at least 18 years of age.

_____   _____
Signature of Study Participant   **Date**

_____
Print Name of Study Participant

_____   _____
Signature of Researcher   **Date**

Appendix D

Resources

- **Walk-in-Counseling Center**

  Address: 2421 Chicago Ave, Minneapolis, MN 55404

  Phone: (612) 870-0565

- **The Crisis Connection**

  Phone: 612-379-6363   free 24/7 phone counseling

- **Minnesota Organization on Fetal Alcohol Syndrome**

  Visit the following website to find your family resource coordinator:

  http://www.mofas.org/for-families/families/support/family-resource-coordinators-frc/

- **Contact your Employee Assistance Program**

  Free counseling options may be available to you