

Comparison of Caregiver Service Experiences in Federally Funded Systems of Care and Nonfunded Communities

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Purpose

- Describe the service experiences of families served in federally funded systems of care and comparison systems.
- Examine the extent to which planned services were received, how well services embodied system of care principles, and how caregivers' beliefs about clinical change relate to receipt and appraisals of services.

The Evaluation Framework

**System Development
(System of Care Assessment)**

**Service Delivery and Practice
(Practice-Level Assessment)**

**Child and Family Descriptive and
Outcome Studies**

System of Care Service Delivery

Services should:

- Be planned with the family's full involvement
 - Be shaped by the needs and preferences of the child and family
 - Draw on child and family strengths
- Be culturally appropriate
- Be provided in the least restrictive setting
- Be accessible within the child's and family's community

Providers should:

- Collaborate and coordinate around family's service plan

System of Care Principles Assessed

- **Family Focused:** Services should be dictated by the needs of the child and family, based on the family's strengths, and provided in a manner which maximizes opportunities for involvement and self-determination in planning and delivery.
- **Individualized:** Children with emotional disturbances and their families should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.
- **Culturally Competent:** Children and their families should receive services that are provided in a way that is sensitive and responsive to cultural differences and special needs.
- **Accessible:** Children and their families should have access to a comprehensive array of services that address the child's physical, emotional, social, and educational needs.

Comparison Communities Participating in the Substudy

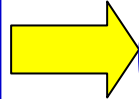
Funded in 1997

Federally Funded & Non-Federally Funded Communities	Population Characteristics
Birmingham, Alabama & Montgomery, Alabama	Urban, small city, White/African American population, some poverty
Region III, Nebraska & Region IV, Nebraska	Expansive rural areas (23 counties in each), largely White population

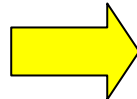
How Do Caregivers and Providers Participate in the Substudy?

Initial Interviews

Initial Interview conducted with caregiver

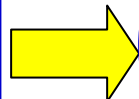


Caregiver records experience in daily diary

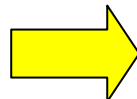


Caregiver interviewed about experience with services over the past 2 weeks

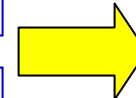
Initial Interview conducted with provider



Provider records experience in daily log



Provider interviewed about experience providing services to family over past 2 weeks



Case record review conducted at the end of the 16-week substudy

How Many Participants Are Enrolled in the Study?

- In total, 184 children were enrolled in the Practice-Level Assessment substudy.
 - 98 children were enrolled in Nebraska
 - (49 each in Regions III & IV)
 - 86 children were enrolled in Alabama (Birmingham = 36, Montgomery = 50)
- Goal: To enroll 50 children in each community.

Who Are the Children of the Caregivers Involved in the Substudy? Nebraska Sites

Demographic Characteristics	Region III Funded System of Care (N = 49)	Region IV Comparison Community (N = 49)
Gender		
Male	77.6%	63.3%
Female	22.4%	36.7%
Average Age	11.4	13.8
Race		
White	87.5%	85.7%
Black	0%	2.0%
Hispanic	6.4%	10.2%
Native American	4.3%	6.1%
Asian	0%	2.0%
Referral Source***		
Juvenile Justice	0%	27.7%
Mental Health	82.6%	44.7%
Education	6.5%	2.1%
Child Welfare	6.5%	21.3%
Other	4.4%	4.2%
Income		
< 15,000/year	18.7%	36.1%
> 15,000/year	81.3%	63.9%

*** $p < .001$

Who Are the Children of the Caregivers Involved in the Substudy? Alabama Sites

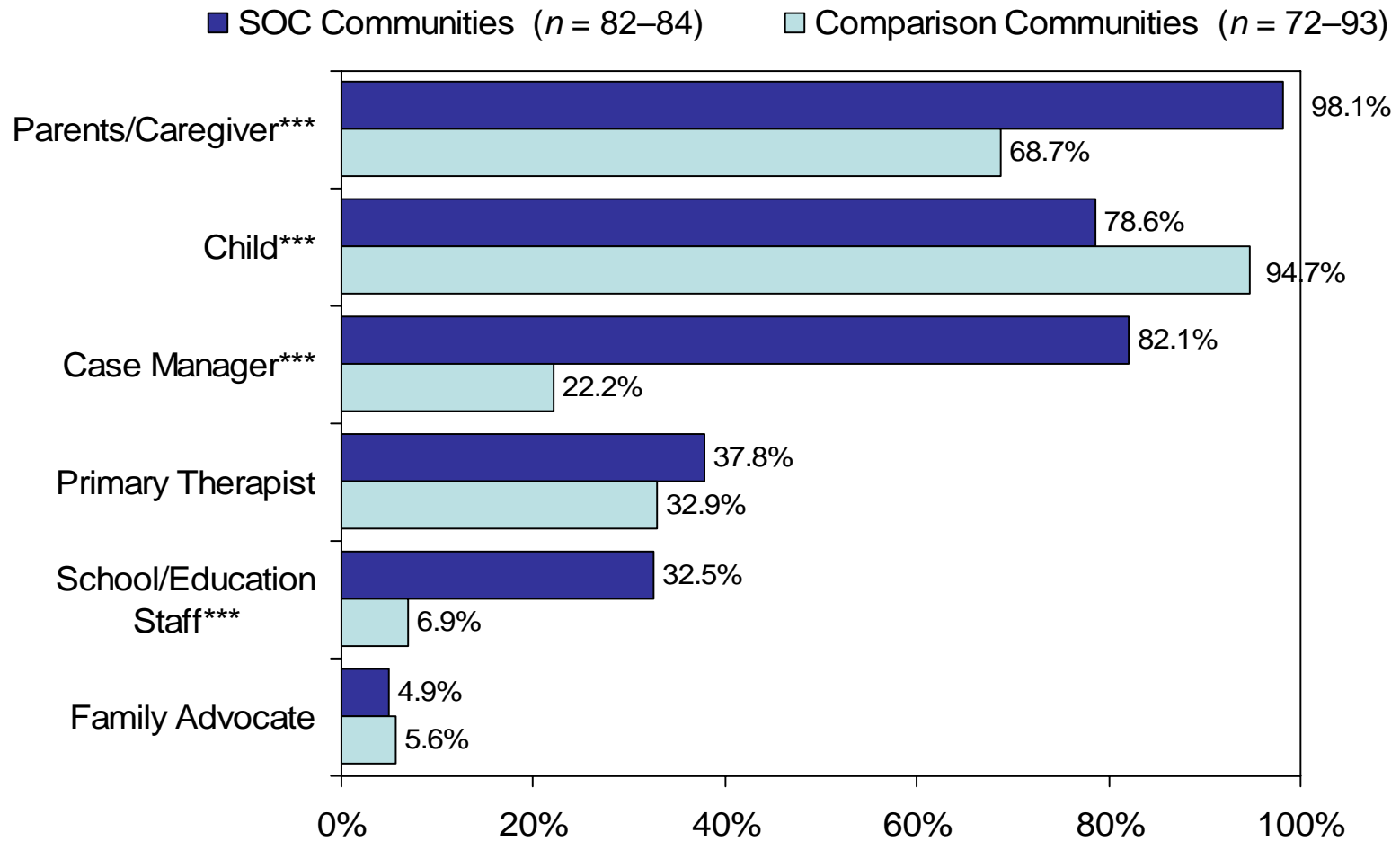
Demographic Characteristics	Birmingham Funded System of Care (N = 36)	Montgomery Comparison Community (N = 50)
Gender		
Male	72.2%	54.0%
Female	27.8%	46.0%
Average Age***	13.4	10.9
Race		
White	38.9%	32.0%
Black	58.3%	68.0%
Hispanic	0%	4.1%
Native American	5.6%	0%
Asian	0%	0%
Referral Source***		
Juvenile Justice	77.8%	0%
Mental Health	0%	41.7%
Education	19.4%	6.3%
Child Welfare	2.8%	0%
Other	0%	35.4%
Income Level		
< \$15,000/year	34.3%	64.6%
> \$15,000/year	65.7%	35.4%

***p < .001

Service Planning Process

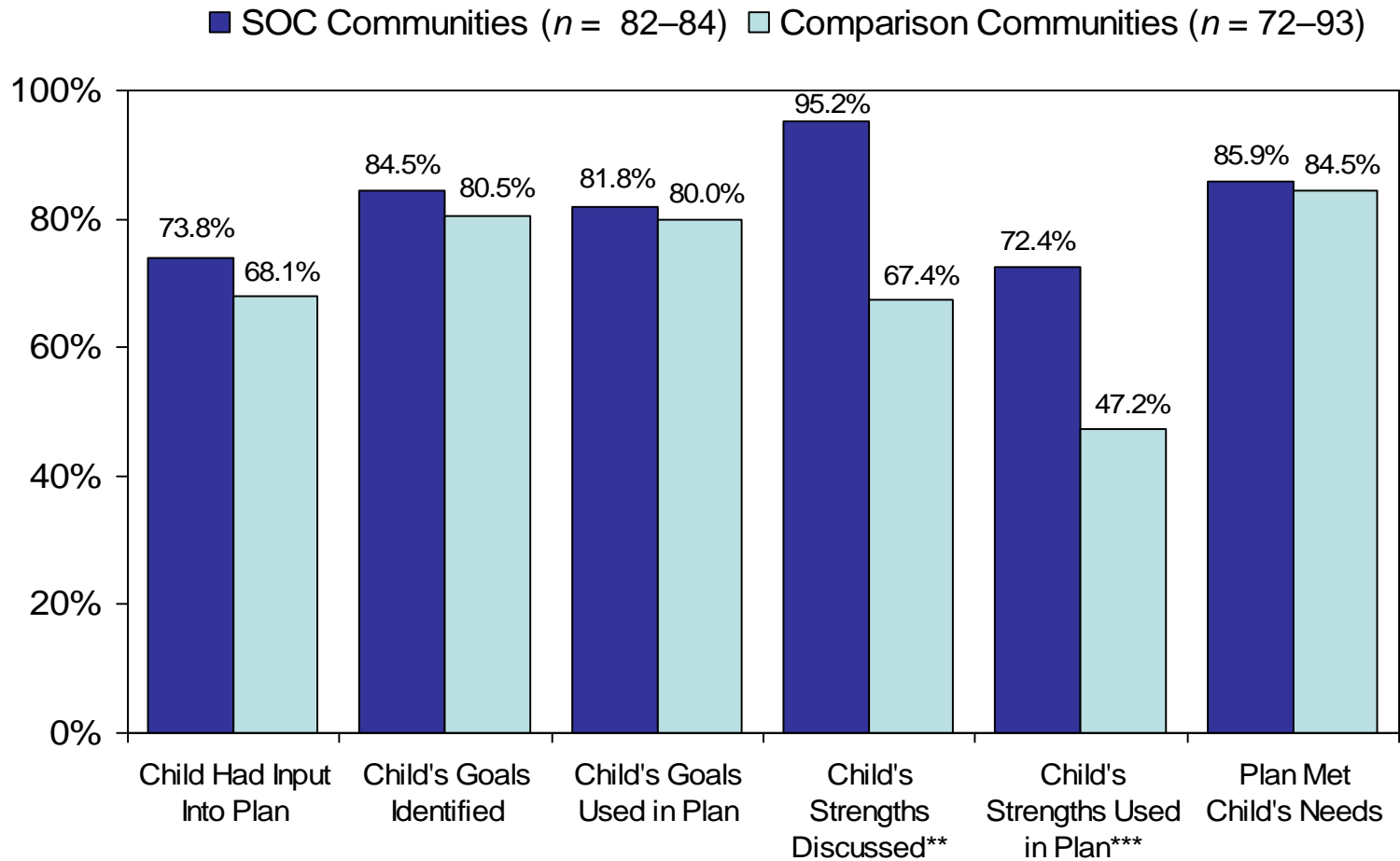
- Interviews were conducted with caregivers and providers about initial service planning process.
- We report differences by system of care site from caregiver interviews.

Who Attended the Initial Service Planning Meeting?



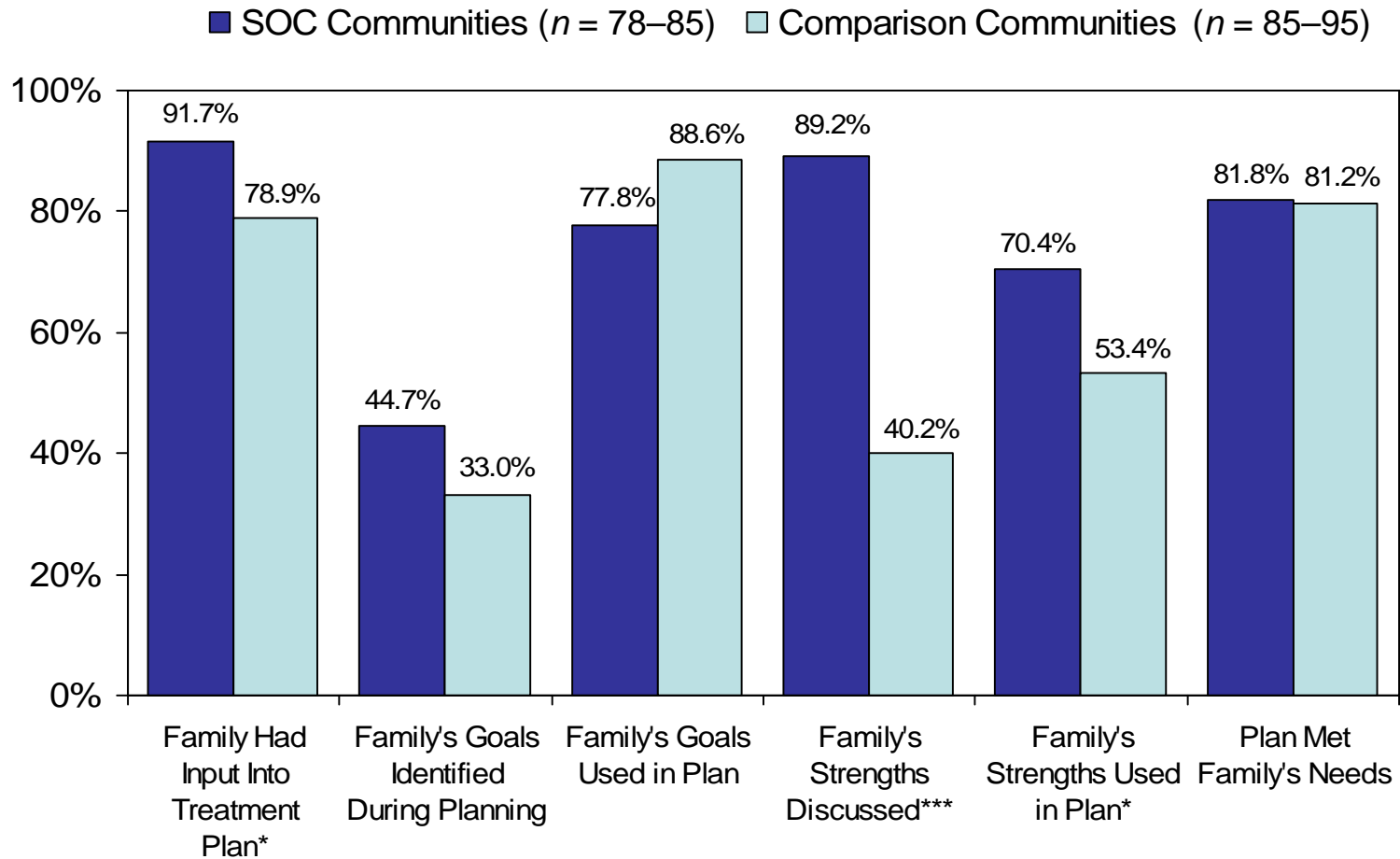
*** $p < .001$.

How Individualized Was the Treatment Planning Process?



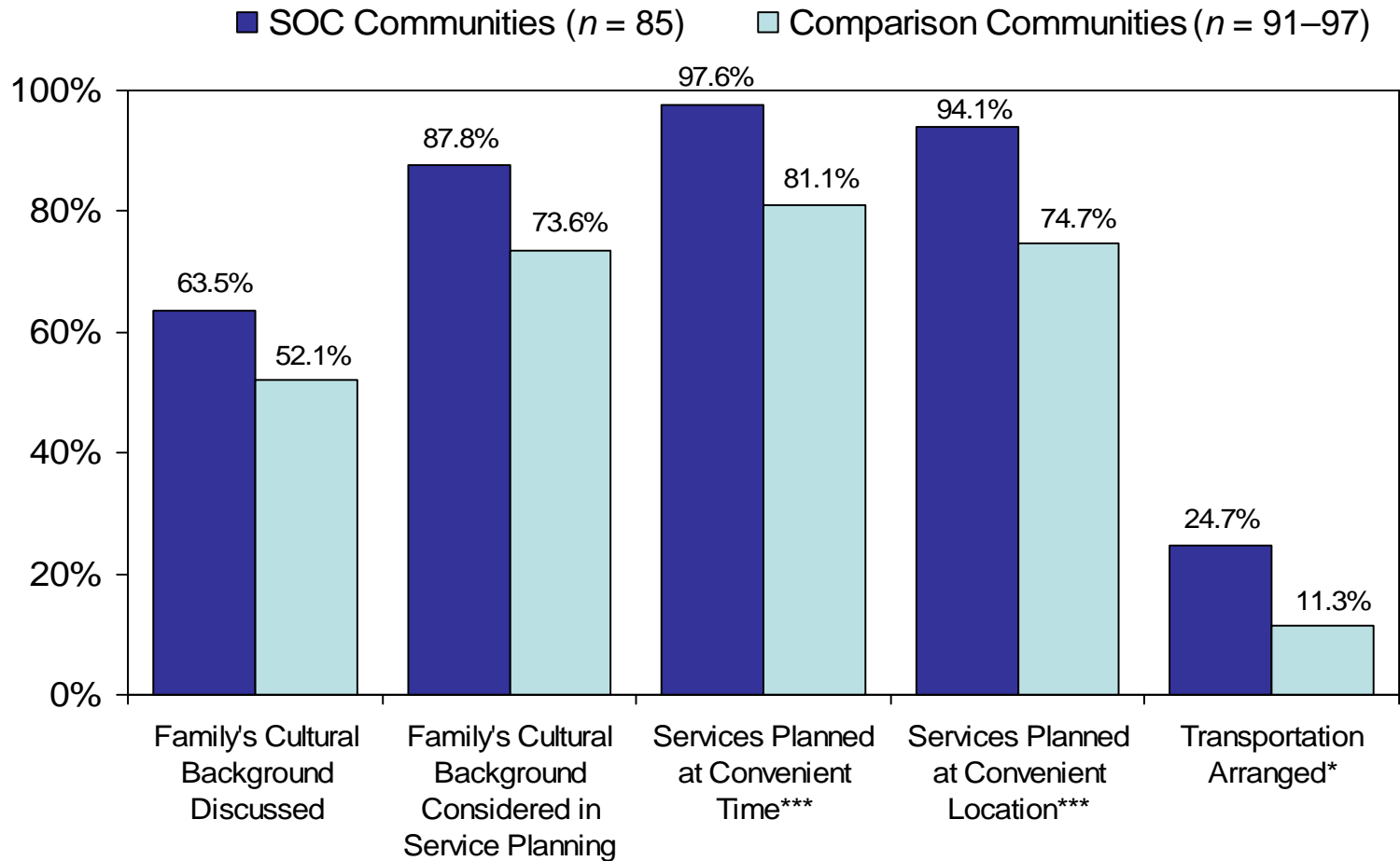
** $p < .01$, *** $p < .001$.

How Family Focused Was the Treatment Planning Process?



* $p < .05$, *** $p < .001$.

How Culturally Competent and Accessible Was the Treatment Planning Process?

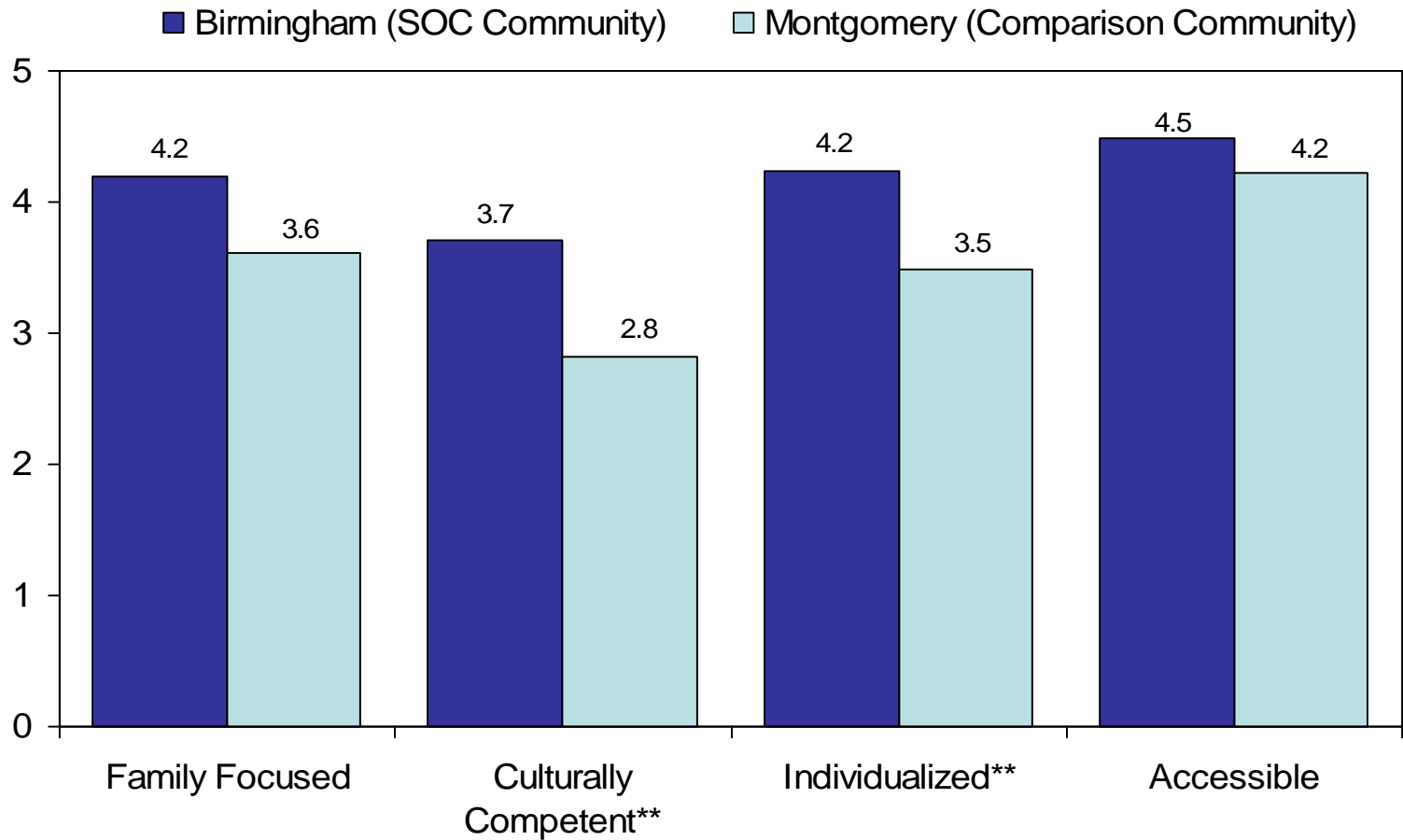


* $p < .05$, *** $p < .001$.

Did Services Follow System of Care Principles?

- Biweekly phone interviews conducted with caregivers to assess their service experiences.
 - Caregivers rated the extent to which services were
 - Family focused (4 items)
 - Culturally competent (3 items)
 - Individualized (4 items) and
 - Accessible (4 items)

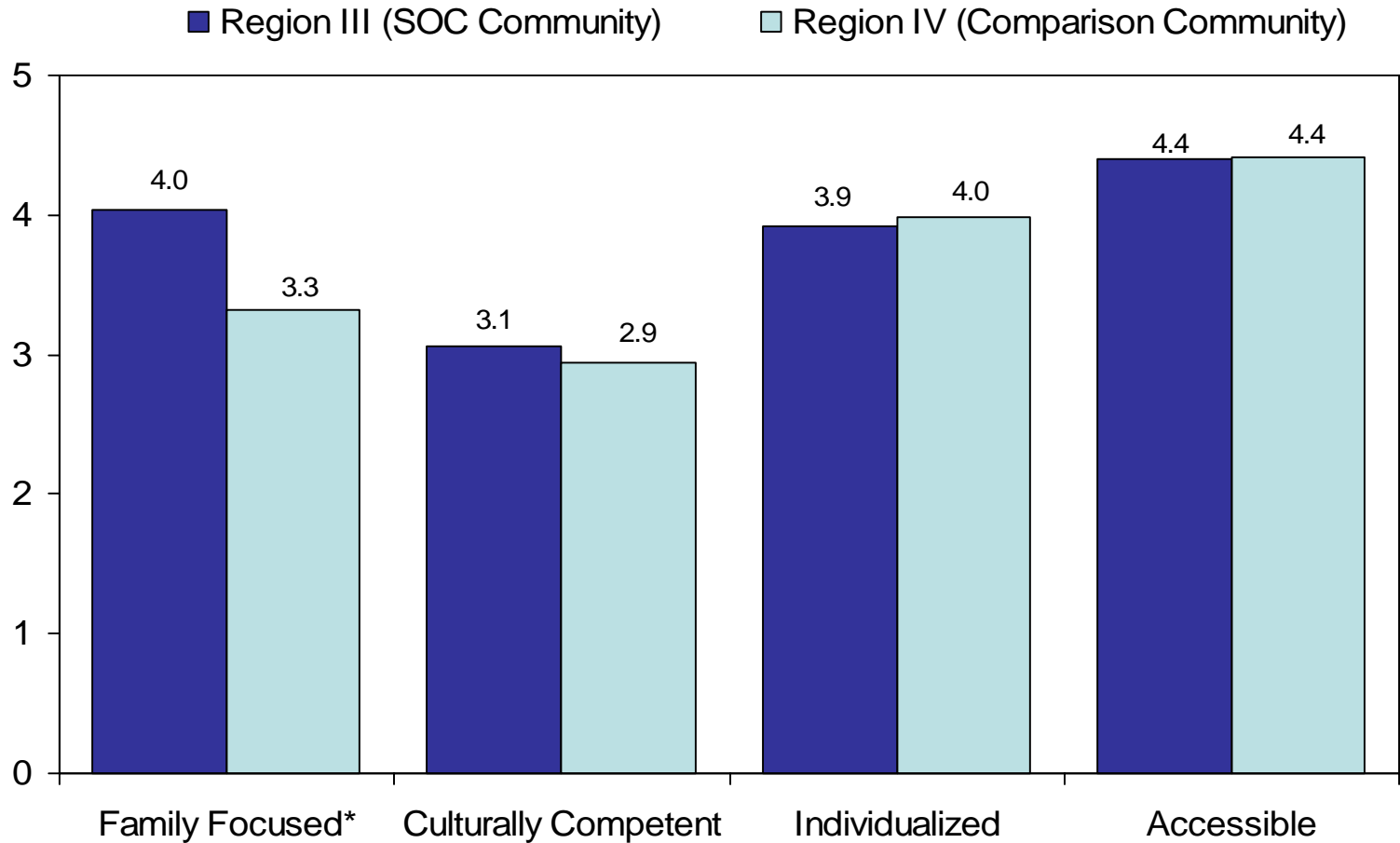
Did Caregivers at System of Care Sites Rate Services Higher on System of Care Principles? Alabama



Week 8

** $p < .01$.

Did Caregivers at System of Care Sites Rate Services Higher on System of Care Principles? Nebraska



Week 8

* $p < .05$.

Regression Models Controlling for Potential Cofactors

Alabama

	Culturally Competent		Individualized	
	B	SE	B	SE
Birmingham (v. Montgomery)	.968	.367*	.654	.297*
White (v. non-White)	-.652	.345⁺	-.755	.278**
Caregiver Education (high school graduate vs. non-graduate)	.023	.417	-.278	.338
Caregiver Strain	-.037	.076	.037	.062
CBCL Total Problems	.004	.016	.000	.013

+ $p < .10$, * $p < .05$, ** $p < .01$.

Regression Models Controlling for Potential Cofactors Nebraska

	Family Focused	
	B	SE
Region III (v. Region IV)	.737	.247**
White (v. non-White)	-.311	.349
Caregiver Education (high school graduate vs. non-graduate)	.183	.384
Caregiver Strain	-.159	.055**
CBCL Total Problems	.006	.015

** $p < .01$.

Summary: Service Planning

- Caregivers in system of care sites were more likely to report that providers used their input and used child and family strengths in making treatment decisions.
- Caregivers were more likely to report that they had a case manager and an education staff member in planning meetings.
- Caregivers were more likely to report that services had been planned at convenient times and locations.

Summary: Caregiver Appraisals

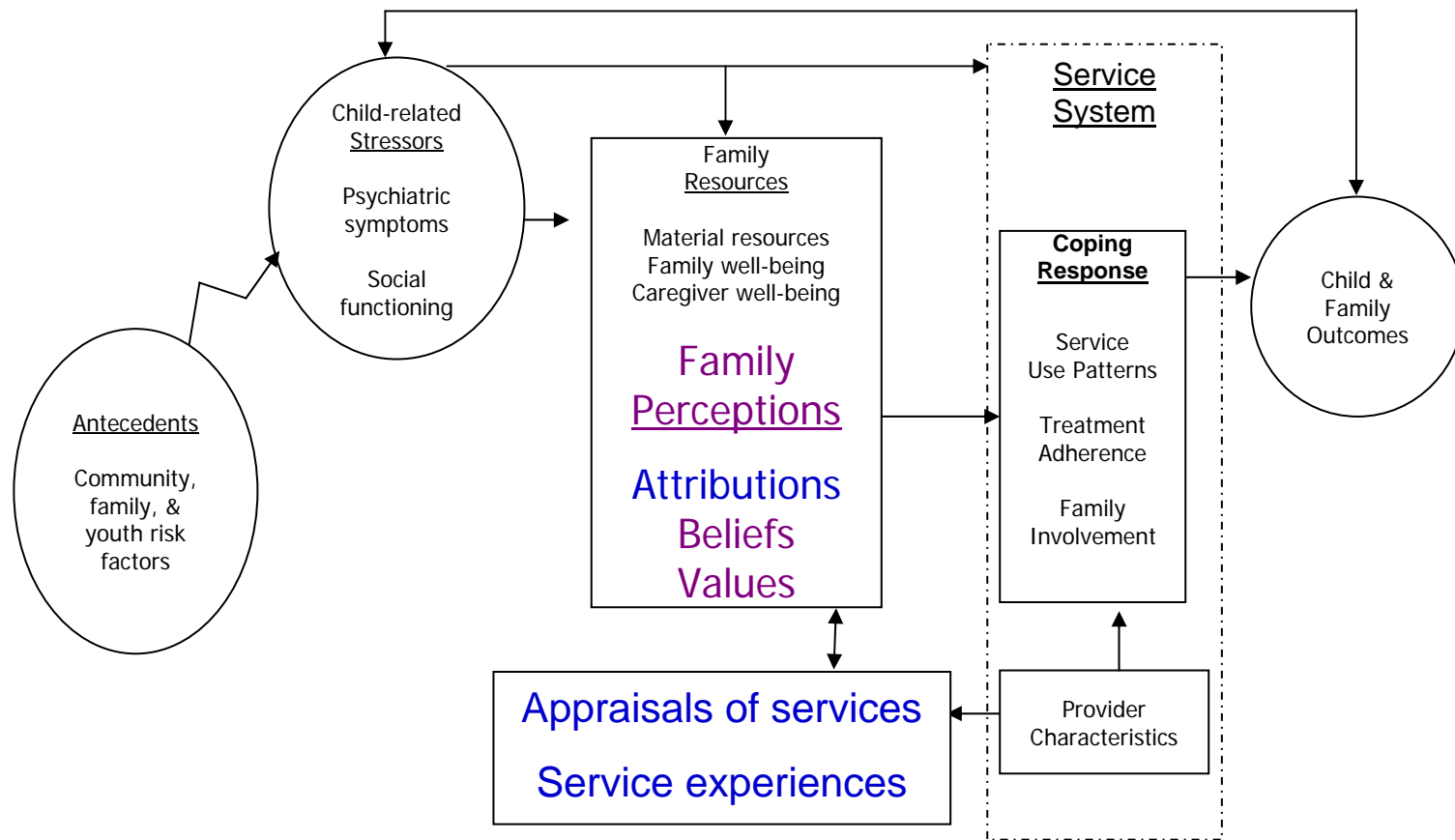
- In Alabama, caregivers from the system of care site reported their services were significantly higher on cultural competence and individualized principles.
- In Nebraska, caregivers from the system of care site reported their services were significantly higher on family-focused principles.

Attributions, Appraisals and Missed Appointments

This study examined the relationship among caregivers' attributions about their children's improvement, their appraisals of services, and their reasons for missing appointments.

We expected pre-treatment attributions, service experiences and reasons for missing appointments to be related to their appraisals of services.

Conceptual Framework



Modified Double ABCX Model (Heflinger, Northrup, Sonnichsen, & Brannan, 1998)

Attributions about Improvement

Attributions – Perceptions about who/what is most responsible for improvement in children

Assessed with four questions at baseline and at 16 weeks:

- To what extent do you feel positive changes in your child's emotional and behavioral problems can be affected by the services he/she receives?
- To what extent do you feel positive changes in your child's emotional and behavioral problems can be affected by his/her own efforts?
- To what extent do you feel positive changes in your child's emotional and behavioral problems can be affected by his/her service providers' efforts?
- To what extent do you feel positive changes in your child's emotional and behavioral problems can be affected by his/her caregivers' efforts?

1=Not at all 2=Slightly 3=Moderately 4=Mostly 5=Completely

Reasons for Missed Appointments

- Caregivers reported if any planned services were not received and why
- Open-ended responses categorized into three groups
 - Service system or provider reasons (e.g., on waiting list, no service available, provider did not show up)
 - Child reasons (e.g., child refused to go, child did not show up, child cancelled)
 - Family reasons (e.g., did not schedule/could not be reached, did not show up, cancelled)

Appraisals of Services

- Service Experience Questionnaire (SEQ)
 - Individualized care
 - Family focus
 - Cultural competence
 - Coordination of services
 - Access to services

Other Variables

- Number of services received during 16 week diary observation period
- Child externalizing behavior T-score (i.e., Child Behavior Checklist)
- Child internalizing problems T-score (i.e., Child Behavior Checklist)
- Child age
- Child gender (i.e., girl compared to boy)
- Child race (i.e., White compared to minority)

	<i>Mean</i>	<i>(SD)</i>
Number of services received (Median=36)	54.5	56.19
Child externalizing problems	67.32	11.47
Child internalizing problems (T-score)	63.00	11.24

Attributions

Change Over Time

	Initial Interview		16-week Interview	
	<i>M</i>	<i>(SD)</i>	<i>M</i>	<i>(SD)</i>
Improvement attributable to <u>services</u>	3.60***	(.91)	3.55	(1.02)
Improvement attributable to <u>child/youth</u>	3.56***	(1.02)	3.78	(.89)
Improvement attributable to <u>provider</u>	3.75***	(.90)	3.55	(1.02)
Improvement attributable to <u>caregivers</u>	3.80***	(.88)	3.73	(.89)

Services Not Received Over 16-week period

	<i>N</i>	<i>(%)</i>
Number of services planned but not received	37	20.3

<u>For Families Who Missed Any Services</u>	<i>M</i>	<i>(SD)</i>	<i>Range</i>
Number of service/provider-related reasons	1.86	1.43	1 – 6
Number of child-related reasons	1.31	.78	1 – 4
Number of family-related reasons	1.92	1.04	1 – 5

Appraisals of Services

Used Service Experience Questionnaire (SEQ) scores collected after last diary interview

	<i>Mean</i>	<i>(SD)</i>
Individualized care	3.58	(1.19)
Family focused care	3.54	(1.29)
Culturally competent care	3.60	(1.23)
Accessibility	3.73	(1.19)
Service coordination	3.76	(1.17)

Analysis

Used regression analysis to predict appraisals of services (SEQ)

Predictors included:

- Attributions
 - Service and provider efforts combined
 - Child efforts
 - Caregiver efforts
- Service experience
 - Number of services received
- Reasons for missing appointment
 - Service/provider-related reasons
 - Child related reasons
 - Family reasons
- Controlled for
 - Child externalizing symptoms
 - Child internalizing symptoms
 - Child age
 - Child race

Predicting Appraisals

	Individual		Family Focus		Cultural Comp	
	B	SE	B	SE	B	SE
Child efforts	.19	.13	.14	.14	.21	.14
Service/provider efforts	.54****	.13	.47***	.14	.52***	.13
Caregiver efforts	-.35*	.12	-.15	.17	-.20	.16
# Services received	.00	.15	.00	.00	.00	.00
Serv/prov reasons	-.07	.07	-.08	.08	-.05	.07
Child reasons	-.15	.19	-.25	.21	-.14	.20
Family reasons	-.22**	.09	-.28**	.10	-.18*	.09
Externalizing	.02	.01	.02	.01	.02	.01
Internalizing	-.02*	.01	-.03*	.01	-.03**	.01
Age	-.06*	.03	-.06	.04	-.07*	.03
Girl	.31	.22	.23	.25	.22	.24
White	-.10	.19	-.08	.21	-.09	.20

**** $p < .0001$, *** $p < .001$, ** $p < .01$, * $p < .05$

Predicting Appraisals

	Accessible		Coordination	
	B	SE	B	SE
Child efforts	.10	.14	.20	.13
Service/provider efforts	.40**	.13	.52****	.12
Caregiver efforts	-.18	.16	-.31*	.15
# Services received	.00	.00	.00	.00
Serv/prov reasons	-.07	.07	-.07	.07
Child reasons	-.16	.20	-.17	.19
Family reasons	-.24**	.09	-.17*	.09
Externalizing	.01	.01	.01	.01
Internalizing	.02	.01	-.02	.01
Age	-.07	.03	-.06*	.03
Girl	.47*	.23	.43*	.22
White	.09	.20	.04	.19

**** $p < .0001$, *** $p < .001$, ** $p < .01$, * $p < .05$

Summary of Findings

- Attributions changed over time
 - Originally, caregivers rated children's efforts as less important to improvement than services, providers, or caregivers
 - By the end of the 16-week period, caregivers rated their children's efforts as more important to improvement than service, provider, or caregiver efforts

Summary of Findings

- Missed services were not uncommon
 - 20% of caregivers reported that a planned service was not received
 - Caregivers cited family-related reasons more often than other reasons for missed services, closely followed by service/provider reasons, with child-related reasons following at a distance

Summary of Findings

- Predicting appraisals
 - Caregivers who considered service and provider efforts to be more important to child improvement tended to appraise services more positively
 - Caregivers who appraised services more negatively were more likely to report a greater number of family-related reasons for missed appointments
 - When children had more internalizing symptoms, caregivers reported less favorable appraisals of services
 - Older child age was related to more negative appraisals
 - Caregivers of girls tended to rate services more positively

Conclusions

More of a “No Duh!” Than an “Aha!”

- By meeting the needs of children and families better, we can reduce family-related barriers to treatment completion and service plan adherence
- Caregivers of children with more internalizing problems tended to rate services more negatively