

The Effectiveness of a Community-Based Intervention for Parents with FASD

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Abstract The purpose of this study was to evaluate the effectiveness of the Step by Step program in which mentors work with parents affected by Fetal Alcohol Spectrum Disorder (FASD) on a one-to-one basis. Mentors help clients identify and work towards meeting their needs and achieving their goals. Data from 24 closed client files was collected and analyzed and as predicted, the program was effective in helping clients reduce their needs and achieve their goals. The client's reason for leaving the program as well as whether or not they had a formal FASD diagnosis had an impact on their success in the program. Data collected on additional mental health issues, experience of abuse and addictions helped to characterize the sample of clients and correlations were found between client's experience of abuse and their past and/or present addictions issues. Limitations of this study as well as future implications were also discussed.

Keywords Fetal Alcohol Spectrum Disorder · Parenting · Community-based intervention · Mental health · Addictions

Introduction

Adults affected by Fetal Alcohol Spectrum Disorder (FASD) are faced with an invisible disability; cognitively they often have serious impairments yet their disability is often not immediately or visibly apparent. FASD refers to individuals who have physical, mental, behavioural, and learning disabilities as a result of maternal alcohol consumption (Chudley et al. 2005). Individuals with FASD continue to require services and resources throughout adolescence and adulthood because the problems associated with FASD do not go away with age and may even worsen. The demands and expectations of individuals with FASD increase in adulthood, which puts adults with FASD at particular risk. Adults with FASD have numerous neuropsychological deficits including impairments in attention, verbal learning, executive functioning (Kerns et al. 1997), and IQ (Streissguth et al. 1991). One study found that adults with FASD scored at the second grade level for arithmetic, third grade for spelling, and fourth grade for reading (Streissguth et al.). Connor et al. (2000) found that adults with FASD were most impaired on executive function tasks that involved shifting, attention, visual-spatial abilities, and working memory. The significant executive function difficulties in adults with FASD may lead to difficulties with employment, interpersonal situations, planning and problem solving, parenting and response inhibition which may lead to social and legal problems and require assistance (Connor et al.; Grant et al. 2004).

In young adults, prenatal alcohol exposure is also associated with alcohol problems (Baer et al. 2003) as well as increased psychiatric disorders and traits (Barr et al. 2006). Streissguth et al. (1991) found that among adolescents and adults with FASD adaptive functioning skills were at the level of a 7-year-old, with deficits being most

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pronounced on socialization skills. In 1996, Streissguth, Barr, Kogan and Bookstein conducted a study on secondary disabilities among 415 individuals with FASD (253 adolescents and adults). Secondary disabilities are deficits that are not evident at birth but may result from primary disabilities (i.e., neuropsychological impairments) and environmental interactions and may be prevented by appropriate environmental supports (Streissguth 1997). It was found that among the adolescents and adults with FASD, 60% had disrupted school experience, 49% demonstrated inappropriate sexual behaviours, 60% had been in trouble with the law, 35% had alcohol and drug problems and 79% (aged 21 years and older) had problems with employment. Thus, adults affected by FASD are at extremely high risk of making poor choices, and suffering from secondary disabilities including mental health disorders, addiction issues, difficulty in finding and maintaining work and stable housing, and maintaining an intact family.

Parents with Disabilities

Individuals with intellectual disabilities are characterized by limitations in intellectual functioning and adaptive behaviour (Kazdin 2007). Individuals with intellectual disabilities face numerous challenges, including higher instances of physical and mental illnesses, risk of abuse and exploitation, social isolation, low socio-economic status, poor health, inadequate housing, family discord, higher susceptibility to psychological distress and their children are more likely to be mistreated (Kazdin; O’Keeffe and O’Hara 2008; Llewellyn et al. 2008). Given these issues, individuals with intellectual disabilities face significant obstacles in becoming successful parents.

Successive studies have shown that parents with intellectual disabilities have child removal rates as high as 40–60% internationally (see Llewellyn et al. 2003b). A study of two Children’s Courts in NSW, Australia found that almost one-third (29.5%) of children in statutory child protection proceedings had parents with psychiatric (21.8%) or intellectual disabilities (8.8%) (Llewellyn et al. 2003a). In more than half of the cases involving parents with intellectual disabilities, the children were made state wards (most severe ruling). These results are evidence that many parents with intellectual disabilities cannot successfully parent children on their own and need help from multiple services in meeting the complex needs of themselves and their families.

Llewellyn et al. (2003b) tested the efficacy of a home-based intervention on promoting child health and home safety for parents with intellectual disabilities who were parenting preschool age children. The intervention improved parents’ ability to identify home dangers and safety precautions. Parents also improved on their

understanding of health and illnesses, emergency skills, accessing health services, and administering medication. All of the improvements were found to have been maintained at a 3 month follow-up (Llewellyn et al.). This study shows that although parents with disabilities may face more obstacles, interventions can be effective in giving these parents the knowledge and skills necessary to be successful parents.

FASD is one of the leading known causes of mental retardation (NIAAA 1990) and many individuals with FASD go onto have children of their own, yet pregnancy and childbirth among adults with FASD is a common issue that has not been adequately addressed (Grant et al. 1997). Streissguth et al. (1996), found that out of 253 individuals with an FASD over the age of 12, 28% of females ($n = 30$) and 10% of males ($n = 14$) had one or more children. The 44 clients had a total of 76 children, with 50% or more no longer in the care of the client; of the 30 mothers with FASD, 36% had their children removed by Child Protective Services. Forty percent of these women were reported to have been drinking during pregnancy with 17% having a child with an FAS or FAE diagnosis and 13% being suspected of being affected by prenatal alcohol exposure.

There is very little research available on parents with FASD or programs that support these individuals in parenting. Abraham and Hardy (2006) interviewed three parents with FASD (2 diagnosed and 1 self-identified), three parent advocates, and nine service providers. These 15 individuals identified the need for desirable services and supports, new methods and models for service delivery, and barriers to receipt of support and services for parents with FASD. Desirable services included practical services such as reminder for and transportation to appointments, support networks such as FASD support groups, and informal social supports for parents with FASD. They also identified a need for parenting material that is understandable to persons with FASD, a need for ongoing support, as well as adoption of a neurocognitive understanding of FASD to be included (Abraham and Hardy).

One important study was done by Grant et al. (2004) in which the Parent–Child Assistance Program (PCAP), was modified for women with FASD parenting children. The PCAP program is a 3-year home visitation program for women who are at risk for giving birth to children with an FASD, and in a chapter written by Grant et al. in 1997, aspects of the PCAP model that would be suitable to parents with FASD were identified. These aspects include the one-to-one relationship with a mentor, helping the clients obtain formal diagnoses of FASD for themselves and their children, helping evaluate and develop their parenting needs, obtaining disability status as a means to obtain financial stability, and connecting to alcohol/drug abuse treatment if necessary. The PCAP model would also help

these parents with FASD learn to meet the basic needs of themselves and their families, including housing, food, hygiene, safety and stability and help the clients to make appropriate connections with community resources that will remain with the client long after they are no longer in the Birth to 3 program. The 2001 pilot study by Grant et al. included 12 mothers with FASD working with PCAP advocates who were educated in many areas of FASD including diagnostic characteristics, behavioural problems, and day to day management of individuals with FASD. PCAP advocates supported clients in obtaining formal FASD diagnoses and participated in weekly case consultations to develop tailored interventions for their clients as well as address service barriers they may be experiencing. During this study, 15 major clinics and agencies that were linked with the clients in the study were trained and educated in FASD. The outcomes that Grant et al. found in this study included improvement of the client's connections to medical and mental health care services, increased use of contraceptives, decreased alcohol and drug use, and obtaining stable housing.

In February 2003, Catholic Social Services (CSS) began a program similar to the modified PCAP model, called Step by Step, to support parents affected by FASD. In the Step by Step program, mentors work with families for up to 3 years, supporting families to strengthen their connections to the community, access resources such as income and employment supports, find and keep stable housing, access addictions supports, respite and recreation resources as well as crisis management. The program mentors also work actively with families to access neuropsychological assessments as needed for both the parents and any children in the family who may be affected by FASD. Mentors work collaboratively with each family to identify strengths, and work on goals that will stabilize and strengthen the family's connections to other resources in the community for longer-term stability. Step by Step is one of the first programs in Canada to work with FASD affected adults who are parenting.

In summary, adults with FASD face many challenges when parenting and are at considerable risk for negative life outcomes, yet there is very little research on the effectiveness of intervention programs to support adults with FASD who are parenting. The aim of this research project was to determine the effectiveness of the Step by Step program for parents with FASD. Specifically, we examined whether there was a reduction in the number of client needs and an increase in goal scores from pre to post program. We also examined commonalities of client backgrounds, mental health diagnoses, history of abuse, substance abuse, and client satisfaction with the program. The results of this study have significant implications for reducing secondary disabilities among parents with FASD,

for improving the outcomes of parents with FASD and their children, and for informing other programs and policy.

Method

A retrospective analysis was conducted using anonymous data collected by CSS through the HOMES database. Only closed files having at least one post needs or goals measure were used. Client files were also reviewed to collect additional client information including history and mental and physical diagnoses. Ethics approval was obtained from an institutional review board.

Participants

In order to compare pre and post needs and goals scores it was necessary to have at least one post measure for each file used in this study. There were 29 client files in total that had been closed between the inception of the program in February, 2003 and the study's cut-off date of December 31, 2007; of the 29 files, 5 were missing post data so the final sample of clients consists of 24 closed client files. Basic demographics of the participants are presented in Table 1, showing that the majority of the participants were Aboriginal and female. Although the program is designed to work with a client for a maximum of 3 years (36 months), the mean length of time clients spent in the program was 24.5 months with some clients exceeding the designated time span. Of the clients who completed or left the program, 37.5% lost contact with their mentor, or chose to end the program. Another 37.5% ended the program

Table 1 Step by Step client demographics

Characteristic	
Mean age (range)	30 (19–47)
Ethnicity <i>n</i> (%)	
Aboriginal	14 (58.3%)
Canadian/caucasian	7 (29.2%)
Other	3 (12.5%)
Gender (<i>n</i>)	
Female	23
Male	1
Mean months in program (range)	24.5 (3–45)
Education (mean grade completed and range)	9.95 (2–12)
Additional education <i>n</i> (%)	
Some upgrading/GED	5 (20.8%)
Some vocational or college	3 (12.5%)
Modified/special program	2 (8.3%)

because they had completed the full 3 years or had been connected enough to other programs that they no longer required services, and 12.5% chose to end the program because their mentor left the agency and they did not wish to be connected to a new mentor. Only one client ended the program due to losing custody of their children.

Fifty percent of the clients in the study sample were diagnosed with an FASD. Twenty-five percent of the sample were assessed and identified as having possible or suspected prenatal exposure but maternal drinking could not be confirmed and the rest were suspected of having an FASD but did not have access to an assessment during their time in the program. Of the 24 clients in this sample, four were supported by the Step by Step program in obtaining an FASD assessment with three of these clients being formally diagnosed and one diagnosed as having possible/suspected prenatal exposure to alcohol.

Procedure

Step by Step Program

The idea for the Step by Step program resulted from a gap in service that was recognized by the staff at CSS in two other FASD programs: First Steps, and Coaching Families. The First Steps program is an FASD prevention program based on the PCAP model and the Coaching Families program works with families raising children affected by FASD. In February 2003, CSS launched the Step by Step program with the financial support of the McDaniel Family Foundation which had previously funded the First Steps program. The funding was for two mentors to work for a 3 year period, and in February 2006 on-going funding was secured with the Provincial Department of Children and Youth Services as well as from the Catholic Social Services Sign of Hope Campaign.

As stated previously, the model for the program is loosely based on the PCAP model which was also the foundation for CSS First Steps program. The program model matches each client with a mentor for a period of 3 years and clients are supported by their mentors in accessing supports such as housing, addiction treatment resources, financial supports and parent supports to stabilize themselves and their families. In some cases, families are also able to access the supports of a volunteer (screened and supported by CSS) who works longer-term with mothers to model appropriate parenting and life skills. Protective factors that the Step by Step program aims to provide include: reducing the risk of breakdown in families, strengthening life and parenting skills, and increasing success and independence within families. The work that mentors in the Step by Step program do with parents is from a strength based focus, working to support and

improve the quality of life and help minimize the negative impact of life's barriers for these FASD affected parents.

One of the challenges that exists for adults with FASD is access to a neuropsychological FASD diagnostic assessment. Going through the diagnostic experience can be challenging for adults with FASD as they may have difficulties negotiating the health system to access a clinic, remembering and keeping appointments, there are often long waiting lists and the paperwork may be overwhelming. A major goal in the Step by Step program is to support parents in obtaining an FASD diagnosis and where appropriate, for any affected children. A good assessment is helpful in creating individually focused supports for the client within the Step by Step intervention program and within the community. Historically, all of the CSS FASD programs have worked together with several diagnostic sources such as the Glenrose Rehabilitation Hospital FASD Diagnostic clinic; the clinic and the programs recognize the vital importance of having an assessment and also having follow-up supports in the community for families impacted by FASD.

HOMES

The Hull Outcome Monitoring Evaluation System (HOMES) is a program evaluation software package designed by the Canadian Outcomes Research Institute that is accessed through the internet using a database account. Used throughout all of CSS programs, HOMES is designed to function as a case management tool, storing intake information and case notes, producing client demographic information, and producing service plans (called progress reports). In addition, HOMES is able to produce aggregate data and produce outcomes measurements. HOMES data is inputted directly by all front-line mentors. Upon intake into the program, the client's basic demographics including age, gender and ethnicity are collected and entered into the HOMES database. After two or three meetings with the client the mentor does a Needs Assessment, which measures the client's needs and issues and their severity. The HOMES Goals Assessment identifies and measures the client's goals for the next 6 months in the program and is done as a collective process between the client and the mentor soon after intake. The work that the mentor and the client do together is informed by these initial assessments. A HOMES Progress Assessment is then done every 3–6 months by the mentor to assess the client's progress in achieving their goals and meeting their needs. The Progress Assessment continually rates existing needs, indicates new needs and is a reflection of the mentor's understanding of the client and their situation. As with the needs, the goals are re-rated by the mentor during the Progress Assessment as per the client's level of attainment. Goals will be closed

and removed from the service plan if completed successfully and the mentor and client will then choose new goals to work on during the next 6 month period. The HOMES Discharge Summary includes a final rating on the client's needs and goals done by the mentor when the client has chosen to end or has successfully completed the program.

Needs

Upon intake into the program a client is rated on 40 needs including knowledge about child development, mental health and addiction issues, and life skills such as budgeting and housing. Table 4 contains a list of the 28 categories that each of the 40 needs fall into. Each need is rated by the mentor and the client's scores are summed and then converted into a *t*-score. Needs are rated as: (0) At all times this is not a service issue, requires no attention; (1) Most of the time this is not a service issue, requires no attention; (2) Minor issue, which requires monitoring or occasional attention; (3) Major issue, which most of the time requires attention or (4) Priority issue, which always requires immediate and intense attention. A higher score on any particular need indicates that the client needs more help and support in this area from the program and the mentor. A decrease in need scores from pre to post program would indicate success in that the client's needs have decreased in severity.

Goals

The client and the mentor work together to establish two to four goals that the client would like to work on for every 6 month period during their time in the Step by Step program. There are 21 pre-written goals to choose from or the mentor can write their own goal(s). These two to four goals are then rated on a scale of -2 to 2 with a lower score on a goal indicating that the client requires more intense and/or immediate support in this area. Goals are rated as (-2) A priority service goal which requires immediate and intense attention; (-1) A major service goal which, most of the time, requires attention; (0) A minor service goal which requires monitoring or occasional attention; (1) Most of the time this is not a service goal, requires no attention or (2) At all times this is not a service goal, requires no attention. The goals include topics such as community concerns, connecting to resources, personal skill management, self-reliance, addictions management, and parenting. As with the needs, the scores the client receives on their goals are summed and converted into a *t*-score. An increase in goals scores from pre to post program indicates that the client was successful in or made progress towards completing or achieving their goals.

Client Satisfaction Surveys

In the Step by Step Program, Client Satisfaction Surveys are given to clients yearly to fill out and return anonymously. The Satisfaction Survey asks clients to rate different aspects of the program and also includes open-ended questions about what clients liked the most, the least and what they would change about the program. Thirty satisfaction surveys were collected from the inception of the program to December 31, 2007.

Results

Client files were reviewed to collect additional demographic information. Table 2 lists the concurrent mental health diagnoses of the 24 participants. Depression was the most common mental health issues, with 50% of the participants reporting having been diagnosed with or treated for depression. Table 3 lists client reported abuse over their lifetime. An alarming 71% of the clients reported experiencing at least one type of abuse in either childhood, adulthood or both. Sixty-five percent of these clients reported experiencing two or more types of abuse over their lifetimes. As this measure is based on self-report, the actual incidence of abuse among these individuals may be significantly higher. Clients also reported on their drug and

Table 2 Client diagnosis information

Mental health concerns	Percentage (<i>n</i>)	General pop. (DSM-IV-TR)
Depression	50% (12)	5–9%
ADHD/ADD	42% (10)	3–7%
Anxiety/panic attacks	38% (9)	3%
PTSD	25% (6)	8% ^a
Cognitive delays	25% (6)	2–10%
Tourettes	8% (2)	.01–.02%
Self-harm/suicidal	8% (2)	
Other	29% (7)	

^a Lifetime prevalence

Table 3 Experience of abuse

Type of abuse	Percentage (<i>n</i>)
Physical	45.0% (11)
Sexual abuse/assault and/or rape	37.5% (7)
Mental, emotional and/or verbal	33.3% (8)
Type not specified	8.3% (2)
Domestic violence	8.2% (2)
Neglect	4.2% (1)

alcohol use. Sixty-three percent of the sample reported past or present alcohol and/or drug abuse, with 54% reporting abusing alcohol, 58% reporting using soft drugs (marijuana, hash and/or mushrooms) and 54% using hard drugs including crack, cocaine, crystal meth, ecstasy, LSD, IV drugs and/or solvents. Thirteen percent of the clients that reported having drug or alcohol issues reported having attending rehab or meetings in the past and 27% reported being in rehab or attending meetings at the time of the intake into the program.

Next we examined whether there was a significant difference in needs and goals scores from pre to post program. We conducted separate repeated measures ANOVAs for the needs and goals *t*-scores. There was a significant reduction in the clients' needs scores from pre to post program, $F(1, 23) = 10.75, P < .01, \eta_p^2 = .32$. There was also a significant increase in the clients' goals scores from pre to post program, $F(1, 21) = 14.75, P < .01, \eta_p^2 = .41$. (see Fig. 1).

We also looked at which needs and goals showed the largest change from pre to post program. The 28 need categories are listed in Table 4 with *n* being the number of clients that were listed as having a need in that category (rated 1 or higher). The three most common need categories were: Family Parenting, Relationships and Peers, and Behavioural Problems. The mean columns show the pre and post mean scores for all clients who had one or more needs in that category as well as the overall difference between pre and post mean need scores. A larger negative difference in means from pre to post program is ideal, as it indicates that the overall severity in that need category has been reduced. Of the need categories that had an *n* over 10, Experience of Abuse, Social Problems, Housing and Transportation, and Community Resources showed the largest decreases in scores. The categories of Grief and Loss, General Safety, Personal Care, and Community Coordination all showed negative change in the difference

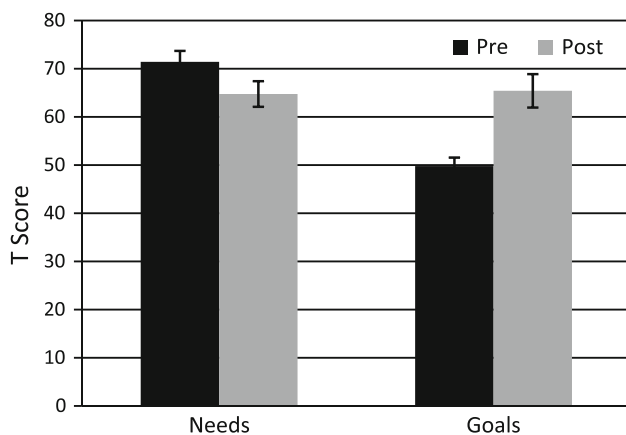


Fig. 1 Change in Needs and Goals *t*-scores from pre to post program

column, indicating that the severity of these needs actually increased from pre to post program. It should be noted, however, that these categories had small *ns*, ranging from only one to seven clients. As shown in the table, *n* decreases from pre to post program in some need categories; the change occurs because when a client is given a rating of 0, meaning that the need they were initially rated on is no longer an issue for them and requires no attention, they are no longer included in the total *n*.

The goals used in the Step by Step program including the 21 pre-written goals as well as the goals created by mentors fall into 17 categories as shown in Table 5. The three most common goal categories were Parenting, Self-Reliance, and

Table 4 Need scores by category (*n* = 24)

Need category	<i>n</i>		Mean		
	Pre	Post	Pre	Post	Difference
Experience of abuse	10	9	4.10	1.70	-2.40
Social probs, housing and transportation	10	9	3.20	2.00	-1.20
Community resources	10	6	3.30	2.10	-1.20
Independence and financial issues	19	17	3.89	3.05	-0.84
Behavioural problems	21	20	5.41	4.59	-0.82
Mental health issues	17	15	4.41	3.71	-0.70
Relationships and peers	21	18	4.14	3.57	-0.57
Family parenting	22	19	3.18	2.68	-0.50
Communication	12	11	3.17	3.08	-0.09
Health issues	9	7	2.89	1.78	-1.11
Emotional health	9	8	2.50	1.90	-0.60
Addiction problems	8	8	6.75	4.75	-2.00
Greif and loss	7	7	2.00	2.71	0.71
Decision making and personal control	6	5	2.50	1.50	-1.00
Other ^a	4	3	3.50	2.25	-1.25
General safety	4	4	2.60	3.00	0.40
Criminal or criminal type behaviour	3	3	4.33	1.67	-2.66
Sexuality issues	3	3	4.67	3.00	-1.67
Academic, general	2	1	2.00	1.00	-1.00
Cultural and spiritual	2	1	2.50	1.50	-1.00
Self harm and suicide issues	2	2	2.00	1.50	-0.50
Vocational and employment	2	1	2.00	1.50	-0.50
Cognitive thinking styles	1	1	3.00	4.00	1.00
Personal care	1	1	2.00	3.00	1.00
Community coordination	1	0	3.00	0.00	-3.00
Abusive to others	1	0	2.00	0.00	-2.00
Sexual exploitation issues	1	0	2.00	0.00	-2.00
Family contact and relationships	1	1	3.00	2.00	-1.00

^a Other category was used for three out of four clients as a family planning need. For one client the need was for home organization and expressing anger in a positive manner to family

Community Connection. As with the needs table, the mean columns in the goal scores table show the pre and post mean scores for all clients who had goals in that category as well as the overall difference between pre and post mean goal scores. Progress or success in the goals categories is seen as an increase in goal scores from pre to post program, so a larger positive difference in means is ideal as clients are given higher scores as their goals are achieved. There were only four goal categories that had *ns* over 10, with Self-Care and Health showing the largest positive change. Personal Skills Management and Personal Cognitive Management showed negative differences, however the latter category only included one client. Unlike the needs categories, *n* does not change in the goal ratings.

Length of time spent in the program by clients was not correlated with differences between their pre and post needs *t*-scores, $r(23) = -.06$, $P > .05$, or goals *t*-scores, $r(21) = .34$, $P > .05$. We also conducted an ANOVA to test whether there was a difference in the overall change in needs and goals scores between participants who did and did not have a formal FASD diagnosis. Participants who had a formal FASD diagnosis had a larger reduction in their needs scores ($M = -10.83$, $SD = 11.45$) as compared to clients who did not have an FASD diagnosis

($M = -2.50$, $SD = 6.22$), $F(1, 23) = 4.91$, $P < .05$, $\eta_p^2 = .18$, but group differences were not significant for the change in goal scores, $F(1, 21) = .08$, $P > .05$. We also looked at whether or not having a formal FASD diagnosis was correlated with clients reporting having experienced abuse in their lifetimes, having any past or present addictions issues, or having additional mental health diagnoses and did not find any correlations, with all P s $> .67$. Experience of abuse was significantly correlated with drug and/or alcohol abuse, $r(23) = .45$, $P < .05$. Because these four variables were all dichotomous, Phi correlations were used.

Finally, we compared clients who had a negative reason for leaving the program (lost contact, lost custody of children) with clients who ended the program for other reasons (completed the 3 years or their mentor left the program) and found that the two groups differed on the change in their goal *t*-scores, $F(1, 20) = 5.70$, $P < .05$, $\eta_p^2 = .23$. Clients who had a negative reason for leaving the program had very little change (increase) in their goal scores ($M = 2.75$, $SD = 11.30$) and clients that did not have a negative reason for leaving the program showed a much larger increase in their goal scores ($M = 22.62$, $SD = 20.39$). The two groups did not differ on the changes in their needs *t*-scores or any pre or post needs or goals *t*-scores (all P s $> .05$). The length of time clients spent in the program was correlated with client's reason for leaving the program, $r(22) = .57$, $P < .05$; clients who had a negative reason for leaving the program also spent shorter lengths of time in the program.

Table 5 Goal scores by category ($n = 20$)

Goal category	<i>n</i>	Mean		
		Pre	Post	Difference
Self-care and health	10	-1.00	1.00	2.00
Self-reliance	13	-0.54	0.46	1.00
Community connection	11	-0.36	0.09	0.45
Parenting	15	-1.00	-0.60	0.40
Personal skills management	9	-0.44	-0.56	-0.12
Resources	8	-1.12	0.75	1.87
Interpersonal interaction	8	-0.75	-0.62	0.13
Other ^a	7	-0.86	1.14	2.00
Problem solving	3	-1.67	0.67	2.34
Early intervention	3	-1.33	1.00	2.33
Safety	3	-1.33	1.00	2.33
Without a category	2	-0.50	0.00	0.50
Vocational	2	-0.50	-0.50	0.00
Family involvement	1	-2.00	3.00	5.00
Assessment	1	0.00	2.00	2.00
Communication	1	-1.00	0.00	1.00
Personal cognitive management	1	0.00	-1.00	-1.00

n does not change from pre to post program as it does with Needs

^a Other category was used for 5/7 clients as a family planning goal. Two out of those 5 clients had a second goal in the other category (credit report and medical appointment) and the remaining 2 clients had a goal in this category for obtaining housing. Family parenting was eventually moved under the category of Self-Care and Health

Client Satisfaction Surveys

The rating questions yielded very positive results. Of 17 clients, 82% agreed that their mentor helps them learn to solve their problems while 12% were neutral and only one person disagreed. Seventeen clients were asked if their mentor motivates them to take care of their own health and that of their children and 100% agreed. Thirteen other clients were asked if their health had improved over the last year and 62% said yes, 23% were neutral, and 2 clients responded no, not much. Twelve of these clients responded to the question of whether their child[ren]'s health had improved over the last year and 92% responded yes while 8% were neutral. Of the 16 clients who were asked if their mentor helps them build on their strengths, only one disagreed with this statement.

The answers that clients gave to the open-ended questions were also very positive. When asked what they did not like about the program, 70% (20) of the clients stated "nothing" or that they were unsure and 7% (2) of the clients said "getting a new mentor." When clients were asked what they liked the best about the program, 28% (8)

stated the help and/or support, 21% (6) new knowledge/information and/or resources, and 17% (5) the mentor or program employees. When clients were asked about suggestions to make the program better, 46% (6) stated nothing or that they could not think of anything and 15% (2) stated that the program should be longer than 3 years. Twenty-three percent (3) did not answer the question and two people had other suggestions.

Discussion

The aim of this study was to evaluate the effectiveness of CSS' Step by Step program, which provides support for parents who have FASD and are parenting. Half of the participants had a formal diagnosis of an FASD and half were suspected of having FASD. We examined whether parents in this program showed improvements from pre to post program in meeting their needs and achieving their goals. Another aim was to characterize the demographics of clients in the program and additional barriers they may be facing in addition to FASD.

Needs and Goals

As predicted, we found a significant decrease in client need scores and an overall increase in goal scores from pre to post program. Of the need categories that had 10 or more clients with at least one need in that category, Experience of Abuse showed the highest level of change. This category addresses reducing incidence of crisis for the client, increasing the client's level of safety and connecting the client to a support network as well as protective factors within their community. Social Problems, Housing and Transportation, and Community Resources were the two need categories that showed the second largest reduction in severity which is important because these needs address many of the barriers that adults with FASD as well as other mental health diagnoses face on a day to day basis. Although Family Parenting was the most common need category it showed little change compared with many of the other categories. During discussions with the Step by Step mentors, program manager, and program supervisor it was revealed that learning parenting skills is often secondary to much more urgent needs such as housing, food, safety, addictions, and stabilization. The Step by Step mentors do advocate for clients to receive family parenting training but its success is often dependant on whether or not the client and family are stable and having their basic needs met. It is difficult to comment on the change in many of the need categories due to the small sample size.

Only four of the Step by Step goal categories had *ns* over 10: Self-Care and Health, Self-Reliance, Community

Connection, and Parenting. Of these, Self-care and Health as well as Self-Reliance showed the most change. As with the needs category of Family Parenting, the goal category of Parenting had the highest *n*, but it also showed the smallest change from pre to post program (of the goal categories with *ns* greater than 10). This small change could likely be attributed to the same reasons there was little change in the Family Parenting need category from pre to post program; clients often have more urgent goals that need to be achieved, such as meeting the family's nutritional needs (Self-Care & Health category) or obtaining safe and appropriate housing (Self-Reliance category). Due to the small sample size, we did not have the power to run statistical analyses, however, as hypothesized most of the scores in each goal category increased from pre to post program.

Additional Issues

Not only do the parents in the Step by Step program face obstacles due to the invisible disability of FASD, we found that most of them are also dealing with secondary disabilities, such as concurrent mental health issues. In fact, 83% had at least one additional mental health diagnosis and 38% had three or more additional mental health diagnoses, with the most common being depression, ADHD/ADD, and Anxiety/Panic Attacks. These results are consistent with results found by Clark et al. (2004) in one of the few Canadian studies on adults with FASD, in which 92% of the sample had a mental health disorder with high rates of ADHD, depression, and panic disorder. Benjet et al. (2003) found that individuals with mental illnesses are more likely to be viewed as incompetent and judged harshly, less likely to be desired as employees or tenants, and more likely to receive harsh treatment. So in addition to the barriers already faced by individuals with FASD such as difficulty obtaining stable employment or housing, their mental health issues likely further exacerbate these problems. In their review, Benjet et al. found that mothers with depression tended to use criticism and coercion with their children more often than non-depressed mothers and used fewer questions and a less positive tone of voices and were often less consistent. Half of our sample study of Step by Step clients were found to have a secondary diagnosis of depression which indicates that they would likely require coaching on positive parenting styles and skills. Furthermore, 12 of the 24 Step by Step clients had a need in the Mental Health Issues category and although we did not have the power to do statistical analyses, scores in this category reduced from pre to post program. The Mental Health Issues category addresses reducing incidence of crisis and increasing the level of safety for the client and their family, helping clients acquire positive parenting

skills and helping clients establish a support network and protective factors in the community. This is important because as Benjet et al. note, parental functioning in the community as well as parents having social supports impact outcomes for children of parents with major disorders.

As previously stated, 71% of clients reported experiencing abuse at some point in their lives and 65% had experienced two or more types of abuse. This is consistent with the results found by Streissguth et al. (2004) where 67% of a sample of 415 patients with an FASD had been victims of physical or sexual abuse or of domestic violence. Experience of Abuse was the need category that showed the largest decrease in severity from pre to post program, which indicates that the work being done within the Step by Step program is helping clients address this issue.

Rates of drug and alcohol use found in this study were higher than the results found in other studies on adults with FASD. Streissguth et al. (2004) found that 33% of clients 12 years and older had alcohol problems and 23% had problems with street drugs, and Alati et al. (2006) found that at age 21, 25% of adults who were exposed to alcohol in utero met the criteria for alcohol abuse disorders according to the DSM-IV diagnostic criteria. Our results are somewhat higher, with 54% of Step by Step clients reporting having past or present alcohol addiction issues and 58% with street drugs. However our sample is a clinically referred sample and many of these clients reported these problems as being past issues, with 27% being in rehab or attending meetings at the time that these questions were being asked. Eight clients had one or more needs in the Addiction Problems category and there was an overall reduction in this need category from pre to post program. One of the goals in the category of Self-Care and Health addresses addictions issues, working to help clients connect to addictions counseling and reduce or abstain from the use of alcohol or drugs. Of the goal categories with *ns* over 10, the Self-Care and Health category showed the most improvement from pre to post program.

We found that the length of time that clients spent in the program was not correlated with changes in their needs or goals *t*-scores from pre to post program. This lack of correlations may be due to the small sample size of this study but it also may indicate that clients showed improvement regardless of the amount of time they spent in the program. The length of time that clients spent in the program was correlated with the client's reason for leaving the program, indicating that clients who spent a shorter length of time in the program were found to have left the program for negative reasons. Clients who had a negative reason for leaving the program also showed less increase in their goal scores from pre to post program than those who did not

have a negative reason for leaving. This may demonstrate that a client's attitude towards the Step by Step program, including how they feel about their mentor and whether or not they view their own time in the program as successful, may impact their ability to achieve their goals. Clients who left the program due to losing contact or losing custody of their children may have not been personally invested in the program or may have a more negative outlook towards the program. Reduction in needs scores from pre to post program was not correlated with client's reason for leaving the program. This result may indicate that mentors are still helping clients address their needs regardless of the client's outlook or attitude towards the program. It may also be due to limited power in this study.

One of the most interesting findings was that clients who had a formal FASD diagnosis showed a larger reduction in their needs scores from pre to post program compared to clients who did not have an FASD diagnosis. Streissguth et al. (1996) found that having FAE rather than FAS is associated with having a higher level of secondary disabilities. Both of these results are likely associated with adults who have a full FASD diagnosis having better access to financial help and services due to their disability. Having an FASD diagnosis was not correlated with significant differences in goal scores. This result may be due to the fact that regardless of their diagnosis, the Step by Step mentors are able to help clients achieve their goals. Lastly, having a formal FASD diagnosis was not correlated with client addiction issues, experiences of abuse or having concurrent mental health diagnoses, but experience of abuse was significantly correlated with client drug and/or alcohol abuse. These results indicate that the sample group was homogenous in their experiences regardless of whether or not they had a formal FASD diagnosis and that clients who experienced abuse may be turning to substances as a coping mechanism.

Limitations

One of the major limitations of this study is the small sample size, resulting in reduced power in analyses. Although all of the clients in the sample were suspected of having FASD, some were unable to access FASD assessments and others were not diagnosed due to maternal drinking not being confirmed. Many of the measures in this study are based on client self-report, so actual rates of addictions issues and experiences of abuse may be higher. Because the needs and goals measures are rated by the program mentors, the presence of a bias in the ratings is a possibility; however, mentors were not aware that these results would be used to evaluate the effectiveness of the program or the success of their work with clients. Some measures could not be included in analyses because they

were missing data, likely due to mentors leaving their positions before completing post needs and goals measures for clients as well as inconsistency in data collection procedures. The Client Satisfaction Surveys were modified twice between the inception of the program and our study cut-off, making the *ns* small for some of the questions, due to questions being changed, added or removed. The most significant limitation to this study is that there is no long term post program measure of whether or not clients have retained any of the positive changes that they made during their time in the program. A 6-month or 1-year follow-up with clients to re-rate the needs and goals would be ideal to measure whether or not clients regress, maintain or continue to improve post program.

Implications and Future Directions

One of the most important aspects of community-based research is the feedback that programs receive about their services. All of the results of this study have been reported to staff members in the Step by Step program. Some of the limitations of this study, such as missing post-measures, multiple changes in the Client Satisfaction Survey, and the lack of a follow-up on clients have been addressed with the Step by Step program supervisor and program manager. As a result, necessary changes are being made at the program level that will facilitate better data collection procedures and make future program evaluation research easier. It is also important that program staff are given feedback about whether or not the work they do is successful; in the field of human services it is often difficult to measure the success of individuals or of programs in a quantitative manner. The qualitative feedback collected in this study illustrates how clients feel the program has changed or improved their lives and is helpful in pinpointing what works well with clients with FASD; results showed that the success of the program relies heavily on the security and stability that clients feel within the mentor-client relationship. The Step by Step mentors help clients learn new skills, increase stability and also deal with the multiple barriers they face in addition to FASD. There are systematic barriers and issues including access to disability services, access to an FASD diagnosis as well as dealing with Child and Family Services that clients require assistance with. As found in this study, internal barriers for the clients include concurrent mental health concerns, physical diagnoses, past and/or present experiences of abuse, and addictions issues. The mentor's ability to help the client deal with these systematic and internal barriers is facilitated by the trust, honesty, and safety developed within the client-mentor relationship.

The Step by Step mentors as well as staff members from CSS' other FASD programs have reported that they have enjoyed receiving feedback about how successful their

work with clients has been as well as things they could improve. The results and limitations found in this study also have implications for developing other programs for parents with FASD. The prevalence of FASD in child-bearing adults and the success of the Step by Step program in helping these individuals decrease the severity of their needs and achieve their goals indicate that there is a need for more programs such as this one to be available for parents with FASD.

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