PARTNERS FOR SUCCESS INTERVENTION FOR YOUTH AND YOUNG ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

LEIGH E. TENKKU, PHD, MPH, UNIVERSITY OF MISSOURI

JESSE WALLS, MSW, SAINT LOUIS UNIVERSITY

CASSIE MORGAN, LCSW, SAINT LOUIS UNIVERSITY

JOANNE SALAS, MPH, SAINT LOUIS UNIVERSITY

PURPOSE

Design an intervention to meet the needs of youth and young adults diagnosed with Fetal Alcohol Spectrum Disorders

INTEGRATING TWO THEORIES OF CHANGE

Behavior Modification

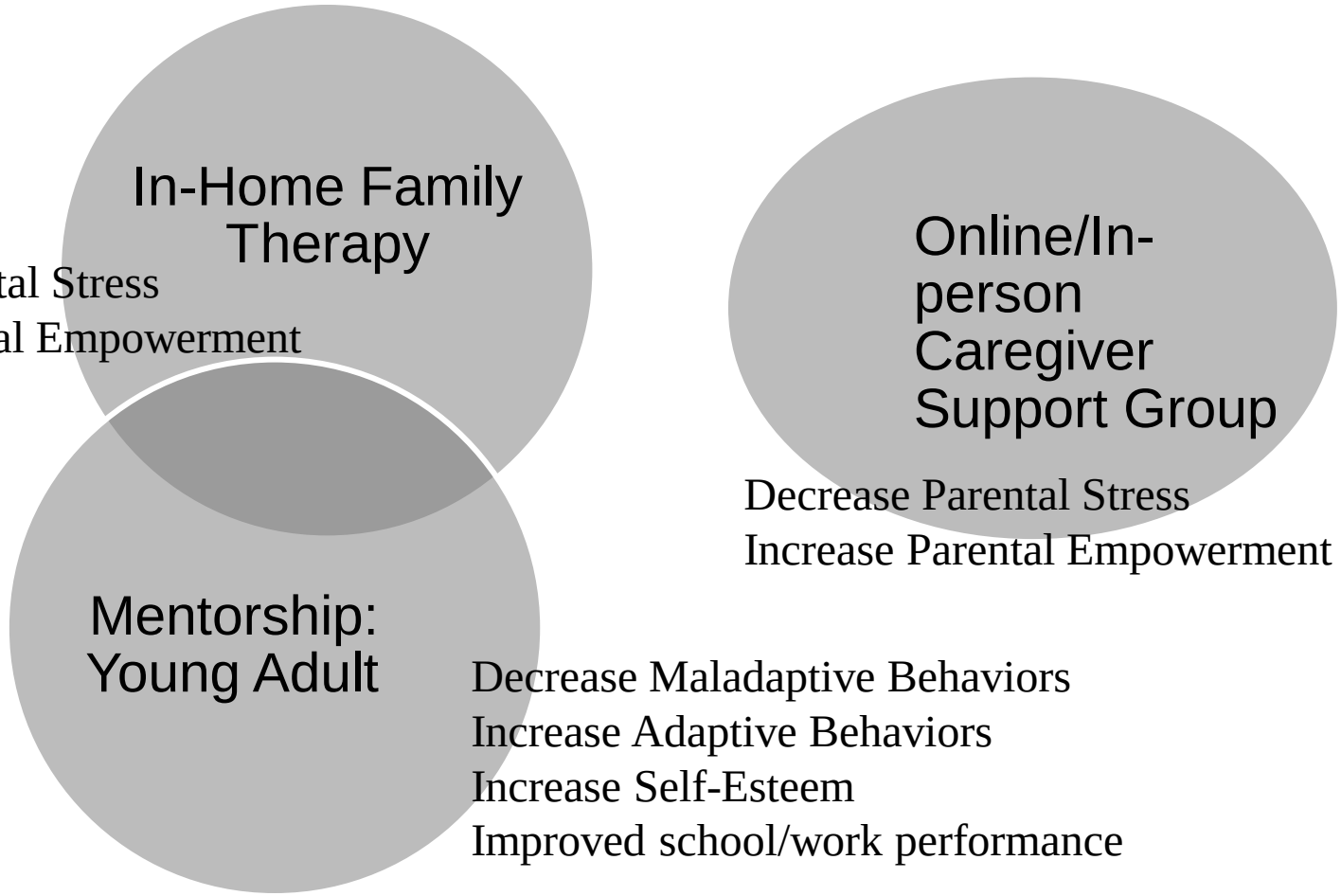
- Informed by Dr. Carmichael Olson's use of positive behavioral support with children living with FASD in the Families Moving Forward Program

Environmental Accommodations

- Informed clinical work of Diane Malbin focusing on changing the environment for individuals with FASD

PARTNERS FOR SUCCESS

3 IN 1 FASD INTERVENTION / INTEGRATING TWO PERSPECTIVES



PFS THERAPIST

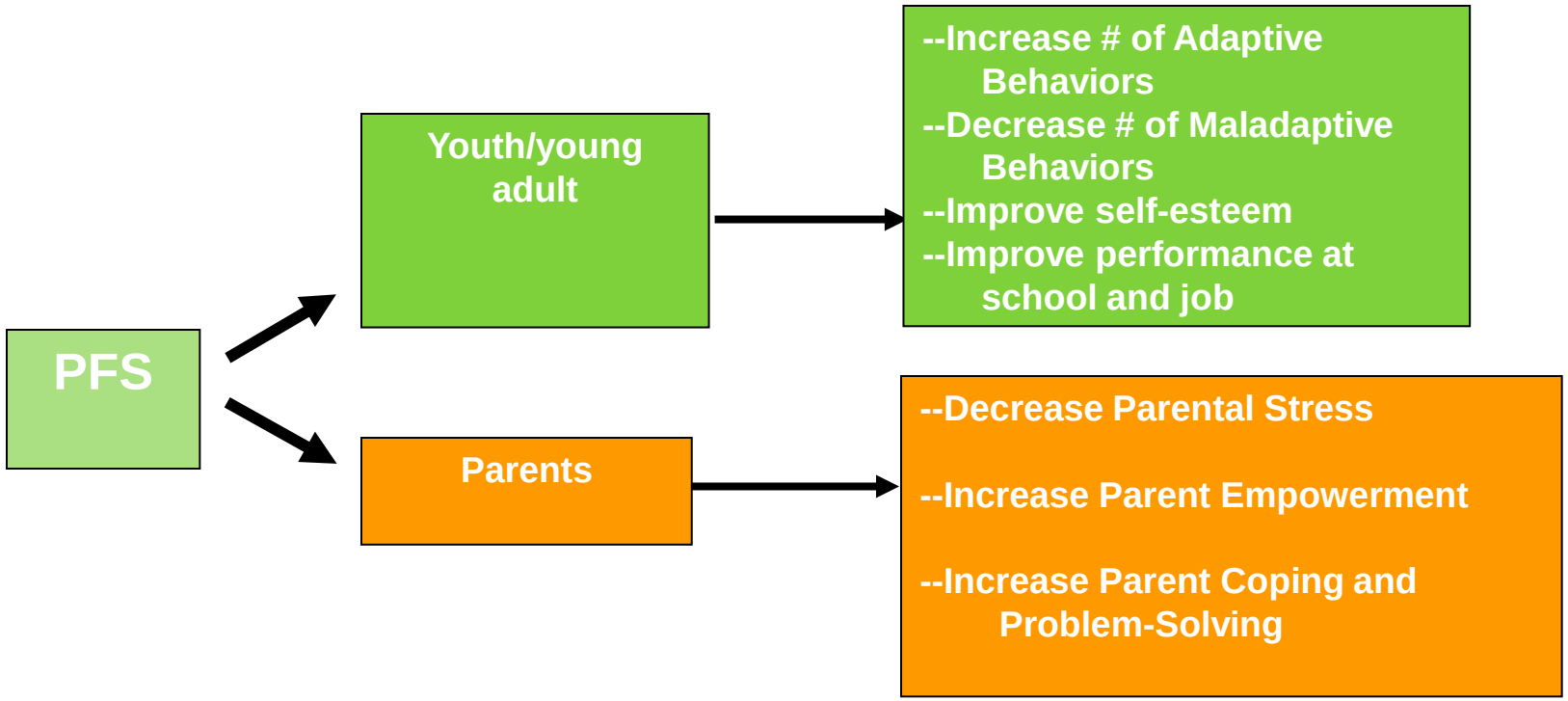
General Theoretical Approaches	FASD Benefits
Cognitive Behavioral Therapy (CBT)	Decrease parental stress Increase parent empowerment and parent coping skills Supports relearning
Solution-Focused Therapy (SFT)	Addresses non-FASD related mental health issues within family unit through a family-centered, family-lead therapeutic approach Supports brainstorming and adaptations for in addressing changes related to FASD

PFS MENTOR

Mentor provided

- On-location advocacy for young adult
- Promotes self-advocacy skills by the young adult
- Facilitates PFS principles in the school/work setting
- Models socialization skills
- Supports family goals identified during in-home therapy
- Mentoring elements modeled after the P-CAP intervention (Dr. Therese Grant).

CONCEPTUAL MODEL



Midwest Partners for Success (PFS) Intervention

Funding: Three year CDC funded project

Purpose: Design, implement, test intervention for youth and young adults with FASDs ages 13-25

Study Design: Compare standard treatment with standard treatment PLUS PFS intervention

Recruitment: Recruit 100 participants randomized to receive intervention (50 in each group) from social service agencies, schools, institutions, clinics, mental health treatment programs

Setting: 25 mile radius around City of St. Louis

RECRUITMENT

Extensive recruitment process.

No clinic in MO that specifically sees youth and young adults with suspected FASD symptoms (Sx).

Had an original list of service agencies that said they most likely had cases of youth/young adults with FASD Sx.

Met and trained staff in over 200 local professionalsagencies and settings in St. Louis to describe what FASD is and how to identify.

Created a Study Referral Sheet for the agencies to use.

Suggested to all agencies to just send us all client cases where the client was diagnosed with ADHD.

THUS, important to note that over half (22 or 58.5%) of the participants were receiving some type of social support service.

PFS ASSESSMENT - YOUTH

- **Measured by clinical assessments**
  - FABS for eligibility screening
  - Four-digit code for diagnosis
- **Change in Maladaptive behaviors defined as social skills deficits**
  - Columbia Impairment Scale
  - Social Skills Improvement System (SS Rating Scales)
- **Strengths measured using BERS-2** (Behavioral and Emotional Rating Scale)
- **Self-Esteem** measured with the Rosenberg SE Scale
- **Life Consequences Survey** (created by CDC colleagues)

PFS ASSESSMENT - PARENTS

- **Parent Coping:** Ways of Coping Scale (WOC)
- **Parent Problem-Solving: WOC** Problem solving subscale
- **Parent Empowerment:** Parent Empowerment Scale
- **Parent Stress:** Stress Index for Parents of Adolescents
- **Parent Locus-of-Control:** Parent Locus of Control Scale

- **Life Stressors and Social Resources:** Both Parent and young adult completed

OTHER ASSESSMENTS

- Dose of Therapy
- Dose of Mentor
- Client Satisfaction with Intervention (Client Satisfaction Questionnaire)
- Parent Satisfaction with Intervention

INTERVENTION STRUCTURE

- Two-group randomized controlled trial: Community Standard (CS) alone or CS + PFS
- Followed 42 youth and young adults with FASD
- Six-mo. intervention with 3 mo. F/U
- Intervention provided through local agency in St. Louis

DEMOGRAPHIC CHARACTERISTICS

Completion Status: June 7, 2013 (N=45)		
	Control (n=25)	PFS (n=20)
Diagnosis Completion	24	20
Baseline	22	19
End of Intervention	13	14
3-months post	11	7

Demographics by group (N=41)				
	Overall (N=41)	Control (n=22)	PFS (n=19)	
Variable	n (%)	n (%)	n (%)	p-value
Mean Age at start of study (SD)	15.0 (3.0)	15.3 (3.5)	14.6 (2.3)	.44
Race				.28
White	21 (51.2)	13 (59.1)	8 (42.1)	
Non-White	20 (48.8)	9 (40.9)	11 (57.9)	
Gender				.40
Male	23 (56.1)	11 (50.0)	12 (63.2)	
Female	18 (43.9)	11 (50.0)	7 (36.8)	
US Born (yes)	27 (65.6)	13 (59.1)	14 (73.7)	.33
Children enrolled - multiples*				.55
Single	25 (61.0)	15 (68.2)	10 (52.6)	
Two	10 (24.4)	4 (18.2)	6 (31.6)	
Three or more	6 (14.6)	3 (13.6)	3 (15.8)	
Marital Status – Caregiver				.91
Married/partnered	27 (65.9)	16 (72.7)	11 (57.9)	
Not married	14 (34.2)	6 (27.3)	8 (42.1)	
Household income				.23
Less than $35,000	10 (24.4)	7 (31.8)	3 (15.8)	
$35,000 or more	31 (75.6)	15 (68.2)	16 (84.2)	

FASD DIAGNOSIS RESULTS

Fetal Alcohol Behavior Scale (FABS) Streissguth

Four Digit Code(developed by Astley & Clarren) is 0-22 with 22 at highest level of FASD severity.

FABS
45 cases Screened for eligible for the study

Four-Digit Code
55% of 42 cases alcohol exposure known XX suspected for FASD
Only 4 cases with severity score of 22

LIFE CONSEQUENCES SCALE (BERTRAND)

Based upon previous work (2004) published by Ann Streissguth, psychologist from University of WA, those with FASD had a host of what she called secondary disabilities. Bertrand from CDC created an 11-item Life Consequences Scale for these studies.

Trouble maintaining school attendance

Trouble maintaining stable living environment

Observed victimized, perpetrated violence/abuse

Ever involved in criminal/juvenile system

Ever have trouble with employment

Trouble achieving independent living skills

Difficulties with regulation behaviors

Difficulties with physical, social, sexual development

Difficulty finding companionship

Difficulty with drugs/alcohol

Psychiatric or mental health problems (For the STL sample)

- **Predominant condition: ADHD, ADD**
- **28 participants were currently in either outpatient or inpatient treatment**

LIFE CONSEQUENCES RESULTS- COMBINED STUDIES

Combined results from both SLU and UCLA studies

Sample size: 175 caregivers of youth and young adults ages 12-28.

21% met criteria for FAS, 40% for pFAS and 39% for ARND

Top four life consequences were:

83% psychiatric or mental health problems

79% difficulty with behavior regulation/management

79% difficulty achieving independent living skills

68% difficulty with physical, social, sexual development.

Least likely to:

Have trouble with the law (16%)

Have alcohol and drug use (10%)

YOUTH OUTCOMES

Young Adult Outcomes, T1 to T3 by group (N=41)

Variable	Control (n=22) Mean (SD) Time1	Time2	Time3	PFS (n=19) Mean (SD) Time1	Time2	Time3	p-value*
Adaptive Behaviors (SSIS)							
Social Skills Domain	67.4 (9.5)	67.3 (13.2)	69.3 (11.1)	71.1 (9.2)	75.4 (15.1)	78.0 (17.0)	.84
Communication	71.1 (14.1)	71.4 (15.2)	73.0 (9.7)	76.9 (11.8)	80.7 (12.3)	80.7 (15.9)	.86
Cooperation	66.2 (12.3)	67.9 (18.1)	71.8 (12.9)	71.9 (15.6)	77.2 (15.0)	81.3 (16.0)	.95
Assertion	79.0 (13.6)	78.1 (15.5)	81.9 (14.3)	83.5 (13.6)	84.5 (13.5)	79.0 (20.9)	.28
Responsibility	59.0 (14.1)	61.8 (14.6)	66.9 (10.4)	63.6 (14.8)	73.1 (18.0)	81.8 (23.0)	.59
Empathy	80.4 (14.9)	72.6 (17.6)	74.6 (19.8)	79.5 (13.8)	83.8 (15.9)	82.8 (24.6)	.23
Engagement	80.3 (17.1)	83.1 (13.8)	78.7 (14.0)	80.5 (8.8)	85.3 (10.8)	86.6 (7.3)	.55
Self-control	73.2 (9.5)	77.2 (14.6)	75.7 (15.4)	71.9 (12.8)	79.8 (13.3)	80.3 (16.0)	.88
Problem Behaviors Domain	**143.1 (11.8)**	136.5 (14.4)	**139.9 (13.6)**	**134.8 (18.9)**	125.6 (17.8)	**126.4 (27.1)**	.40
Externalizing	**141.3 (18.1)**	135.4 (12.4)	**134.1 (17.2)**	**140.9 (22.9)**	129.4 (20.1)	**124.7 (28.1)**	.84
Bullying	**134.1 (24.9)**	124.4 (27.1)	**124.2 (28.7)**	**128.9 (28.8)**	119.6 (22.8)	**119.0 (33.2)**	.55
Hyperactivity/Inattention	**139.5 (13.0)**	135.2 (14.7)	**132.1 (13.0)**	**138.1 (17.7)**	129.8 (16.3)	**125.2 (24.7)**	.36
Internalizing	**139.4 (19.0)**	131.4 (15.7)	**139.2 (16.9)**	**125.2 (17.0)**	117.9 (17.7)	**121.5 (22.6)**	.17
Autism Spectrum	**140.1 (16.8)**	130.5 (19.3)	**139.0 (17.6)**	**131.7 (12.9)**	124.9 (13.4)	**127.8 (17.5)**	.65
Maladaptive Behaviors (CIS)	111.2 (14.5)	112.3 (18.1)	111.2 (16.4)	111.9 (13.9)	**106.0 (11.8)**	**105.6 (14.8)**	.33
Self-Esteem (RSES)	99.6 (13.9)	98.8 (21.6)	101.2 (18.5)	93.3 (14.4)	96.3 (18.8)	94.2 (23.0)	.52

* group x time p-value in marginal multilevel mixed model

YOUNG ADULT STRENGTHS

Emotional and Behavioral Strengths (BERS) by group (N=41)				
	Overall (N=41)	Control (n=22)	PFS (n=19)	
Variable	Mean (SD)	Means (SD)	Mean (SD)	p-value*
Overall Strength Index	91.7 (14.0)	93.7 (14.9)	89.5 (12.9)	.35
Interpersonal Strength	89.3 (16.9)	91.6 (19.5)	86.6 (13.3)	.34
Family Involvement Strength	93.3 (10.9)	92.3 (12.6)	94.5 (8.6)	.53
Intrapersonal Strength	97.3 (15.1)	99.5 (15.8)	94.7 (14.3)	.32
School Functioning Strength	93.1 (14.5)	98.3 (14.5)	87.4 (12.4)	.02
Affective Strength	97.3 (12.1)	96.1 (11.9)	98.7 (12.6)	.51
Career Strength	97.9 (13.4)	100.9 (12.9)	94.5 (13.4)	.13
* 2 sample t-test				

LIFE STRESSORS AND RESOURCES

Life Stressors and Resources (LISRES) by group (N=41)				
	Overall (N=41)	Control (n=22)	PFS (n=19)	
Variable	Mean (SD)	Mean (SD)	Mean (SD)	p-value*
Stress/Resource Index [n(%)]				.64
High	10 (24.4%)	6 (27.3%)	4 (21.1%)	
Low	31 (75.6%)	16 (72.7%)	15 (78.9%)	
Stressors Scale				
Physical health	95.4 (12.3)	93.7 (10.9)	97.3 (13.9)	.37
Home and neighborhood	97.8 (14.7)	99.2 (17.5)	96.2 (10.9)	.53
Financial	107.0 (14.2)	107.7 (13.8)	106.3 (14.9)	.75
Work	93.0 (14.6)	96.7 (15.9)	89.4 (12.7)	.21
Spouse/partner	102.9 (27.6)	102.3 (25.3)	104.2 (33.2)	.87
Children	149.3 (19.8)	148.6 (21.8)	150.1 (17.5)	.82
Extended family	106.3 (20.6)	108.2 (23.3)	104.1 (17.2)	.54
Friends	110.5 (23.0)	111.0 (24.8)	109.9 (21.6)	.89
Negative Life events	**109.9 (18.0)**	**117.5 (20.5)**	**100.7 (7.7)**	**.001**
Resources Scale				
Financial	107.1 (13.1)	108.0 (12.8)	106.1 (13.7)	.66
Work	93.6 (16.6)	91.9 (18.5)	95.3 (15.1)	.62
Spouse/partner	93.9 (20.7)	92.9 (24.5)	96.0 (10.5)	.65
Children	87.4 (9.9)	86.3 (7.6)	88.8 (12.3)	.47
Extended family	99.9 (12.9)	100.9 (15.7)	98.8 (8.9)	.59
Friends	102.3 (13.7)	102.5 (16.0)	102.1 (11.3)	.94
Positive life events	100.6 (13.1)	104.2 (15.1)	96.2 (8.6)	.04

* 2 sample t-test for all variables but index. Stress-Resource Index is a 2-sample chi-square test.

Stress/Resource index represents the ability to cope with the stresses in life. It is a ratio of the average resource/average stress profiles. If 1 or greater, then high (resources to deal with stressors). If less than 1 then low.

RESULTS: PARENT OUTCOMES

Parent Outcomes, T1 to T3 by group (N=41)

Variable	Control (n=22) Mean (SD) Time1	Time2	Time3	PFS (n=19) Mean (SD) Time1	Time2	Time3	p-value*
Parental Coping/Problem Solving (%)							
Confrontive	12.4 (3.8)	11.8 (4.0)	10.8 (3.8)	10.9 (4.3)	12.0 (5.7)	13.3 (2.8)	.22
Distancing	6.8 (6.4)	7.5 (3.4)	10.2 (4.2)	6.4 (3.0)	8.1 (5.0)	7.4 (7.0)	.06
Self-controlling	16.2 (4.6)	13.9 (6.4)	15.8 (5.4)	14.5 (4.3)	16.4 (6.4)	16.9 (6.8)	.04
Seeking social support	18.3 (7.9)	16.5 (7.8)	16.1 (8.7)	17.5 (5.9)	14.3 (7.4)	17.0 (6.2)	.34
Accepting responsibility	5.4 (4.6)	11.4 (3.8)	9.7 (4.1)	7.5 (5.6)	7.1 (3.7)	5.3 (3.9)	.01
Escape-avoidance	9.6 (4.6)	8.0 (4.9)	7.9 (5.6)	7.0 (4.7)	6.5 (3.7)	7.6 (5.0)	.89
Planful problem solving	17.1 (6.0)	17.5 (4.9)	14.9 (4.3)	20.5 (6.5)	19.3 (6.8)	19.2 (8.6)	.58
Positive reappraisal	14.3 (6.5)	13.4 (5.1)	14.6 (4.7)	15.7 (5.1)	16.3 (7.1)	13.4 (5.4)	.36
Total Positive Coping	55.0 (9.1)	58.8 (7.5)	55.3 (11.4)	61.2 (10.5)	57.0 (12.5)	54.9 (14.9)	.03

PARENT OUTCOMES

Parent Outcomes, T1 to T3 by group (N=41)

	Control (n=22) Mean (SD)			PFS (n=19) Mean (SD)			
Variable	Time1	Time2	Time3	Time1	Time2	Time3	p-value*
Locus of Control							
Parental efficacy	20.4 (5.4)	21.1 (6.5)	20.0 (3.5)	19.7 (4.3)	18.3 (4.7)	18.6 (2.4)	.40
Parental responsibility	38.0 (5.9)	35.5 (7.3)	34.5 (7.1)	35.1 (4.6)	35.3 (6.4)	37.1 (8.1)	.16
Child control of parent's life	17.4 (5.0)	14.7 (5.6)	13.6 (3.1)	15.9 (4.6)	15.1 (3.7)	16.9 (4.6)	.43
Belief in fate/chance	21.7 (6.4)	24.5 (5.7)	21.7 (7.2)	22.5 (5.9)	23.5 (4.9)	26.1 (8.4)	.17
Parent control of child behavior	34.0 (7.9)	34.1 (10.2)	33.3 (12.4)	33.0 (5.4)	29.1 (4.9)	33.7 (5.4)	.05
Overall locus of control	131.3 (16.6)	129.9 (22.1)	123.1 (16.5)	126.2 (14.5)	121.2 (16.6)	132.4 (20.6)	.02

* group x time p-value in marginal multilevel mixed model

UNEXPECTED RESULTS

Family Dynamics: strengths and weaknesses appeared to be important

OPEN FAMILY	CLOSED FAMILY
Open to new parenting styles	Closed to parent styles
Open to therapy guidance	Closed to therapy
Willing to see young adult in different ways	Unwilling to see their youth in new light

Asked parents how many hours per week they spend with the child

- **Help with social skills**
- **Help with schoolwork**
- **Help with school issues**
- **Help with problem solving work issues**

Majority number of hours for each category was split between <1 hr per week and 1- to <3 hrs per week.

CONCLUSIONS

PFS Youth/Young Adult did improve or remained stable over time with the intervention but were not significantly different than controls.

Families and youth have a LOT to deal with on a day to day basis.

Family dynamics defined as OPEN appeared to have greater overall sense of improvement as identified qualitatively by the PFS therapist.

Sample size contributed significantly to our results.

Using a local agency that was not a significant provider to families with FASD youth to provide the intervention may not have been our best choice.

Hope to replicate with other agencies.

IMPLICATIONS FOR THE FIELD

In-home therapy for families of youth and young adults with FASD may improve family coping style and overall understanding of the condition of having an FASD.

Techniques provided to families and youth may strengthen their abilities (both parents and youth) to manage the condition on a day-to-day basis.

We believe the Treatment Intervention may work within a social service agency but this needs to be tested further.

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