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2013

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Child  
Food

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**Evaluation of the Capable Kids  
and Families Program : Year 2 Findings**

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# Introduction

The Community Partnership’s Capable Kids and Families program (CKF), an initiative operating in south central Missouri, is designed to identify and fill the gaps in services provided to families of children (age birth to 6 years) with disabilities /or developmental delays. The rate of childhood disability in the United States has been increasing steadily over the past twenty years, due in part to increases in the numbers of low-birth-weight babies and in the survival rate of babies born prematurely (Halfon, Houtrow, Larson, & Newacheck, 2012; American Academy of Pediatrics, 2013). Recent statistics for the state of Missouri indicate that between 16 and 18 percent of the children born each year have special needs—such as Down syndrome, vision or hearing problems, developmental disorders or delays, or cerebral palsy—which often require Early Intervention services (March of Dimes, 2012). According to the Missouri Department of Elementary and Secondary Education reports, the number of children aged 0 to 3 who receive Early Intervention (First Steps) services continues to increase (Missouri Department of Elementary and Secondary Education, 2013a). As of February 2013, it was estimated that 4,999 children ages 0 to 3 were receiving state-supported Early Intervention services and an additional 7,138 children ages 3 to 7 with disabilities received special education services (Missouri Department of Elementary and Secondary Education, 2013b). Nevertheless, many of these children and their families are underserved—they do not have access to the necessary services, primarily due to their lack of knowledge about resources, the expense of beneficial therapy equipment, and a keen sense of isolation (Capable Kids and Families, 2010).

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## Program Description

The CKF program is designed to provide families with support through home visitation services, supportive group meetings and activities, connections to other agencies, and a comprehensive resource-lending program. The resource-lending program allows families to borrow books, tapes, and toys at no expense. The program’s resources specifically focus on developmentally appropriate equipment that



therapists have directed families to use. With the equipment in the home, the family learns to incorporate therapeutic activities with their child throughout the week and not only during sessions with a physical therapist. Thus, parents or guardians become an integral part of their child's therapy team. The family can keep the equipment until the child no longer needs it and is ready to move on to the next appropriate piece of equipment.

### **Home Visiting and Service Referrals**

The CKF program also includes home visiting and service referrals by trained specialists. CKF family specialists have a bachelor's degree in a relevant field (early childhood, special education, etc.) and are experienced and knowledgeable about child development and health as well as the parent-child relationship. During the home visit, specialists offer developmental activities for the child, discuss family needs and link families to available resources, and coordinate therapy equipment needs with the child's therapists. The visit addresses the needs of the entire family with the goal of reducing the stress and isolation often faced by families of children with disabilities. The CKF program is based on the assumption that the relationship between families and home visiting staff is an important benefit of home visiting. These relationships decrease family isolation, decrease parent stress, and offer support to further each child's potential. In addition, CKF specialists use the home visits to discuss available community resources with families and determine if these additional resources would be beneficial. Families with involved children may be unaware of the services available to aid their child's growth and development. Being involved with CKF can help families learn about how to access resources for child care, health care, recreation, educational opportunities, respite services, and other areas. If parents or legal guardians choose, CKF staff may be present during the initial calls to the service provider. The time staff spend with families also helps the families incorporate developmental equipment and strategies into family activities already occurring. All of these strategies can help the parent or guardian feel more confident in their abilities to meet their child's needs.

### **Therapy Equipment Loan Program**

The CKF program believes that providing parents or guardians with the appropriate tools to implement follow-up therapy activities will help children make greater developmental gains. The program has purchased more than 1,700 pieces of therapy equipment for families to use. Families are encouraged to consult with their child's therapist for equipment recommendations. Equipment is available to address concerns in the following areas: gross and fine motor skills, speech and language development, sensory integration, ability switches and adapted toys, visual and auditory processing, cognitive development and problem solving, positioning, and mobility.

## **Supportive Group Meetings and Activities**

Socialization activities provide opportunities for inclusive play and connections to other families in the disability community through playgroups and outing opportunities. Resource sharing and support from their peers makes parents feel more competent. Socialization activities give families opportunities to provide information, resources, and emotional support to new parents or guardians looking for answers to and solutions for issues involved in rearing a child with a disability. They also provide a safe forum for discussing common fears and concerns. Simply knowing that other families experience similar situations can help to alleviate feelings of isolation and helplessness. Hearing about lessons learned, especially from more experienced parents or guardians, can help new parents to build successful coping skills.

Inclusive play takes place in a playroom that has been designed to offer opportunities for children of all abilities. For example, the Somotron ball pool has soothing vibrations and soft lights that provide a relaxing experience and foster movement, speech, and tactile awareness. The Equipony simulates therapeutic horseback riding to improve balance and coordination. Toys like these provide play activities on many levels.

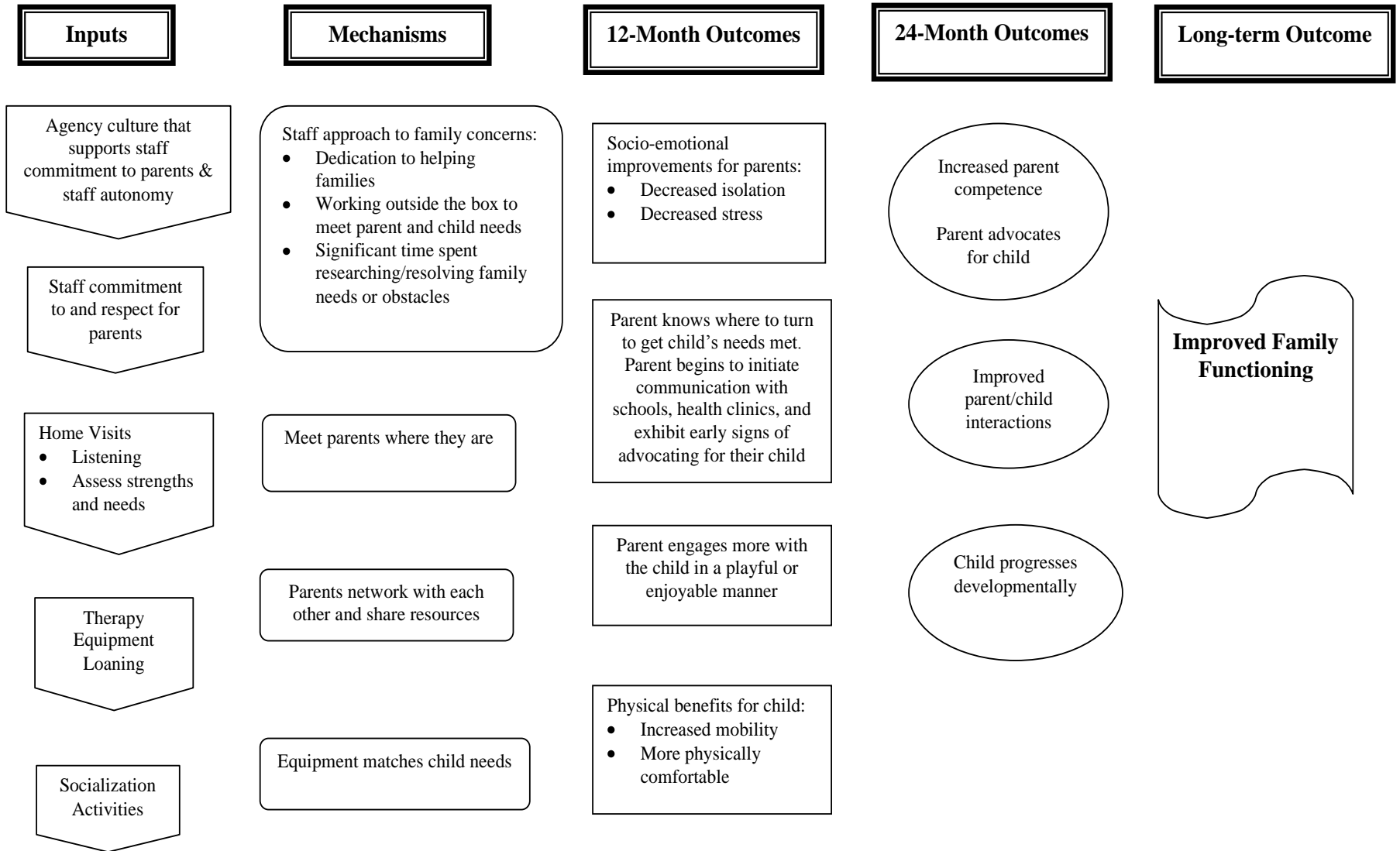
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## **Evaluation Plan**

The Community Partnership (TCP) contracted with Chapin Hall to evaluate the CKF program starting in the fall of 2011 and concluding June 30, 2013. The goals of the evaluation were to examine parent and guardian outcomes and parent-child interactions for families participating in the CKF program. These outcomes and interactions were compared to those of a group of families who receive services from programs and agencies other than CKF. The CKF team created a logic model for the CKF evaluation that outlines the short- and longer-term goals of the program (see Figure 1). According to the logic model, the overall goal of the program is to improve family functioning by strengthening parent and guardian competence, improving parent-child interactions, and improving child health through access to support systems, therapeutic equipment and community resources. This exploratory evaluation focused primarily on the examination of parent or guardian functioning and parent-child interactions. The expectation was that over time, CKF families would show more favorable scores on indicators of parent or guardian functioning and parent-child interactions.

Six broad domains were examined to identify potential differences between CKF and comparison group families. They included: (1) understanding their child's strengths and needs, (2) helping their child learn and develop, (3) ability to advocate for their child, (4) support systems, (5) accessing community, and resources, and (6) positive interactions with their child.

**Figure 1. Capable Kids and Families Logic Model**



## **Methods and Sample**

The evaluation used a quasi-experimental comparison group design to compare a group of families who received services from the CKF program with a group of similar families who received other Early Intervention services, not from CKF. The primary method for data collection was a mail survey created by The Community Partnership with input from Chapin Hall. The survey was administered by TCP at three different times over an 18-month period. Families were provided with a hard copy of the surveys. They were asked to select the response that best fit their family for each measure. The surveys were returned to TCP for data entry. To supplement the survey data, we also conducted six focus groups with parents or legal guardians living in rural and urban locations in Missouri who had a child with a developmental disability or delay. The focus groups occurred near the end of the evaluation period.

### **Mail Survey**

To create a comparison group, The Community Partnership obtained from other service agencies the names of 508 families of preschool children with special needs who lived in similar communities as the families who received services from CKF. Although the original evaluation design planned for data collection to begin in the fall of 2011, difficulty in securing a comparison sample delayed initial data collection until the winter and spring of 2012. Time 2 data were collected in the fall/winter of 2012 and Time 3 data were collected in the spring of 2013.

CKF families completed the survey as part of their participation in the CKF program. TCP sent surveys to 109 CKF families enrolled in the CKF program in three communities (two rural and one urban). Eighty-seven families (80%) completed the surveys (see Table 1). Potential comparison group families were enrolled in other programs serving children with disabilities in six similar communities (five rural and one urban). TCP sent invitation letters and consent forms to the 508 families asking them to participate in the survey; they received signed consent forms from 172 (34%) of them. Of the 172 comparison families who were sent surveys to complete, 146 (85%) returned them. Comparison group families were given a gift card for participation in the survey.

At Time 2, The Community Partnership sent surveys to 136 CKF families—primarily those who completed surveys at Time 1 and newly enrolled families. One hundred eighteen families returned completed surveys (87%). At Time 2, families from the CKF program came from two rural communities and one urban community. TCP sent surveys to 148 comparison families at Time 2; 116 returned completed surveys (78%). The comparison families were families enrolled in other programs serving children with disabilities in six communities (five rural and one urban).

At Time 3, the Partnership sent surveys to 134 CKF families; 82 of these families completed and returned the surveys (61%). One hundred nineteen comparison families received surveys, and 93 (78%) completed and returned the surveys. Table 1 summarizes the number of respondents at each of the three time points.

**Table 1. Survey Sample Sizes over Time**

	Time 1		Time 2		Time 3	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>CKF Program</b>						
Invited to participate in survey	—	—	—	—	—	—
Signed consent form and received survey	109	—	136	—	134	—
Completed and returned survey	87	80	118	87	82	61
<b>Comparison Group</b>						
Invited to participate in survey	508	—	—	—	—	—
Signed consent form and received survey	172	34	148	—	119	—
Completed and returned survey	146	85	116	78	93	78

### Survey Measures

The survey was made up of four measures. Three were administered to families at all three time points and one measure was administered at just Time 2 and Time 3. Parents or guardians were asked to complete all of the family surveys: the Family Outcomes Survey (FOS)<sup>1</sup>, the Parent-Child Interaction Questionnaire (PCIQ), the Family-Professional Practices (FPP) scale, and a Family Demographic Survey. Copies of all four instruments can be found in the appendix.

The FOS is a 24-item self-report questionnaire that assesses family functioning on five broad domains: understanding your child’s strengths, needs, and abilities; knowing your rights and advocating for your child; helping your child develop and learn; having support systems; and accessing community resources.

The second measure completed by parents or guardians, the Parent-Child Interaction Questionnaire (PCIQ), was developed by CKF program specialists with a previous research team for this evaluation. The PCIQ asks parents or guardians to rate their experiences of five daily routines (mealtime, getting dressed, leaving the house, bath time, and bedtime) in terms of how enjoyable, stressful and satisfying each was during the past two weeks. The goal of this measure was to assess the stress families felt throughout the day. Parents or guardians are also able to share their thoughts about each activity in an open-ended format.

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<sup>1</sup> The Family Outcomes Survey (FOS) was developed by the Early Childhood Outcomes Center with support from the Office of Special Education Programs, U.S. Department of Education.

Beginning with the Time 2 data collection, another instrument was completed by participating families—the Family-Professional Practices Scale (FPP). This 20-item instrument asks parents or guardians to rate their CKF specialist or, for comparison families, a professional of their choosing who has worked with their child. Rating is done on a five-point scale ranging from “very dissatisfied” to “very satisfied.” The questions on the scale focused on respect, encouragement, and education and support that are provided by the professional to the family.<sup>2</sup>

In addition to the FOS, PCIQ, and FPP, parents or guardians completed the Family Demographic Survey describing their family structure, employment and income, and their child’s diagnosis and receipt of services.

### **Focus Groups**

In mid-April 2013, we conducted six focus groups with parents or legal guardians of children with a developmental disability or delay who lived in rural and urban locations in Missouri. The purpose of these focus groups was to supplement information gathered through the mail survey and to deepen our understanding of families’ experiences with the CKF program and other services. There were three focus groups for families who participated in CKF programs and three comparison focus groups comprised of families who did not participate in the CKF program but received other services. To recruit participants, CKF reached out to all survey respondents. The three comparison communities were strategically chosen to try to closely match the CKF communities in terms of population and available services. In addition, to recruit participants in comparison communities, CKF asked local social service providers to post flyers and inform families on their caseloads about the opportunity. Contact information was then shared with CKF, which sent out initial postcards to potential participants requesting confirmation of their intent to participate or not. Reminder postcards confirming the focus group date, location, and time were also sent. CKF shared the contact information with the Chapin Hall evaluation team, who called each potential participant to confirm the volunteer nature of the study, answer any questions, and again confirm the focus group logistics. Recruitment for CKF participants followed the same procedures described above but other social service agencies were not asked to recruit families. Participants were each given a gift card to thank them for taking the time to participate in the focus groups.

There were 28 focus group participants (eight in the comparison groups; 20 in the CKF groups), all of who identified themselves as the primary care providers for their children, grandchildren, or foster

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<sup>2</sup> The FPP was constructed by The Community Partnership in consultation with Chapin Hall; it consists of 17 items from an instrument called the Family-Centered Practices as well as a few items related to the professional’s relationship with the target child from another measure, the Family-Professional Partnership Scale (Summers et al., 2005). The response scale for the FPP is based on the one used in the Family-Professional Partnership Scale.

children. All but one participant was female. The majority of the participants were caregivers for children between the ages of 0 and 6 years, except for two participants at comparison sites who cared for children ages 7 and 9.

Each of the focus groups lasted approximately 90 minutes. The focus group facilitator used a semi-structured discussion guide that allowed room for new topics to emerge during the group (see Appendix C). All of the focus group discussions were recorded, transcribed, and then coded using a “grounded theory” approach (Glaser & Strauss, 1967; Lincoln & Guba, 1985; Miles & Huberman, 1994; Patton 2002). We examined interview transcripts line by line to look for ideas and themes and developed codes based on the ideas and patterns. Although the interview topics provided an initial guide for analysis, we also looked for other themes and meanings that were not in the original protocol.

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## **Overview of this Report**

In the following chapter, we present quantitative data from survey, collected at three time points. We discuss the survey results over time for families participating in the CKF program as well as other programs, and then for rural families and for urban families. In the next chapter, we provide qualitative information from the families who participated in the focus groups about their service experiences. We end the report with conclusions and recommendations for program practices and further study of the program.

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# Survey Findings over Time

The primary purpose of this exploratory study was to compare parent or guardian functioning and parent-child interactions over time for two groups of families: those who participate in the CKF program and a comparison group of non-CKF families. Thus, in this chapter we focus only on findings for the program and comparison families who completed surveys at all three time points.<sup>3</sup> We also look specifically at the data over time for these families based on their location (urban vs. rural). In Appendix A, we present additional findings from the surveys for all respondents, covering basic demographics as well as the results of the three outcome measures for the full samples at each time point.

Below, we describe the demographic characteristics of the families in the program and comparison groups who responded at all three time points. We then present Time 3 findings from the three outcomes measures—the Family Outcomes Survey, the Parent Child Interaction Questionnaire, and the Family-Professional Practices Scale—for those families who responded at all three time points.

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## Child and Family Characteristics

Parents or guardians completed a Family Demographic Survey describing basic socioeconomic characteristics including family structure, family members' race/ethnicity, family income, and employment status. They were also asked to provide information about the diagnosis and disability status of their child as well as the types of services their child was currently receiving. Table 2 presents baseline characteristics of the sample of children whose parents who completed the survey at all three time points. The responses are broken out by program enrollment. We found that just under two-thirds of the children in the sample were male and most were white. Less than a quarter of the children had a “severe”

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<sup>3</sup> Our sample includes a total of 114 parents who completed surveys at the three time points with regard to the same child. (An additional 14 families completed surveys at all three time points, but completed them on different children in the family. These 14 families have been excluded from the analysis.)



disability. The mean (*sd*) age of the children in the study was 3.1 years (*1.37*). The most prevalent types of disability or diagnosis were language or speech delay and developmental delay.

**Table 2. Baseline Characteristics of Children in the Sample**

Characteristic	All children <i>N</i> = 114	CKF program <i>n</i> = 35	Comparison program <i>n</i> = 79
Age at time of survey, years (mean, <i>sd</i> )	3.1 ( <i>1.40</i> )	3.1 ( <i>1.42</i> )	3.1 ( <i>1.41</i> )
Sex of child (%)			
Male	59	58	60
Female	41	42	40
Race/ethnicity of child (%)			
White	80	83	78
Black	10	9	10
Hispanic	4	6	3
Other	7	3	9
Severity of disability (%) <sup>a*</sup>			
Mild	47	28	54
Moderate	38	45	35
Severe	16	28	11
Type of disability/diagnosis (%)			
Language or speech delays	57	57	57
Developmental delays	47	57	43
Autism	18	11	20
Cognitive mental delay*	16	29	10
Visual impairment*	14	26	9
Cerebral palsy*	13	23	9
Down syndrome	13	17	11
Physical disability***	15	37	5
Hearing impairment	7	9	6
Traumatic brain injury**	8	20	3
Pervasive developmental delay	4	9	1
Spina bifida	1	0	1
Muscular dystrophy	1	0	1
Other genetic disorder	15	17	14
Other health impairment	25	26	24
Number of disabilities (mean, <i>sd</i> )	2.5 ( <i>1.94</i> )	3.4 ( <i>2.46</i> )	2.2 ( <i>1.53</i> )
More than one disability/diagnosis (%)	57	66	53
More than two disabilities/diagnoses (%) <sup>*</sup>	38	54	30

<sup>a</sup> At Time 1, 101 of 114 respondents provided information on severity of disability. Chi square differences statistically significant at \**p* < .05, \*\**p* < .01, and \*\*\**p* < .001.

For most characteristics, the children in each group were fairly similar. Children in both the CKF program and in the comparison programs were about 3 years of age at Time 1. More than half of the children in both programs were male and white. However, the CKF children were significantly more likely to have been diagnosed with a “moderate” or “severe” disability than children in the comparison programs. The

most common diagnoses for both the CKF children and the comparison children were language or speech delays and developmental delays. However, children enrolled in the CKF program were significantly more likely to have diagnoses of cognitive mental delays, visual impairment, cerebral palsy, physical disabilities, and traumatic brain injury than children in the comparison group.

Demographic data about parents or guardians and households, presented in Table 3, indicate that there were a few significant differences between families in the CKF program and families in the comparison group. For example, the two groups had significant differences in the number of primary caregivers who are employed outside the home and in family household income.

**Table 3. Baseline Characteristics of Parent or Guardian and Household**

	<b>All Parents or Guardians N = 114</b>	<b>CKF Program n = 35</b>	<b>Comparison Program n = 79</b>
Location of family residence (%)			
Rural	59	49	63
Urban	41	51	37
Parent aware of child's disability (%)			
Before birth	11	15	9
At birth	29	29	29
Marital status (%)			
Married	83	91	80
Single	12	9	14
Live-in partner	4	0	5
Other	1	0	1
Respondent relationship to child (%)			
Mother	90	86	92
Father	3	3	3
Other	3	6	1
Primary caregiver's education (%)			
Did not complete high school	6	3	8
High school diploma/GED	8	6	9
Some college or technical school	29	26	30
College degree	42	37	44
Graduate degree	15	29	9
Primary caregiver employment			
Employed outside home (%)*	38	20	46
Hours worked per week (mean, <i>sd</i> )	31.0 (12.14)	25.4 (15.13)	31.7 (11.72)
Secondary caregiver employment			
Employed outside home (%)	81	91	76
Hours worked per week (mean, <i>sd</i> )	41.8 (8.66)	43.6 (7.63)	41.0 (9.04)
Household income (%)*			
Less than \$10,000	12	9	13
\$10,000-\$29,999	26	12	32
\$30,000-\$49,999	23	18	25
\$50,000-\$69,999	14	27	9
\$70,000 or more	26	35	22
Household income not adequate (%)	29	28	29
Income meets needs, but not wants (%)	29	14	35
Income meets needs and some wants (%)	42	57	35

Chi square differences statistically significant at \* $p < .05$ , \*\* $p < .01$ , and \*\*\* $p < .001$ .

## Service Use

### CKF Programs versus Comparison Families

Parents or guardians enrolled in the CKF program reported that the most commonly used services at all three time points were occupational therapy, speech therapy, and physical therapy (see Table 4). Over time, we noticed one difference—there was a significant increase in families using special education between Time 1 (20%) and Time 2 (43%). The increase in the use of special education could be due to the child becoming older and entering school. We cannot determine from these data whether the services are accessed directly through the CKF program or from other service providers.

**Table 4. Percent of CKF Families Using Specific Services ( $n = 35$ )**

	Time 1	Time 2	Time 3
Speech therapy	86	86	83
Occupational therapy	83	83	83
Physical therapy	77	69	71
Early Intervention services	43	29	29
Preschool special education	37	49	46
Home visiting	31	23	34
Vision therapy	26	26	17
Prekindergarten	20	23	23
Special education	20	43	37
Developmental therapy	17	23	11
Applied Behavioral Analysis	14	9	11
Day care or child development center	11	11	14
Early Head Start	3	6	3
Head Start	3	0	3

Note: Paired sample  $t$ -tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: `specialeducation1` vs. `specialeducation2`.

The services most used by comparison families were similar to those used by CKF families: speech therapy, occupational therapy, and physical therapy (see Table 5). Over time, there were a number of significant differences between comparison families and CKF families. We found increases in the use of developmental therapy and special education and a decrease in the use of home visiting. The decrease likely reflects the child becoming older and the lack of home visiting programs for children after they turn 3 years old. In addition, we observed somewhat higher percentages of use in most of the service areas among the CKF families than in the comparison families. This may reflect the fact that CKF families have greater needs, but it may also reflect the ability of CKF to link families to more services.

**Table 5. Percent of Comparison Families Using Specific Services (*n* = 79)**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
Speech therapy	71	76	67
Occupational therapy	54	56	49
Physical therapy	39	46	48
Preschool special education	28	25	33
Early Intervention services	24	29	25
Home visiting	24	22	11
Day care or child development center	14	13	9
Special education	14	25	39
Prekindergarten	11	14	22
Applied Behavioral Analysis	6	6	10
Developmental therapy	5	14	11
Early Head Start	5	5	9
Head Start	3	3	4
Vision therapy	5	4	4

Note: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: developmentaltherapy1 vs. developmentaltherapy2; homevisiting1 vs. homevisiting3; specialeducation1 vs. specialeducation2; specialeducation1 vs. specialeducation3; specialeducation2 vs. specialeducation3.

### **CKF versus Comparison Families at Time 3**

We also looked at differences between the CKF and comparison families at Time 3 and found that CKF families were more likely to be using home visiting (34% vs. 11%,  $p < .05$ ), occupational therapy (83% vs. 49%,  $p < .01$ ), physical therapy (71% vs. 48%,  $p < .05$ ), and vision therapy (17% vs. 4%,  $p < .05$ ) than comparison families. While CKF families' more frequent mention of home visiting use is positive, it should be noted that home visiting is an integral component of the CKF program. Therefore, we would expect a high percentage, if not all, of the CKF families to report using home visiting services. However, because the results were obtained from survey data, it is not clear how respondents interpreted the term "home visiting" in this context. Home visiting is commonly used to refer to home-based services delivered on a weekly or biweekly basis during the first 2 years after birth. The pattern of results related to the more frequent use of services by CKF families could be driven by the fact that CKF families report having children with more disabilities or diagnoses than the comparison families. They also suggest that one of the benefits of the CKF program is its ability to link families to needed resources, although we cannot determine from these data whether the services were accessed directly through the CKF program or through other means.

### **Rural versus Urban Families**

Given that prior research has shown that rural and urban populations often have different service needs and access challenges (see DeVoe, Krois, & Stenger, 2009; Hartley, 2004; and Telfair, Haque, Etienne, Tang, & Strasser, 2003), we examined the differences in service use between the two populations. When

we examined just the rural families over the three times of measurement (see Table 6), we found significant increases in the percentage of rural families using Applied Behavioral Analysis between Time 2 (5%) and Time 3 (10%), prekindergarten between Time 1 (5%) and Time 3 (15%), preschool special education between Time 1 (15%) and Time 3 (30%), and special education between Time 2 (12%) and Time 3 (21%). We also noted a significant decrease in the percent of rural families using home visiting between Time 1 (34%) and Time 3 (16%). The significant increase in the percent of rural families using prekindergarten, and special education could be due to the child getting older and entering school.

As shown in Table 7, the only significant difference for urban families noted was in the use of special education between Time 1 and Time 2 and between Time 1 and Time 3. At Time 1, 30 percent of the survey respondents who lived in urban areas reported using special education. At Time 2, however, the percent increased significantly, to 57 percent. By Time 3 it had increased again, to 64 percent. As with prekindergarten, this significant increase in the percent of urban families using special education could be due to child getting older and entering school.

**Table 6. Percent of Rural Families Using Specific Services (*n* = 67)**

	Time 1	Time 2	Time 3
Speech therapy	70	70	60
Occupational therapy	57	52	45
Physical therapy	43	43	45
Early Intervention services	28	31	31
Preschool special education	15	21	30
Special education	6	12	21
Home visiting	34	27	16
Prekindergarten	5	12	15
Applied Behavioral Analysis	6	5	10
Day care or child development center	10	13	10
Developmental therapy	9	16	9
Early Head Start	3	5	6
Head Start	3	3	3
Vision therapy	5	5	3

Note: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: appliedbehavioralanalysis2 vs. appliedbehavioralanalysis3; homevisit1 vs. homevisit3; prekindergarten1 vs. prekindergarten3; preschoolspecialeducation1 vs. preschoolspecialeducation3; specialeducation1 vs. specialeducation3; and specialeducation2 vs. specialeducation3.

**Table 7. Percent of Urban Families Using Specific Services (*n* = 47)**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
Speech therapy	83	92	89
Occupational therapy	72	81	81
Physical therapy	62	66	70
Special education	30	57	64
Preschool special education	53	49	47
Prekindergarten	28	23	32
Home visiting	15	15	21
Early Intervention services	32	26	19
Developmental therapy	9	17	15
Vision therapy	21	19	15
Applied Behavioral Analysis	13	11	11
Day care or child development center	17	11	11
Early Head Start	6	6	9
Head Start	2	0	4

Note: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: *specialeducation1* vs. *specialeducation2*; and *specialeducation1* vs. *specialeducation3*.

### **Rural versus Urban Families at Time 3**

We also looked at differences between urban and rural families at Time 3 and found that urban families were more likely to be receiving most kinds of services, and to a greater degree, than rural families. These included services such as speech therapy (89% vs. 60%,  $p < .01$ ), occupational therapy (81% vs. 45%,  $p < .001$ ), physical therapy (70% vs. 45%,  $p < .01$ ), and vision therapy (15% vs. 3%,  $p < .05$ ), among others. Early Intervention was the only service area that was an exception; rural families reported higher use than urban families (31% of rural families vs. 19% of urban families). Although the findings of greater use of services among urban families are consistent with literature on access to health care and social services among low-income populations referenced above, the reasons for the differences in this particular survey sample are not clear. As we discuss below, findings from the focus groups suggest that families living in rural areas feel more isolated than families in urban areas.

We also looked at the rural population by enrollment in the CKF program versus comparison programs at Time 3. We found just two significant differences in the rural population.<sup>4</sup> A significantly ( $p < .05$ ) greater percentage of rural CKF families (41%) used home visiting than rural comparison families (8%) and more rural CKF families used occupation therapy (71%) than did rural comparison families (36%). Although the following differences were not statistically significant, more rural comparison families

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<sup>4</sup> Tables with these results are available from Chapin Hall upon request.

reported using day care or child development centers than rural CKF families. Rural comparison families also reported using Head Start while none of the rural CKF families reported using Head Start.

We further looked at the urban sample's Time 3 service usage by enrollment in the CKF program and comparison programs. We found just one significant difference ( $p < .05$ ) between urban CKF families and urban families in the comparison group—the use of physical therapy.<sup>5</sup> Over three-quarters (89%) of urban CKF families used physical therapy while 59 percent of urban comparison group families reported using physical therapy. Unlike with the rural sample, we did notice a trend suggesting urban comparison families are more likely than urban CKF families to use services such as Applied Behavioral Analysis, developmental therapy, Early Head Start, prekindergarten, and special education. The differences were not significant, but they were interesting to note. It may be that non-CKF families in urban areas—unlike those in rural areas—need and are able to access these particular services to supplement their child's care whereas CKF families, because of the support of the CKF program, feel less of a need for these services.

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## **Outcome Measures**

Over the course of the evaluation, three measures of outcomes were administered to families. Two measures were administered at all three time points and one, the Family-Professional Practices Scale, was administered only at Time 2 and Time 3. Just as with the Family Demographic Survey, families were provided with hardcopy surveys. They were asked to select the response option that best fit their family for each measure and then return the surveys to The Community Partnership for data entry.

### **Family Outcomes Survey**

The Family Outcome Survey was administered at all three time points. There are 24 items on this scale and each uses a five-point response scale ranging from “not at all comfortable” to “completely comfortable.” The 24 items are then grouped into five outcome subscales. Four of the subscales consist of between four and five items and the fifth subscale is made up of seven items. In Appendix B we provide means and standard deviations for each individual item included in each Family Outcomes Survey subscale.

### **Program versus Comparison Families**

To analyze the Family Outcomes Survey (FOS) responses, we used analysis of variance (ANOVA) to examine differences in mean scores for each outcome subscale over time. We did this first for just the CKF families and then repeated it for just the comparison families. Looking at the five subscales in the Family Outcomes Survey for just the CKF families (see Table 8), we found one statistically significant

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<sup>5</sup> Tables with these results are available from Chapin Hall upon request.

difference on the outcome subscale of “knowing your rights and advocating for your child” between Time 1 and Time 3; the sample’s mean score at Time 3 was significantly higher than at Time 1. All the families had relatively high mean ratings over time on all five subscales. The mean ratings ranged from a low of 4.0 for “knowing rights and advocating for the child” and “having a support system” at Time 1 to a high of 4.4 for “understanding the child’s strengths and needs” at Time 2.

**Table 8. Mean Scores of CKF Families on the Family Outcomes Survey Subscales<sup>a</sup> (n = 34)**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
Understanding child’s strengths and needs (mean, <i>sd</i> )	4.2 (0.60)	4.4 (0.65)	4.2 (0.52)
Knowing rights and advocating for the child (mean, <i>sd</i> )	4.0 (0.68)	4.1 (0.71)	4.1 (0.66)
Helping child develop and learn (mean, <i>sd</i> )	4.3 (0.71)	4.2 (0.75)	4.2 (0.63)
Having support systems (mean, <i>sd</i> )	4.0 (0.77)	4.1 (0.77)	4.1 (0.70)
Accessing community resources (mean, <i>sd</i> )	4.2 (0.76)	4.2 (0.84)	4.3 (0.78)

Notes: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: knowingyourrights1 vs. knowingyourrights3.

<sup>a</sup> Outcomes are multi-item factors representing mean scores ranging from 1 (not at all comfortable) to 5 (completely comfortable). Appendix B shows the individual items by factor.

Next, we restricted our sample to just the comparison families and looked at the five subscales in the Family Outcomes Survey over time (see Table 9). Between Time 1 and Time 3, we found one statistically significant difference on the outcome subscale of “Helping your child learn and develop”; the sample’s mean score at Time 3 was significantly lower than at Time 1. All of the comparison families had relatively high mean ratings over time on all five subscales. The lowest mean rating was 4.0 for “knowing your rights and advocating for the child” at Time 1 and at Time 3 and “having a support system” at Time 2. The highest mean rating was 4.4 for “understanding the child’s strengths and needs” at all three time points as well as “helping your child develop and learn” at Time 1.

**Table 9. Mean Scores of Comparison Families on the Family Outcomes Survey Subscales<sup>a</sup> (n = 79)**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
Understanding child’s strengths and needs (mean, <i>sd</i> )	4.4 (0.53)	4.4 (0.62)	4.4 (0.56)
Knowing rights and advocating for the child (mean, <i>sd</i> )	4.0 (0.81)	4.1 (0.85)	4.0 (0.87)
Helping child develop and learn (mean, <i>sd</i> )	4.4 (0.65)	4.2 (0.66)	4.2 (0.73)
Having support systems (mean, <i>sd</i> )	4.2 (0.75)	4.0 (0.87)	4.2 (0.81)
Accessing community resources (mean, <i>sd</i> )	4.3 (0.66)	4.2 (0.77)	4.3 (0.78)

Note: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: helpingyourchilddevelop1 vs. helpingyourchilddevelop3.

<sup>a</sup> Outcomes are multi-item factors representing mean scores ranging from 1 (not at all comfortable) to 5 (completely comfortable). Appendix B shows the individual items by factor.



Finally, we compared mean ratings for the CKF families and the comparison families at Time 3 for each of the FOS subscales and found no significant differences between the two groups.<sup>6</sup>

### Rural versus Urban Families

We examined whether family outcome patterns differed within the rural and urban subgroups. As shown in Table 10, we found two significant differences for rural families over time. Between Time 1 and Time 2, we found that the mean for the subscale “helping your child develop and learn” decreased somewhat for rural families. Between Time 2 and Time 3, the mean for the subscale “having support systems” increased.

**Table 10. Mean Scores of Rural Families on the Family Outcomes Survey Subscales<sup>a</sup> (*n* = 67)**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
Understanding child’s strengths and needs (mean, <i>sd</i> )	4.3 (0.59)	4.4 (0.65)	4.4 (0.62)
Knowing rights and advocating for the child (mean, <i>sd</i> )	4.1 (0.76)	4.1 (0.84)	4.1 (0.80)
Helping child develop and learn (mean, <i>sd</i> )	4.4 (0.65)	4.3 (0.68)	4.3 (0.68)
Having support systems (mean, <i>sd</i> )	4.1 (0.79)	4.0 (0.89)	4.2 (0.84)
Accessing community resources (mean, <i>sd</i> )	4.2 (0.69)	4.2 (0.75)	4.3 (0.74)

Note: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at *p* < .05 or less: Helpingyourchilddevelopandlearn1 vs. Helpingyourchilddevelopandlearn2; and Havingsupportsystems2 vs. Havingsupportsystems3.

<sup>a</sup> Outcomes are multi-item factors representing mean scores ranging from 1 (not at all comfortable) to 5 (completely comfortable). Appendix B shows the individual items by factor.

We also looked at the Time 3 data for the rural sample of respondents by enrollment in CKF or comparison group programs.<sup>7</sup> Although we found no significant differences, rural families in the CKF program tended to report being more comfortable than rural families in the comparison group for three subscales: knowing rights and advocating for the child, having support systems, and accessing community resources. The one area at Time 3 where the rural comparison group families felt more comfortable than rural CKF families was “understanding their child’s strengths and needs.”

We also examined the feelings of the urban families at all three time points. Our findings are detailed in Table 11. We found no significant differences—the responses to all five subscales were rather stable across the three time points.

<sup>6</sup> We conducted additional analyses to compare individual items that made up the five FOS subscales. In the domain of Having Support Systems, we found two significant differences. CKF families rated this item “I am able to talk with other families who have a child with similar needs” significantly higher than families in the comparison group at Times 2 and 3 (*p* < .05). In contrast, comparison families responded significantly higher than CKF families to this item: “I am able to take care of my own needs and do things I enjoy” at Times 1 and 3 (*p* < .05). (These results are available from Chapin Hall upon request.)

<sup>7</sup> Tables with these results are available from Chapin Hall upon request.

**Table 11. Mean Scores of Urban Families on the Family Outcomes Survey Subscales ( $n = 46$ )**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
Understanding child's strengths and needs (mean, <i>sd</i> )	4.4 (0.50)	4.4 (0.60)	4.4 (0.46)
Knowing rights and advocating for the child (mean, <i>sd</i> )	4.0 (0.79)	4.0 (0.77)	4.0 (0.85)
Helping child develop and learn (mean, <i>sd</i> )	4.2 (0.68)	4.2 (0.70)	4.1 (0.70)
Having support systems (mean, <i>sd</i> )	4.1 (0.71)	4.2 (0.77)	4.1 (0.68)
Accessing community resources (mean, <i>sd</i> )	4.3 (0.69)	4.2 (0.84)	4.2 (0.84)

Note: Paired sample *t*-tests indicate that no time-to-time differences are statistically significant at  $p < .05$  or less.

<sup>a</sup> Outcomes are multi-item factors representing mean scores ranging from 1 (not at all comfortable) to 5 (completely comfortable). Appendix B shows the individual items by factor.

When we examined only the urban families by their enrollment in CKF or comparison group programs, we again found no significant differences. However, there was a tendency for urban CKF families to be less comfortable than their urban comparison group families on all five of the subscales.<sup>8</sup>

### **Parent-Child Interaction Questionnaire**

The Parent-Child Interaction Questionnaire (PCIQ) is a 15-item survey that asks parents or guardians to rate, on a five-point scale, how their child has been over the past two weeks with regard to five activities: mealtime, getting dressed, leaving the house, bath time, and bedtime in an effort to measure stress in this particular population. The tool attempts to measure the variability of enjoyment, stress and satisfaction, experienced by families throughout the day. Each of the five sections also includes an open-ended question that gives the respondent an opportunity to provide more detail.

### **CKF versus Comparison Families**

Our analysis first compared the mean scores over time on the five activities for just CKF families (see Table 12). Overall, CKF parents or guardians rated bath time as the most enjoyable as well as the most satisfying, although they also rated it as the most stressful (along with getting dressed). We found just one significant difference over time: parents reported that bedtime became more stressful between Time 2 (2.6) and Time 3 (2.9).

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<sup>8</sup> Tables with these results are available from Chapin Hall upon request.

**Table 12. Mean Scores of CKF Families on the Parent-Child Interaction Questionnaire ( $n = 34$ )**

	Time 1	Time 2	Time 3
<b>Mealtime (mean, <i>sd</i>)</b>			
Enjoyable	3.5 (0.72)	3.6 (0.83)	3.6 (0.86)
Satisfying	3.5 (0.63)	3.5 (0.88)	3.5 (0.91)
Stressful	2.9 (0.86)	3.0 (1.03)	3.0 (0.73)
<b>Getting dressed (mean, <i>sd</i>)</b>			
Enjoyable	3.6 (0.82)	3.5 (0.93)	3.7 (0.79)
Satisfying	3.5 (0.88)	3.7 (0.85)	3.5 (0.87)
Stressful	2.7 (0.87)	2.4 (0.75)	2.7 (0.92)
<b>Leaving the house (mean, <i>sd</i>)</b>			
Enjoyable	3.5 (0.83)	3.6 (0.75)	3.7 (0.85)
Satisfying	3.5 (0.95)	3.7 (0.78)	3.6 (0.82)
Stressful	3.0 (0.80)	3.0 (0.83)	2.9 (0.84)
<b>Bath time (mean, <i>sd</i>)</b>			
Enjoyable	4.0 (0.75)	4.3 (0.76)	4.1 (0.86)
Satisfying	4.1 (0.70)	4.2 (0.82)	4.0 (0.88)
Stressful	2.5 (0.81)	2.7 (1.10)	2.6 (1.16)
<b>Bedtime (mean, <i>sd</i>)</b>			
Enjoyable	3.5 (0.96)	3.7 (1.05)	3.7 (0.79)
Satisfying	3.8 (1.02)	3.8 (0.99)	3.7 (0.96)
Stressful	2.8 (1.03)	2.6 (0.72)	2.9 (0.84)

Items are rated on the following 5-point scale: 1 = never, 2 = rarely, 3 = sometimes, 4 = very often, and 5 = always.

\*Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: bedtimestressful2 vs. bedtimestressful3.

In the next analysis, we limited our sample to just comparison families who completed surveys at all three time points. We then compared the mean scores over time for the five activities (see Table 13). Overall, comparison group parents or guardians rated bath time and leaving the house as the most enjoyable as well as the most satisfying, while mealtime and bedtime were the most stressful. We found just one significant difference over time: parents reported that bath time became more “enjoyable” between Time 2 (4.1) and Time 3 (4.3).

**Table 13. Mean Scores of Comparison Families on the Parent-Child Interaction Questionnaire ( $n = 79$ )**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
<b>Mealtime (mean, <i>sd</i>)</b>			
Enjoyable	3.8 (0.94)	3.8 (0.77)	3.8 (0.90)
Satisfying	3.7 (0.96)	3.8 (0.89)	3.8 (0.91)
Stressful	2.6 (0.96)	2.6 (0.91)	2.8 (1.08)
<b>Getting dressed (mean, <i>sd</i>)</b>			
Enjoyable	3.9 (1.04)	3.7 (0.90)	3.7 (0.95)
Satisfying	4.0 (1.01)	3.8 (0.86)	3.8 (0.97)
Stressful	2.3 (1.11)	2.4 (1.03)	2.4 (1.03)
<b>Leaving the house (mean, <i>sd</i>)</b>			
Enjoyable	4.0 (0.95)	3.8 (0.85)	3.8 (0.96)
Satisfying	4.0 (0.89)	3.8 (0.88)	3.8 (0.90)
Stressful	2.5 (1.07)	2.6 (1.05)	2.6 (1.16)
<b>Bath time (mean, <i>sd</i>)</b>			
Enjoyable	4.1 (1.10)	4.1 (0.81)	4.3 (0.81)
Satisfying	4.1 (1.04)	4.1 (0.77)	4.2 (0.84)
Stressful	2.2 (1.30)	2.2 (1.01)	2.1 (1.06)
<b>Bedtime (mean, <i>sd</i>)</b>			
Enjoyable	3.5 (1.14)	3.6 (1.02)	3.8 (1.10)
Satisfying	3.7 (1.20)	3.6 (1.06)	3.7 (1.15)
Stressful	2.7 (1.30)	2.7 (1.12)	2.7 (1.21)

Items are rated on the following 5-point scale: 1 = never, 2 = rarely, 3 = sometimes, 4 = very often, and 5 = always.

\*Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: bathtime enjoyable2 vs. bathtimeenjoyable3.

When we compared mean ratings for the CKF families and the comparison families at Time 3 for each of the PCIQ items, we found one significant difference between the two groups. CKF families rated bath time as somewhat more stressful (2.6), on average, than comparison families (2.1,  $p < .05$ ).

### **Rural versus Urban Families**

As we did with the Family Outcomes Survey, we looked at data for rural families only and urban families only (see Table 14). Looking at the rural families only, we found two significant differences over time. First, there was a decrease in enjoyment of mealtime between Time 2 and Time 3. The mean scores for rural families decreased from 3.8 at Time 2 to 3.6 at Time 3. Second, mealtime became more stressful between these two time points. The mean scores rose from 2.6 at Time 2 to 2.9 at Time 3.

**Table 14. Mean Scores of Rural Families on the Parent-Child Interaction Questionnaire ( $n = 67$ )**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
<b>Mealtime (mean, <i>sd</i>)</b>			
Enjoyable	3.7 (0.83)	3.8 (0.75)	3.6 (0.94)
Satisfying	3.7 (0.87)	3.8 (0.86)	3.6 (0.96)
Stressful	2.7 (0.83)	2.6 (0.96)	2.9 (1.07)
<b>Getting dressed (mean, <i>sd</i>)</b>			
Enjoyable	3.8 (1.06)	3.7 (1.01)	3.8 (0.96)
Satisfying	3.8 (1.09)	3.8 (0.92)	3.7 (1.01)
Stressful	2.5 (1.11)	2.4 (0.98)	2.4 (1.01)
<b>Leaving the house (mean, <i>sd</i>)</b>			
Enjoyable	3.8 (0.90)	3.7 (0.89)	3.7 (0.93)
Satisfying	3.9 (0.93)	3.7 (0.82)	3.7 (0.85)
Stressful	2.6 (1.04)	2.7 (0.97)	2.7 (1.07)
<b>Bath time (mean, <i>sd</i>)</b>			
Enjoyable	4.1 (1.09)	4.1 (0.82)	4.2 (0.88)
Satisfying	4.2 (0.94)	4.1 (0.78)	4.2 (0.76)
Stressful	2.3 (1.21)	2.2 (0.95)	2.3 (1.09)
<b>Bedtime (mean, <i>sd</i>)</b>			
Enjoyable	3.5 (1.08)	3.5 (1.08)	3.7 (1.08)
Satisfying	3.6 (1.16)	3.6 (1.05)	3.6 (1.10)
Stressful	2.8 (1.26)	2.7 (1.09)	2.9 (1.17)

Items are rated on the following 5-point scale: 1 = never, 2 = rarely, 3 = sometimes, 4 = very often, and 5 = always.

\*Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less:

MealtimeEnjoyable2 vs. MealtimeEnjoyable3; and MealtimeStressful2 vs. MealtimeStressful3.

Next, we looked at the Time 3 data for only rural families, taking into account whether they were enrolled in CKF or in other comparison group programs.<sup>9</sup> While no significant differences were found, we did notice that CKF families tended to be a bit more critical than families enrolled in comparison group programs in all of the areas on the survey. Rural CKF families found mealtime, bath time and bedtime to be less enjoyable than the rural comparison group program families. Rural CKF families found mealtime, getting dressed, and bath time less satisfying. Additionally, rural CKF families found all five areas to be more stressful than rural comparison group program families.

Table 15 shows our urban sample over time. No significant differences were found, but we did notice that mealtime, leaving the house, bath time, and bedtime all became more enjoyable over time for this sample. However, getting dressed and bedtime became less satisfying over time. With regard to stressfulness, the urban sample found that getting dressed and bedtime became less stressful over time.

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<sup>9</sup> Tables with this data available from Chapin Hall upon request.

**Table 15. Mean Scores of Urban Families on the Parent-Child Interaction Questionnaire ( $n = 46$ )**

	<b>Time 1</b>	<b>Time 2</b>	<b>Time 3</b>
<b>Mealtime (mean, <i>sd</i>)</b>			
Enjoyable	3.7 (0.97)	3.7 (0.85)	3.9 (0.79)
Satisfying	3.7 (0.91)	3.6 (0.94)	3.8 (0.84)
Stressful	2.8 (1.08)	2.9 (0.95)	2.7 (0.86)
<b>Getting dressed (mean, <i>sd</i>)</b>			
Enjoyable	3.9 (0.87)	3.6 (0.72)	3.6 (0.81)
Satisfying	3.8 (0.83)	3.7 (0.75)	3.6 (0.85)
Stressful	2.3 (0.96)	2.5 (0.92)	2.6 (1.00)
<b>Leaving the house (mean, <i>sd</i>)</b>			
Enjoyable	3.8 (0.98)	3.9 (0.73)	3.9 (0.92)
Satisfying	3.8 (0.96)	4.0 (0.87)	3.9 (0.92)
Stressful	2.7 (1.01)	2.8 (1.04)	2.6 (1.11)
<b>Bath time (mean, <i>sd</i>)</b>			
Enjoyable	4.1 (0.90)	4.2 (0.76)	4.2 (0.76)
Satisfying	4.1 (1.00)	4.2 (0.78)	4.1 (0.97)
Stressful	2.2 (1.14)	2.5 (1.18)	2.1 (1.15)
<b>Bedtime (mean, <i>sd</i>)</b>			
Enjoyable	3.6 (1.10)	3.8 (0.92)	3.9 (0.91)
Satisfying	4.0 (1.10)	3.8 (1.03)	3.9 (1.01)
Stressful	2.5 (1.19)	2.6 (0.90)	2.6 (1.02)

Items are rated on the following 5-point scale: 1 = never, 2 = rarely, 3 = sometimes, 4 = very often, and 5 = always.

\*Paired sample *t*-tests indicate that no time-to-time differences were statistically significant at  $p < .05$  or less.

The last analysis that we did for the PCIQ looked at the Time 3 data for the urban sample and took into account their enrollment in the CKF program or in other comparison group programs.<sup>10</sup> We found three significant differences between the urban CKF families and the urban comparison group families at Time 3. Urban CKF families found leaving the house (3.1), bedtime (3.0), and bath time (2.8) to be significantly more stressful ( $p < .05$ ,  $p < .01$ , and  $p < .05$  respectively) than did their urban comparison group program counterparts (2.3, 2.4, and 1.7 respectively).

### **Family-Professional Practices Scale**

At Time 2 and at Time 3, we asked families to complete an additional survey, the Family-Professional Practices Scale (FPP) to better understand the relationship between the family and the professional who helps their child the most. For CKF families, the professional was their CKF specialist. For families enrolled in comparison group programs, they could choose the service professional who knew their child and family best. Families responded to a 20-item questionnaire using a five-point scale ranging from “very dissatisfied” to “very satisfied.”

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<sup>10</sup> Tables with these results are available from Chapin Hall upon request.

## CKF vs. Comparison Families

We first analyzed the responses of those CKF families who responded to the FPP at both time points it was offered (see Table 16).<sup>11</sup> For all 20 items in the scale, all respondents indicated they were “satisfied” (a 4) or “very satisfied” (a 5). The lowest mean scores was 4.7 for the professional “presents options about the different kinds of supports and resources available for achieving what my family considers important” at Time 3. At Time 2, several items received a mean score of 5.0.

**Table 16. Mean Scores of CKF Families on the Family-Professional Practices Scale (*n* = 61)**

	Time 2	Time 3
Treats my children with dignity	5.0 (0.18)	4.9 (0.25)
Works with my family and me in a flexible and responsible manner	5.0 (0.18)	4.9 (0.28)
Builds on my children’s strength	5.0 (0.22)	4.9 (0.28)
Sees my children in a positive and healthy way	5.0 (0.13)	4.9 (0.30)
Is flexible when my family’s situation changes	4.9 (0.32)	4.9 (0.31)
Works together with my family and me based on mutual trust and respect	5.0 (0.22)	4.9 (0.31)
Treats my family with dignity and respect	5.0 (0.13)	4.9 (0.32)
Values my opinion about my children’s needs	5.0 (0.13)	4.9 (0.32)
Really listens to my concerns and requests	4.9 (0.25)	4.9 (0.36)
Does what they promised to do	4.9 (0.25)	4.9 (0.37)
Recognizes the good things I do as a parent	4.9 (0.30)	4.9 (0.37)
Helps me accomplish my goals and priorities for my children	4.9 (0.35)	4.9 (0.39)
Builds on my children’s and family’s strengths and interests as the primary way of supporting my family	4.9 (0.28)	4.9 (0.40)
Understands my children’s and family’s situation	5.0 (0.22)	4.9 (0.44)
Provides information I need to make good choices	4.9 (0.30)	4.8 (0.43)
Helps me learn about things I am interested in	4.8 (0.49)	4.8 (0.45)
Is sensitive to my family’s cultural and ethnic background	4.9 (0.35)	4.8 (0.47)
Supports me when I make a decision	4.8 (0.47)	4.8 (0.48)
Helps me be an active part of getting desired resources and support	4.9 (0.37)	4.8 (0.50)
Presents options about the different kinds of supports and resources available for achieving what my family considers important	4.8 (0.42)	4.7 (0.55)

Items are rated on the following 5-point scale: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither, 4 = satisfied, and 5 = very satisfied.

\*Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: *treatsfamilywithdignity2* vs. *treatsfamilywithdignity3*; *seeschildreninapositive2* vs. *seeschildreninapositive3*; *valuesmyopinion2* vs. *valuesmyopinion3*.

Given the high levels of satisfaction with their relationships with the CKF provider at the first time point (collected at Time 2), we did not expect to see much change in a positive direction at Time 3. We did

<sup>11</sup> This resulted in a larger sample for this measure because it included all parents who responded at Times 2 and 3. It should be noted that we considered using this larger sample for the analyses of responses to the other measures as well in order to increase the sample size. We decided that we would rather look at change over a longer period of time. Initial results of the analyses of the other measures with this larger sample were very similar to those using the smaller sample who responded at all three time points.

observe three significant differences between Time 2 and Time 3 for the CKF families, however. Mean scores at Time 3 were significantly lower for whether the CKF specialist “treats my family with dignity and respect,” “sees my children in a positive and healthy way,” and “values my opinion about my children’s needs.”

We first looked at just the comparison families who responded to the FPP at both time points that it was offered (see Table 17). All of the respondents were at least “satisfied” on all 20 items in the scale. The lowest mean score was 4.3 for “presents options about the different kinds of supports and resources available for achieving what my family considers important” at Time 3. The highest mean score was 4.8 for “treats my family with dignity and respect,” “sees my children in a positive and healthy way,” “treats my children with dignity,” and “builds on my children’s strength,” all at Time 2.

**Table 17. Mean Scores of Comparison Families on the Family-Professional Practices Scale (*n* = 91)**

	<b>Time 2</b>	<b>Time 3</b>
Treats my children with dignity	4.8 (0.71)	4.7 (0.69)
Treats my family with dignity and respect	4.8 (0.59)	4.7 (0.70)
Works with my family and me in a flexible and responsible manner	4.7 (0.72)	4.7 (0.72)
Sees my children in a positive and healthy way	4.8 (0.61)	4.7 (0.73)
Is sensitive to my family’s cultural and ethnic background	4.7 (0.71)	4.7 (0.77)
Builds on my children’s strength	4.8 (0.61)	4.7 (0.77)
Values my opinion about my children’s needs	4.7 (0.76)	4.7 (0.77)
Really listens to my concerns and requests	4.6 (0.74)	4.6 (0.71)
Understands my children’s and family’s situation	4.7 (0.76)	4.6 (0.74)
Works together with my family and me based on mutual trust and respect	4.7 (0.70)	4.6 (0.74)
Recognizes the good things I do as a parent	4.7 (0.70)	4.6 (0.74)
Helps me accomplish my goals and priorities for my children	4.6 (0.73)	4.6 (0.75)
Provides information I need to make good choices	4.7 (0.74)	4.6 (0.76)
Supports me when I make a decision	4.6 (0.81)	4.6 (0.76)
Does what they promised to do	4.7 (0.78)	4.6 (0.79)
Builds on my children’s and family’s strengths and interests as the primary way of supporting my family	4.6 (0.85)	4.5 (0.82)
Helps me be an active part of getting desired resources and support	4.5 (0.81)	4.5 (0.84)
Is flexible when my family’s situation changes	4.7 (0.62)	4.5 (0.84)
Helps me learn about things I am interested in	4.4 (0.91)	4.4 (0.87)
Presents options about the different kinds of supports and resources available for achieving what my family considers important	4.5 (0.82)	4.3 (0.94)

Items are rated on the following 5-point scale: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither, 4 = satisfied, and 5 = very satisfied.

\*Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: isflexible2 vs. isflexible3.



We found just one significant difference for the comparison group families over time. We found that the mean score at Time 3 (4.5) was significantly lower than at Time 2 (4.7) for the item service professional “is flexible when my family’s situation changes.”

We also compared Time 3 data for CKF families and comparison families. Although both groups of families viewed their specialist or professional positively, CKF families rated their relationships with their CKF specialist significantly higher than families in the comparison group on 19 of the 20 items included in the FPP scale. For example, comparison families gave the item “presents options about the different kinds of supports and resources available for achieving what my family considers important” a mean rating of 4.3 whereas CKF families gave this item an average rating of 4.7 ( $p < .01$ ). The one item that was not significantly different between CKF families and control families was “is sensitive to my family’s cultural and ethnic background,” which CKF families rated 4.8 and control families rated 4.7.

### **Rural versus Urban Families**

When we looked only at the rural families over time, we found no significant differences (see Table 18). We did notice most of the respondents were slightly less satisfied with their specialists at Time 3 than they were at Time 2. Nevertheless, the responses to all 20 survey items at both time points were within the range of “very satisfied.” The lowest score was 4.5 for “presents options about the different kinds of supports and resources available for achieving what my family considers important” at Time 3.

**Table 18. Mean Scores of Rural Families on the Family-Professional Practices Scale (*n* = 93)**

	<b>Time 2</b>	<b>Time 3</b>
Treats my children with dignity	4.9 (0.61)	4.8 (0.64)
Sees my children in a positive and healthy way	4.9 (0.56)	4.8 (0.65)
Works with my family and me in a flexible and responsible manner	4.8 (0.60)	4.8 (0.65)
Treats my family with dignity and respect	4.9 (0.52)	4.8 (0.66)
Understands my children's and family's situation	4.8 (0.67)	4.8 (0.66)
Really listens to my concerns and requests	4.8 (0.68)	4.8 (0.67)
Works together with my family and me based on mutual trust and respect	4.8 (0.61)	4.8 (0.68)
Recognizes the good things I do as a parent	4.8 (0.65)	4.8 (0.68)
Builds on my children's strength	4.9 (0.57)	4.8 (0.71)
Helps me accomplish my goals and priorities for my children	4.7 (0.67)	4.7 (0.69)
Supports me when I make a decision	4.7 (0.75)	4.7 (0.69)
Provides information I need to make good choices	4.8 (0.68)	4.7 (0.70)
Is sensitive to my family's cultural and ethnic background	4.8 (0.64)	4.7 (0.72)
Helps me be an active part of getting desired resources and support	4.7 (0.70)	4.7 (0.73)
Is flexible when my family's situation changes	4.8 (0.58)	4.7 (0.73)
Builds on my children's and family's strengths and interests as the primary way of supporting my family	4.7 (0.73)	4.7 (0.73)
Values my opinion about my children's needs	4.8 (0.65)	4.7 (0.74)
Does what they promised to do	4.8 (0.67)	4.7 (0.76)
Helps me learn about things I am interested in	4.6 (0.83)	4.6 (0.80)
Presents options about the different kinds of supports and resources available for achieving what my family considers important	4.7 (0.75)	4.5 (0.87)

Items are rated on the following 5-point scale: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither, 4 = satisfied, and 5 = very satisfied.

\*Paired sample *t*-tests indicate that none of the time-to-time differences are statistically significant at  $p < .05$  or less.

Next, we looked at the Time 3 data for only the rural subsample, taking into account whether they were enrolled in the CKF program or in other comparison group programs.<sup>12</sup> As with the enrollment of the combined sample, we found that for the rural sample, the CKF-enrolled families were more satisfied overall with their specialists than the families enrolled in other comparison group programs.

We repeated the analysis for urban residents only (see

<sup>12</sup> Tables with these results are available from Chapin Hall upon request.

Table 19). We found a few significant differences. The Time 3 mean scores were significantly lower than the Time 2 mean scores on the following items: “sees my children in a positive and healthy way,” “is flexible when my family’s situation changes,” and “builds on my children’s strength.” However, all of the scores were in the “satisfied” range. The lowest score was 4.4 for “presents options about the different kinds of supports and resources available for achieving what my family considers important” at Time 3.

We then analyzed the Time 3 data for the urban subsample and looked for differences based on whether respondents were enrolled in the CKF program or comparison programs.<sup>13</sup> As with the rural subsample, the overall responses from the urban subsample were rather positive. The highest mean score was a 4.9 (very satisfied) for “is flexible when my family’s situation changes” and “treats my children with dignity.” Both of these scores were for CKF families. The lowest mean score was a 4.3 (satisfied) on “presents options about the different kinds of supports and resources available for achieving what my family considers important” and “helps me learn about things I am interested in.” Both of these scores were from comparison group families.

We noted that, on average, the urban CKF families were slightly more satisfied than the urban comparison group families on all 20 items. For two items, the urban CKF families were significantly more satisfied than the urban comparison group families. For the item “works with my family and me in a flexible and responsible manner,” urban CKF families scored a mean of 4.8 while the urban comparison group scored 4.6. For the item “is flexible when my family’s situation changes,” urban CKF families scored a mean of 4.9, and the urban comparison group families scored 4.4, indicating the urban CKF families were significantly more satisfied.

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<sup>13</sup> Tables with these results are available from Chapin Hall upon request.

**Table 19. Mean Scores of Urban Families on the Family-Professional Practices Scale (*n* = 59)**

	<b>Time 2</b>	<b>Time 3</b>
Treats my children with dignity	4.8 (0.50)	4.8 (0.43)
Treats my family with dignity and respect	4.9 (0.40)	4.8 (0.44)
Values my opinion about my children's needs	4.8 (0.54)	4.7 (0.44)
Really listens to my concerns and requests	4.7 (0.49)	4.7 (0.47)
Builds on my children's strength	4.9 (0.35)	4.7 (0.49)
Works with my family and me in a flexible and responsible manner	4.7 (0.57)	4.7 (0.50)
Does what they promised to do	4.8 (0.57)	4.7 (0.51)
Works together with my family and me based on mutual trust and respect	4.7 (0.52)	4.7 (0.51)
Sees my children in a positive and healthy way	4.9 (0.36)	4.7 (0.52)
Recognizes the good things I do as a parent	4.8 (0.47)	4.7 (0.55)
Is sensitive to my family's cultural and ethnic background	4.8 (0.54)	4.7 (0.57)
Provides information I need to make good choices	4.7 (0.49)	4.6 (0.59)
Helps me accomplish my goals and priorities for my children	4.7 (0.54)	4.6 (0.59)
Understands my children's and family's situation	4.8 (0.54)	4.6 (0.62)
Is flexible when my family's situation changes	4.8 (0.44)	4.6 (0.68)
Supports me when I make a decision	4.6 (0.62)	4.5 (0.63)
Builds on my children's and family's strengths and interests as the primary way of supporting my family	4.7 (0.66)	4.5 (0.66)
Helps me be an active part of getting desired resources and support	4.6 (0.66)	4.5 (0.73)
Helps me learn about things I am interested in	4.5 (0.73)	4.4 (0.70)
Presents options about the different kinds of supports and resources available for achieving what my family considers important	4.6 (0.64)	4.4 (0.77)

Items are rated on the following 5-point scale: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither, 4 = satisfied, and 5 = very satisfied.

\*Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: seesmychildreninapositiveandhealthyway2 vs. seesmychildreninapositiveandhealthyway3; isflexible2 vs. isflexible3; and buildsonmychildrensstrengths2 vs. buildsonmychildrensstrengths3.

## Summary of Findings

The survey data we collected provided us with a fuller picture of demographic information and outcome measures for the families participating in the CKF program as well as the comparison families. While we found some significant differences when looking at the data, we primarily noticed similarities across the board. All of the families made sure that their child received the services they needed to succeed; the families worked hard to advocate for their child and their child's development; they enjoyed the time they spent with their children; and they appreciated the efforts made by the professionals in their lives and their children's lives.

The children receiving services from both CKF and comparison programs at the Time 1 survey were rather similar; they were about 3 years of age and more likely to be male and white. CKF children, however, were significantly more likely to have a moderate or severe disability and significantly more

likely to have more than two disabilities. Children in both the CKF and comparison programs were most often diagnosed with language or speech delays or developmental delays. However, CKF children were significantly more likely to have been diagnosed with cognitive mental delay, visual impairment, cerebral palsy, a physical disability, a traumatic brain injury, or a combination of these than the children in the comparison group.

The parents or guardians in the CKF and comparison group were similar in some respects. For instance, they were more likely to be married and have at least some education beyond high school. However, in CKF families, the primary caregiver was less likely to work outside the home than in comparison families. This might be due, in part, to the CKF children having greater needs than the comparison children. On the other hand, in comparison families, the secondary caregiver was less likely to be working at the time of the study and comparison families also had a significantly lower household income than CKF families.

The first outcome measure we looked at was the Family Outcomes Survey. All families scored very high on the survey's five subscales, always in the "almost comfortable" to "completely comfortable" range. Looking over time, CKF families, comparison families, rural families and urban families all scored very high on the subscale of "understanding your child's strengths and needs." They tended to rank "knowing your rights and advocating for your child" and "having a support system" a bit lower, in the "almost comfortable" range but not below it.

Next, we looked at the Parent-Child Interaction Questionnaire. Again, on all of the routine activities addressed in this outcome measure—mealtime, getting dressed, leaving the house, bath time and bedtime, all families followed the same trend with all families scoring between "sometimes" and "very often" with regard to these activities being enjoyable and satisfying. On average, all families, regardless of the program they were enrolled in or the area they lived in, responded that these routines were "rarely" to "sometimes" stressful.

The final outcome measure we looked at, the Family-Professional Practices scale, assessed families' relationship with the CKF specialist or other professional who provided therapeutic services to their child and family. Again, we found high levels of satisfaction among both the CKF and the comparison families. Scores on all 20 items were in the "satisfied" to "very satisfied range." However, it is noteworthy that at Time 3, the CKF families rated their relationships with their CKF specialist significantly higher on all but one of the 20 items on the FPP scale. In the next chapter, we present findings from focus groups that further elaborate on the relationships between families and their specialists or professionals.

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# Focus Group Findings

To supplement the findings from the quantitative surveys and deepen our knowledge of the service experiences of families of children with special needs, we facilitated six focus groups. Three groups were conducted with families who participated in CKF programs and three were conducted with families who received other services. Of the 28 parents or guardians who participated in the focus group, 20 parents were receiving CKF services and eight parents were receiving other services. All of the children in the program represented at the focus groups were between the ages of 0 and 6, except for two children in the comparison group who were 7 and 9 years of age. The participants described varying degrees of medical complexity, developmental disability, or delay in their children participating in the programs. Samples of diagnoses include: autism, pervasive developmental delay, Cri Du Chat, cleft palate, Down syndrome, low muscle tone, various chromosome deletions, effects of Shaken baby syndrome, and others.

The goal of the focus groups was to learn directly from the experts—the family members—about their experiences with their children, including, for example: how they learn about services to help care for their children, how they engage with those services, what services are working well, what could be improved, and whether they have unmet needs. We took a holistic approach to the focus groups. In addition to the type of service-oriented questions described above, the semistructured interview guide (see Appendix C) also included queries about social-emotional supports and challenges, and provided opportunities for new topics to emerge. In the analysis, data were coded to reflect new themes as well as predetermined topics. It is through this holistic lens that we present our findings.

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## Support

The issue of support was an overarching theme throughout all of the focus groups. What was meant by “support” varied greatly depending on the context of the discussion. However, given that support, or a lack thereof, emerged in nearly every aspect of the discussions in one form or another, it follows that the findings in this report discuss the issue. Thus, each of the following subsections looks at the various

elements or components of service use with respect to how it does or does not support families using them. Those elements include:

- Service identification: How families become aware of available services
- Service enrollment: How families enroll in available services
- Engagement: How families are engaged with their enrolled services
- Service coordination: The extent to which services used by families are working in concert
- Identifying resources and advocacy: How families advocate on behalf of themselves and their families
- Social-emotional support

## **Service Identification**

### **Awareness of Services**

At the start of the focus groups, participants were asked how they first learned about services to assist in the care and development of their children. Not surprisingly, responses differed depending on when families became aware of their children's special needs, the level of involvement of their children, and when certain services became available in their communities. In Missouri, the First Steps program,<sup>14</sup> which provides services to families with children up to 3 years old, was the first point of entry for the majority of focus group participants. In many instances parents learned about First Steps from hospital staff at the time of their baby's birth. Other families with children whose issues were not present at birth learned about available services through a variety of means.

Seventeen of the CKF focus group participants (85%) reported learning about CKF through First Steps, or a First Steps treatment provider. Following are some of the participants' comments.

[The] hospital sent someone to the home for a one-year-old check-up for [Name] and noticed some delays. That's how we got connected to First Steps, PAT [Parents as Teachers], and Incredible Brain.

First Steps was the first people that I got in contact with. They set [Name] up with occupational therapy, physical therapy, and speech therapy. We had a special instructor that came out once a week also. And then, they also introduced us to PAT and Capable Kids.

Of the remaining 3 CKF participants, two had direct knowledge of the program and one was referred to the program by her respite provider. In multiple focus groups, word of mouth was frequently mentioned as a vital method for parents to learn about services.

We did not have First Steps. We learned about PAT through word of mouth.

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<sup>14</sup> Within this report, references to First Steps may also include First Steps-referred providers, such as occupational, speech, or physical therapists.

We learned about First Steps from PAT, which we had heard about from people we know.

The third participant shared that she was not aware PAT was available in her county until she participated in the focus group for this evaluation.

Some focus group participants expressed dismay that not all medical providers were aware of First Steps and other services in their local communities.

In all honesty, not all the pediatricians are aware of First Steps. Ours was familiar with it, but we have a friend whose pediatrician did not suggest it, and she knew nothing about it. Then she was talking to me, and I told her about it. She contacted them and qualified, and it saved them a world of headaches through therapies and such like that.

### **Service Enrollment**

However, being aware of services does not necessarily mean a family can enroll in those services. One focus group participant came to this country when her child was 2 years old. Due to the child's lack of communication skills, his preschool teachers suspected the child had autism and suggested that the mother contact TouchPoint Autism Services for an evaluation. TouchPoint did diagnose the child as having autism. However, as the mother explained, the child did not have a social security card and he was unable to qualify for their services. A doctor referred the mother to a neurology specialist who confirmed the diagnosis and suggested the mother contact the school district for services.

Other barriers to service enrollment include income requirements, the child not being "delayed enough," or not having the necessary diagnosis. In the following scenario, a mother describes her trials trying to access appropriate services for her daughter who was suspected as having autism.

First, First Steps had to evaluate her to see if she qualified or not. At that point, only her language was delayed. So we had speech therapy come to the home once a week. We were concerned about autism and drove over 2 and a half hours to the Center [Thompson Center for Autism and Neurodevelopmental Disorders]. They think that maybe she had autism at that point, but she was still too young so you cannot say whether this is autism or not. When we got back, First Steps said we couldn't get services for autism because she *didn't score low enough*; she still only qualified for speech. Only when the [First Steps-referred] speech therapist requested that an OT provider observe a speech session because [Name] couldn't communicate, could we get a referral. Because of that, she got Floor Time through First Steps. We had two different people who would each come twice a week for two hours. But, she could only have that for six months because then she turned 3. (Emphasis added)

Another participant shared that First Steps suggested a particular resource to help her family learn coping strategies pertaining to her child's developmental and behavioral issues. She was excited to learn that



there were family and individual opportunities, but then found out that her family did not qualify for the services. Still another parent spoke about being denied services because of income guidelines.

These services shouldn't be income guideline related. They should be offered to anybody who's struggling or has a developmental issue. Now, if they're able to pay, fine pay, but do it on a sliding scale. Kind of like the Ronald McDonald House. If you're able to pay you're supposed to pay for those rooms, but if you can't pay there's a scholarship available. You don't have to stress out about it. I feel like I've lost a lot that could have gotten us to where we are now, quicker, or better because I didn't qualify for stuff.

Participants also spoke about how the lack of an "official diagnosis" can impede their children from accessing services. To illustrate the commonality of the issue, in one focus group of nine participants, four had children with unnamed diagnoses. In a system that often seems compartmentalized by issue, not having a diagnosis can restrict access and limit support. These barriers add pressure to families and tear at the supports they already have in place. In contrast, having a personal connection with the referral source builds up those supports and empowers families.

[Name redacted] Hospital had a program when the baby was born. They sent some nurse into our home, because we are first-time parents. We had no idea how to take care of the baby. That lady was too incredible. She knows everything. She introduced us to Incredible Brain. She introduced us to Parents as Teachers. She introduced anything she can find, just for the benefit of us.

Note the level of support the parent conveyed in the previous quotation: "She introduced anything she can find, just for the benefit of us." That personal touch and connection is what transforms service identification into a supportive element. It is largely how CKF participants described the way they learned of services through CKF.

Probably about three and a half weeks in with First Steps I learned about Capable Kids and made contact. Once we got involved with Capable Kids and the Learning Center it has just expanded our knowledge base and being able to have that networking capability. So honestly, I think if Capable Kids would have been there from the get-go that would have been our primary resource.

Another point made by CKF participants was the availability of service based on a family's need, not based on a specific diagnosis or assessment score.

That's one of the things I love about Capable Kids. They're willing to help. You don't have to have a diagnosis. So many other services they're like, "Send me your diagnosis. Send me the doctor's diagnosis." That's what's so amazing about them.

I want to compliment that no matter the level of disability, they treat you all the same. Does that make sense? Because there are so many more kids out there a million times more disabled than my little

[Name]. They treat us like, “We’ll give you anything you need.” I mean it’s not like, “Well, she’s getting better so she can’t have this or that anymore.”

### **Services for Older Children**

While families can remain with CKF past age 3, other services, such as First Steps and some Parents as Teachers programs, end when a child turns 3 years old. CKF families indicated that continuing to receive CKF services gives them a supportive connection, as described by two focus group participants.

We graduated out of First Steps when he was 3, he’s 5 now. If it wasn’t for Capable Kids, I don’t know where else I would have gone as far as services and support. In First Steps they tell you, “Oh after First Steps you go to [regional service provider name redacted] and they set you up with a case manager.” I’ve yet to get anything from them, any services, or any follow-ups. I have to even fight to get my yearly review which is mandatory for them to do.

It’s a big transition from the First Steps world out because with First Steps you’ve got people in your home every week or however often you have it. You have a service coordinator, who can help you with a lot of things, and then at 3 you transition and you don’t have that kind of person in the school district. There isn’t some sort of case manager who’s helping you with all of these things.

While support remains intact for CKF families, in terms of having a resource and connection to help identify appropriate care opportunities, many families without access to CKF reported a loss of support when their children turned 3. Of the eight non-CKF focus group participants, seven had children in the program who were 3 or more years old. Parents in one of the focus groups discussed their First Steps “hard stop” dates with each other. One parent shared that First Steps always stops the day before the third birthday, and another parent indicated that her First Steps services ended a month before her child’s third birthday. Service interruptions based on the calendar add to the pressure facing families. This is as illustrated by the earlier story of the child who could only receive Floor Time through First Steps for 6 months, and also by the comments below.

After First Steps ended we would have loved to have continued physical therapy with the therapists that she had been with the whole time, but our private insurance wouldn’t cover it and it was just too much. We couldn’t [afford it]. Especially at the frequency we were doing it, there was no way that we could have done it twice a month.

She’d almost met her targets. We had difficulty affording continuing some sort of therapy after First Steps stopped.

Other participants expressed their disappointment with some of the county services that are supposed to be provided when First Steps services end.

You can contact Development Services for [geographic area], but it takes them a while to get back with you because they have so many clients at the same time.

Development Services for [geographic area] just do an annual checkup and IEPs from the kids in preschool going into kindergarten all the way up to fifth grade.

Focus group participants articulated their feeling that, at age 3, therapies and services should fall under the realm of “school-age therapy.” Three of the four participants in one of the comparison groups reported that they were quite pleased with the transition from PAT to the early childhood school opportunity (for ages 3 to 5) in their community.<sup>15</sup> Children in that community are assessed by the PAT program to determine their eligibility for the school-based program,<sup>16</sup> as described by one respondent.

PAT recommended that he go to [school name redacted] so they tested his behavior and his speech. They came together and talked to the PAT director and the [School] teachers. Then they pulled me into the meeting and told me this would be beneficial for him and the right road for him to go on.

The children who attended the school and were represented in this focus group were in a class with eleven students, one teacher, and three aides. The children were pulled out of class for their occupational and physical therapies. However, not all school options fit the families’ needs, as one focus group participant in a different geographic area explained.

My son should be on an IEP, but we rejected all of the services by the [Name] Public Schools for eight very good reasons, so my communication with the therapist is very limited. My son is definitely not getting near what he did when he was in First Steps, but I still feel like the quality is so much better and I’m so much more comfortable with him continuing to get what he does get here [a day care program where he gets pulled out for therapy].

## **Engagement**

How service providers engage children in the program and their families has a direct impact on how families view the service in terms of being supportive. So much of the work necessary to achieve positive outcomes is relationship-based. By relationship-based, we mean the extent to which service providers take into consideration the entirety of a family’s situation versus focusing on just one component (e.g., the child’s delay or disability). Among the questions service providers should consider: Are there feelings of support and trust with the service providers? How does that translate into progress for the families? Are parents or guardians actively included in developing treatment plans and goals? Are parents or guardians given the opportunities and tools to continue therapeutic work in their daily lives outside of the presence of a treatment provider? In this section, focus group participants share their thoughts about the services once they have been enrolled and are engaged with service providers.

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<sup>15</sup> Students can continue within this school-based program through high school, but for the purposes of our discussion we only talked about the program through prekindergarten.

<sup>16</sup> It should be noted that the PAT director in this community is also the director of early childhood education for this particular school program.

## **Non-CKF Home- and Center-Based Services**

A great majority of the focus group participants received a home-based service at some point. First Steps services are dependent upon assessment scores and diagnoses. Consequently, there is not a standard service “dose” among recipients of First Step services. This may be a factor in the wide range of opinions about First Steps-related services.

Some participants conveyed that they looked to their First Steps providers as instructors for their child’s development and care.

For me as a foster parent and not having been a parent before, when they first said that [Name] needed therapy, her hands were clenched all the time; I thought, “Well, I didn’t even know that that was an issue.” I didn’t know that I should have been watching out for that. So, for me, to work with a therapist who can point out she’s got stiffness here and show me some things that to do to help with that. They gave me ideas and things to work with that I could do with her at home.

We started receiving First Step services to kind of teach me. They taught me how to work with her, what milestones we wanted to meet on which months, because we already were at three, almost four months old, and we were behind. We hadn’t even taught her what she was supposed to do in her first month let alone the second month or third month.

However, a common theme discussed in the focus groups was the perception that “luck of the draw” played a significant factor in the quality of experiences families had with First Steps and First Steps-referred services.

We’ve had pluses and minuses with First Steps. Now we have a good [First Steps provider] and I love her, but you know I find that they’re not [consistent]. It depends on who you have.

I have two really good people in my First Steps team and then two that I hardly ever get anything from.

It depends on the therapist you get with First Steps. For example, First Steps basically said, “Oh, she’s caught up with all her milestones; she’s fine.” Well, the hospital knows better and they tell me she has really low muscle tone and we really need to work on this, this, and this. So the person I had for First Steps physical therapy, I did not have much confidence in them. Great person, loved them to death, but not very competent when it came to challenging my kid. Honestly, the only reason I put up with First Steps is because it was free.

As with First Steps, focus group participants reported having varied experiences with other programs across the state. For example, the following three respondents had very different views of the Parents as Teachers program.

When his Parents and Teacher lady would come in, she was amazing with [giving us suggestions]. She would tell you, “Okay, whenever I’m not here, try working on this” and then as long as you followed that, he would progress.

We didn't have any [PAT] home visits because of scheduling issues, but she saw [Name] at school.

We opted out of PAT because our city school district is not great and I was not happy whatsoever with our Parents as Teachers program.

One aspect of in-home services that several non-CKF participants said they would like to see improved is the incorporation of siblings into the services for their child receiving services. Families with more than one child said that their children not receiving services often feel left out and envious of the attention their siblings receive; thus, they would like opportunities for their children to learn from each other.

Even though my kids are older, they still felt left out. They feel like [Name] gets more attention than they do. My middle son is 3 years older than [Name]. I’d like to see them incorporate him into the play so he would help her learn. It’s hard for them to interact together.

[Even though] my son is younger, he has more ability to do what my daughter cannot do. He speaks more words than my daughter. And if they can play together, I think they can learn from each other.

We get respite services, but we can’t leave my son with them because services are only for [Name]. And every time my son sees [his sister] going with [service provider] he is so sad that he is left out.

Participants in each of the three comparison groups also provided insight into the services they received for their children who were over 3 years old. In the community described earlier, in which several children attended the same early childhood school program, respondents shared many favorable comments about the school program and the people running it. All of the respondents with a child who had attended the school talked about the staff’s commitment to their children,<sup>17</sup> with one participant remarking, “The [school name redacted] is awesome. It’s the people running it.” The majority of the parents in that focus group seemed to view the school as their primary means of support. To facilitate communication about their children, the teachers and parents send a notebook back and forth between home and school. The notebook is used to record what happened at school each day. One parent noted that while the notebook is beneficial, the school does not make recommendations for how parents can work with their children at home and she would like such information to be included going forward. Communication that informs, recommends, and includes parents as equal partners bolsters the feelings of connectedness between parents or guardians and service providers and strengthens the web of support for the families.

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<sup>17</sup> Of the four people in attendance at this focus group, three had children currently enrolled at the school and one had a child who had attended until age 5. Three of the four participants seemed to have no reservations about the school.

The opposite is also true. A lack of communication or involvement from service providers weakens the web of support. For example, the participant whose child no longer attended the aforementioned school compared the connectedness she had while at that school with the current support she receives through the state-run school her child currently attends.

[Ever since we changed schools], her therapists can't come to IEP or any other meetings. I guess they don't pay the therapists to come so they can't come to the IEP. It'd be nice if they were at the meetings.

Another parent expressed her concern that while the staff cares for and is committed to her son, she worries that they do not push him to reach his potential.

I'm just worried that they're not pushing him to walk and they're not showing him what he can be. I see him in the stroller all the time. That's what I'm scared of. I've seen him sitting on the floor and the kids are all petting him like a baby and I'm like, I don't want my son to be treated like that.

This scenario illustrates the need not just for service providers to treat parents or guardians as equal partners, but for parents to treat themselves as equal partners and open up the lines of communication with service providers.

Participants in the two other comparison groups also described their experiences with their children's schooling. It is noteworthy that prior to the focus group for this evaluation, one of the two participants attending was under the impression that any preschool services for 3-year-olds would have to be paid for privately. Consequently, after her child aged out of First Steps, she had a year-long gap before transitioning into a preschool with services at age 4. Once at the preschool there was an IEP meeting with the school's speech therapist, preschool teacher, and the parent. The mother reported that the teacher checks in with her from time to time about goals for her daughter.

The second participant in this community represented a child with extremely complex medical issues. The family receives 94 hours of weekly in-home nursing care, down from 114 hours when the child first came home from the hospital. When asked what the family learned from the home nursing staff that would help her child reach her goals, the mother responded, "Nothing really. It's more like respite care. She comes to the home so I can work and sleep, but she can't provide transportation or watch the other children." While the home nursing care clearly provides a support for the family, the mother does not express that she views the home nursing care as part of her supportive system. As far as her daughter's schooling, the parent shared that after aging out of First Steps, she was enrolled in the early childhood program at their local preschool. However, because of her daughter's compromised immune system, she was only able to attend for 2 weeks. When it came time to enroll her daughter into kindergarten, the mother reported that she "fought" with the school district about setting up home schooling. Her daughter missed almost a

month of kindergarten because of the issue with the school district. For the past 2 years, the school has provided an hour and a half of home instruction two days a week. Now, as her daughter approaches the end of the first grade curriculum, she lags behind her peers in the core subjects. However, unless she is one to two grade levels behind her peers, she is not eligible for additional school services. The mother lumped her daughter's school and health situations together saying, "We can see our kids. We try to be proactive. We can see our kids starting to slip, but until they fall clear down to the bottom, there's nothing that can be done to help us."

In the last comparison group community, only one of the participants had a child over the age of 3. The school in which he is enrolled has a special education classroom in which he spends approximately 70 percent of his time. The special education students and the standard education students spend the remaining 30 percent of their time together. The mother reported that, like the school in the first community described above, she and the school share a notebook to communicate about daily issues. However, unlike the first school in which the information flows from the school to the home, this mother described a process in which the school and the parent both share information. For example, the mother uses the notebook to communicate if her son had a bad night. The teachers then take that information and change his schedule accordingly to optimize his learning environment. Such collaborative measures yield mutual understanding and bolster a family's support system.

### **Capable Kids and Families**

Participants in all three of the CKF focus groups enthusiastically described the program as supportive, family focused, and committed to helping them help their children learn and grow. The participants' descriptions about what it was like to be engaged with CKF tended to be more uniform than the comparison groups' descriptions of the services they received. This could be in response to the consistency of the services provided as part of the CKF program: home visitation, playgroups, and the therapeutic equipment/material-lending program. This section focuses on the home visiting component and the resulting support for engaged families.

Home visiting is considered the primary service delivery model for the CKF program. According to the CKF program manual, the goal of CKF home visiting is to establish a relationship with a family in order to identify needs, provide resources to help parents or guardians impact their child's development, and reduce the isolation many families experience. CKF recognizes that "parent development occurs through and within the parents' relationship with their home visits." Participants reported that home visits generally occur on a monthly basis for about an hour, although a number of people noted that additional

home visits are available upon request.<sup>18</sup> Participants also pointed out that they saw the CKF staff as “always approachable” and people on whom they could call at any time.

Home visits are once a month for an hour, but you can request more. They spend time getting to know the child and what they’re working on in therapies, and they check in with us. Then the rest of the time it’s just discussing [what is going on]. A lot of times it’s us venting. We vent and they give us resources about what can help. And of course they bring new tools or toys because they also provide therapeutic tools which we use a lot.

Well first of all like everybody’s saying, they have that nurturing, caring, genuine compassion for your child, you, and your family. They have awesome equipment that helps your child reach his or her goals. They are approachable if you have concerns. They are accessible in many different ways, you can text, call, or you can go in, or whatever.

Even though both kids are in school now, [CKF family specialist] still comes out once a month and sees us. She still brings things that the school can utilize to help with [Name].

One parent described a typical home visit and then her shock and appreciation when she realized the lengths to which CKF would go on her family’s behalf.

[CKF family specialist] would come in the house and sit down. And it was *my* time. She wanted to hear me vent. She was very compassionate about hearing my frustrations. At one point I was looking for a place for a heated pool because I knew that I wanted [Name] to have aqua therapy. So she was like, “Oh okay. You want that? Okay, I’ll research that for you.” I’m like, “You’re going to do what?”” She e-mailed me in a week or two about different programs that were available and what the temperatures were of different swimming pools. Seriously, I would tell her the different things that I needed, the things that were frustrating me, and then *she would find out a way to at least alleviate that burden a little bit*. She is like my go-to person. She would research if I needed help with milk because he’s on a special type of formula. She is like my little assistant. [Emphasis added]

There were times when they would just go over and beyond. My son is about to outgrow his Kid Kart because his legs are getting so long. I wanted another type of a stroller and [the CKF family specialist] researched it. She found out that there’s a company that has like a lending medical equipment place. She asked me if I would meet her out there and we could go and look at what they had. It’s free of charge. All you do is sign the papers and you can get bathtub seats, strollers, sometimes high chairs, or old wheelchairs. But you can make sure it’s going to support them before you go and purchase something, because sometimes insurance has a certain DME [durable medical equipment] requirement. So if you buy a wheelchair and it’s not right, it’s like “oh well.”

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<sup>18</sup> All but two CKF participants received monthly home visits. In one instance there were scheduling conflicts, but that participant was eager to receive home visits after attending the focus group for this evaluation. In the second instance, there was some confusion on the part of the participant about her eligibility for receiving home visiting services through CKF.



CKF staff learn from listening to parents or guardians “vent” about their struggles. Venting to the CKF specialist provides families with the opportunity to express their thoughts and frustrations with somebody who understands the family dynamic, thereby reducing isolation and stress.

I went to [CKF family specialist] and told her that we weren’t doing good, that we were struggling. That’s when I started speaking up. I decided I’m going to talk to women not just about the good days, but the bad days too, because they might have that type of day. Somebody’s listening and we can commiserate together.

Venting also allows the CKF staff to hone in on ways in which they can be helpful and further reduce that stress. “They want me to vent. *That’s how they find out how they’re going to support you.* I’ll say, “[Name] isn’t sleeping. What am I going to do?” Right there [CKF family specialist] is like, “There’s a sleep center that you might want to look at” [emphasis added].

In one of the three CKF focus groups, the participants spoke about an incentive program within CKF that had recently been changed and added as a component of their home visits. Every other month CKF held discussion groups and provided incentives, such as a gas card or gift certificate, to attend. For example, if the topic was “introducing your child to strangers” they would provide information and make suggestions for helping when strangers react to the child with a disability. As of a few months ago, the incentive program changed so that CKF providers now bring the discussion materials to the participants’ homes along with the incentive.

### **Family–Centered Approach**

In contrast to most, if not all, of the services described in the comparison focus groups, CKF services are delivered with the entire family in mind. The family-centered, strengths-based approach is central to the CKF model and provides families with a strong baseline of support. Participants in the CKF focus groups spoke about this aspect of the program with what we would describe as genuine appreciation. The families seemed relieved that the program was not another service that compartmentalized their lives. Their entire family was taken into consideration, not just a particular aspect of the care of their child who was involved in the program, as evidenced by the following quotations.

If Capable Kids comes while my daughter is still taking her nap, my son, who is almost 5, is like, “Let’s see what we have to play with today.” He’s there. He is helping. He shows my daughter how to play with the toys and what she’s supposed to do with them, as opposed to what she would do, like throw them across the room or bang on them. It’s not, “This is [her] time,” or whatever. That’s how it was when the First Steps PTs would come in, and the OTs, and speech services, because he would be distracting. But for Capable Kids it’s like, “Okay, we get toys. This is great.” *So he really likes that and it helps so he doesn’t feel like he’s excluded from it. PT or OT was a time for her and it’s, “You*

*need to go downstairs and play with your toys down there or we'll put in a show for a little bit." But no, this is a shared experience. [Emphasis added]*

They're really mindful of your family, too. My family loves music. They are always bringing us something with music, like a book that has a CD with it, so we can all get involved and play. *They teach us as a family how to play* with [my son] in a way that's going to help him meet his goals and catch up with other children. [Emphasis added]

Our daughter is there when [CKF family specialist] comes to the house. She loves to play with the stuff that they bring for [her brother] and read books with him. And so she benefits from it too, because she's involved.

We were talking about my other son and [CKF family specialist] mentioned a certain kind of sock that could help him with his sensory issues. She checked Capable Kids, but they didn't have it in his size. So she ordered it for him and he's not even in the program. She's like, "Here's that stretchy sock for [Name] so he can get his sensory issues addressed." And he's not even in the program.

One participant shared that she preferred to schedule her child's home visits when her other children were not at home and CKF respected that choice.

CKF participants brought up other ways in which they felt appreciated, understood, and supported by the CKF program. These are examples that are easy to overlook, but indicators of how CKF keeps the family in focus. For instance, one participant noted that CKF "brings items in bags to help us keep them together and not clutter up the place." Another participant expressed her delight in that CKF "brings books for each child in your home, not just the involved child." In another example, a participant described her appreciation for the fact that when she was scheduled to start with a new CKF staff member, that new person came to her home with one of the other coordinators that was familiar to the family from the playgroups. She offered that the process not only helped her family, but she assumed it also helped that new staff member.

### **Playgroups**

Another component of the CKF model is the playgroup. Through playgroups, CKF offers families a safe, adapted play area to network with others who are going through similar experiences. Playgroups allow the children to be children and play and interact with their peer group. As one mother in a CKF focus group shared, "You can't stop letting them be kids. *I think that's what they get here [at CKF], being kids.*"

[Emphasis added] The playgroups are also intended as opportunities to lessen feelings of isolation that family members may have. When comparison group participants were asked if they had the chance, outside of school, to interact with children who might have similar issues, most answered no. As illustrated by the following quotations, many participants in the non-CKF comparison focus groups shared feelings of isolation:

I don't have any support system. It all falls back on me. I'm responsible. [Name] has no friends because of her immune system, or very few friends.

My husband's on the road, a truck driver, so I have to do it all. I don't know many parents since I've moved to this area. My family is scared to help out because of my son's G-tube and his feeding issues.

As shown in the next quote, the comparison focus group participants responded with a resounding "yes" when asked if they would take advantage of an opportunity to have a CKF-type of playgroup to connect with other families.

I'm hoping that there are other programs that I can take my youngest one to go to see if I can get some more help. The school is trying their best, but I am not expecting a whole lot. I want him to see other kids his age and see what they're at, because I have no one to talk to about that.

One mother explained that her apartment building housed many families from her country of origin. Though she has friends, she is aware that when she takes her son to her friends' home, he is very happy just to watch the other children, but he does not play with them. In another comparison group, a mother described that neither her son's school nor his ADHD counselor could find appropriate groups or services to help with his aggression, his physical needs, or his lack of speech. Another parent in a different comparison focus group shared the same issue of not finding appropriate groups for her son.

I think the big thing is that ours is not a disability that there seem to be groups for. You know like autism or Down syndrome or something like that. There's not much for low muscle tone kids that aren't developing as fast and I think that's where my problem is. I have never met anybody that's had the same issues that I've had.

While it may be "easier" in some geographic areas to find a group experience if a family has a particular diagnosis such as Down syndrome, those groups might not be appropriate to the family's needs. In one of the CKF focus group there were a few young mothers who had previously participated in their region's Down Syndrome Association. They spoke about their experiences with that group and with the CKF playgroup.

We've met a few people through the Down Syndrome Association. We are a lot younger than a lot of the moms with Down syndrome and we have babies. It's really hard to talk to the other moms there because they're talking about their teenagers, or about buying a house, or doing all this other stuff. We're like, "We're just starting out." So it's really hard to really connect with them. We go to those playgroups and our kids would play and it's like, "Oh yeah, your kid's so cute." And then that would be the end of it.

The second parent in the conversation continued,

It's a different experience over here [at CKF]. It's a smaller space. It's actually over-stimulating at Down Syndrome Association. There are too many people, too many toys, and so much commotion, and there's too big of an age range. Here it's smaller and I think it's more relaxing. You're not worried like, "Don't put that in your mouth. No, no, no, no. We're going to have to wash that." Oh, we don't have to pick up here either. I love that! They don't make you clean up.

Other CKF families echoed that sentiment that they appreciated CKF's attention to hygiene and cleanliness in the playgroup area.

I couldn't go to those other playgroups anymore because our kids have fragile medical needs. They get sick. I couldn't just take my daughter to the YMCA drop-in room because I knew she'd end up with croup. She'd get croup like eight times in a season. That's very scary. So you try to limit. But then you come here and everyone here is conscious of not bringing their sick child and the people that work in the program they're all very educated. They're like, "Leave the toys. We have a group of volunteers that clean and sanitize them."

Some CKF focus group participants shared that they had not yet availed themselves of the playgroups. One parent explained, "I haven't done the playgroups because of my barriers. Personally, it was just my family life and there have been a lot of adjustments in my family life." Another participant shared that she was looking forward to beginning playgroups with her son, but had not participated due to her son's delayed vaccination schedule. She added that traveling with her son used to be more complicated because she had to "tote" his oxygen and other equipment around. Another participant explained that timing and distance kept her from participating more fully. Her child's therapies conflicted with the playgroups, but she added that whenever she comes to [the CKF community] she "makes it count," and will stop in to CKF.

The CKF participants familiar with the playgroups spoke favorably about them. They described the access to the area and the delight they and their children have in the playrooms.

You can go by there and stop and see them. They are very approachable. They will turn on the lights for you [if you stop by and want to use the playroom or look in the equipment room].

We were in [CKF community] for an appointment and stopped by. It was the first time we went to the playroom and there was nobody there. They just turned the lights on; we had to sign in, but everything was clean and neat. We just played until he was tired and it was wonderful. They're very accommodating, even my babysitter took the kids over to playgroup.

We just started going to playgroup. They love it. I just kept looking at [Name] smiling over in that ball pit, thinking, "Gosh, that looks like fun." So I said maybe I'll get in there and the worker's like, "There's no weight limit, get on in there with her."

While discussing the CKF playgroups, several participants also spoke about other group activities offered at the CKF site. Participants in one group shared, “They have playgroups, art therapy, and field trips.” Participants in another group talked about the free playgroups and the music therapy classes for which there are scholarships available. It is worth noting that they did not necessarily differentiate between programs offered at the sites—for example, the Arc or the Special Learning Center—when discussing the services in which they were engaged. Such streamlined services are a positive indicator of there being support for families. Another support families receive through CKF’s playgroups is the opportunity to connect with and learn from other families.

Capable Kids is a comfortable spot where you meet other mothers. It’s not about your color. It’s not about how much money you make. It’s about these kids. So you can say to that person like, “I’m struggling,” or ask if you need something. I mean that’s where I think we are more networked now.

You meet other moms that understand the experiences you go through or the craziness of your kids’ behaviors or even those of your typically developing kids.

Most of my friends aren’t even married, let alone have children. I feel like they look at me and think, “Wow, you have a kid with Down syndrome? What did you do wrong?” But then I get a lot of support being here [at CKF] and at church. I didn’t do anything wrong. Down syndrome is a normal thing. They don’t know why it happens, it just happens. They don’t know my kid. My kid is great.

CKF participants also shared that the playgroups foster feelings of familiarity or sameness with other children and families. In one of the CKF focus groups, some participants spoke about the impact participating in the playgroups has on their children not in the program.

I have brought my son [sibling’s name] and he doesn’t have a developmental disability. He plays with her [another participant’s] son and she looks at me like, “Who is this kid and what have you done to my child?” Because usually her son just sits on her lap, but with my son he’s playing and interacting with other children. She’s like, “I love your son. I want to take him home and have him do this every day.” So I mean it helps that you have our other children being able to come and interact, because it shows those kids how they’re supposed to play. And it helps my son realize, “Hey my sister isn’t that different. There are other kids that are like her and she is supposed to be played with and interacted with just like a regular kid.”

In a different CKF focus group a participant requested more sibling-based opportunities. She explained,

It’s been very difficult for us to find sibling groups and information for siblings of children with special needs. We put so much of our focus and our attention into our kids with special needs that sometimes the other children don’t get as much as they should. It takes a long time as parents to adjust to having a special needs child. Yet, here we have a sibling that is going through the same things and they don’t understand. Why does she get to go jump on the bed and I don’t get to jump on the bed? A sibling group is something that I would utilize a lot more readily than the playgroups,

because I think it's very important for [sibling] to get that help and understanding from other children that are siblings of children with special needs.

### **Developmental Therapy Equipment**

The third component of the CKF model is the developmental therapy equipment loan program. This aspect of the program offers the most visible and concrete form of support, enabling family members to be active partners in their child's therapy and incorporate therapeutic equipment into regular daily activities. According to the CKF manual, equipment is categorized into fine and gross motor, visual and auditory stimulation, language and oral motor development, switches and adapted toys, infant and preschool skill development, positioning, and sensory integration equipment. Families and therapists are able to look through the CKF catalog of equipment to help determine what would best suit the needs of the child and family. Participants were exuberant about this program and the support it provides their children and families.

Without Capable Kids, I don't know if [Name] would ever reach his goals, because we would have these wonderful ideas and things to do but nothing to do it with. Our First Steps people are wonderful; they have great ideas and they even suggest certain equipment, but *if we didn't have access to these toys, this equipment, how would you move forward?* [Emphasis added]

Indeed, when asked about their families' equipment needs and how those needs were met, responses from the CKF focus group participants and the comparison focus group participants differed widely. Non-CKF participants lamented the high costs of therapeutic equipment.

We spend lots of money, like almost 30 percent of our money on developmental items for her. If you look at the toys in our home, it's almost like a daycare center. I had to buy blocks and stuff to teach her motor control and stuff like that.

Non-CKF participants who could not afford to purchase developmental therapeutic equipment talked about relying on the First Steps-provided equipment during therapy times. Then, in between sessions, they had to make do or wait for the next therapy session.

First Steps brought their equipment, like reverse walkers and he was doing okay with that, but we could not keep it and he was just struggling.

They didn't supply anything. I had to purchase everything. When she was having problems sitting up trying to get her muscle tone and everything, they wanted me to locate one of these seats that they could set you up in. Just a little Bumbo. The lady from First Steps brought one each time she came, and we would let her sit in that for a while, but the Bumbo was hers. I had to use my nursing pillow but we had to maneuver her tubes and everything around it.

It [having access to therapeutic/developmental equipment/tools] would have helped mine. It would have helped her develop quicker. I just couldn't afford the stuff, so we sat at home and waited on the therapy to come.

We do go to the park a lot so that we can work on things like stepping down, stepping up, and stepping over.

All of the non-CKF participants—and the CKF participants—agreed that an equipment loan program would benefit their families, illustrated by the following comments.

They have a lot of stuff and they provide really good equipment. If I think about buying it, it would be too much on us. It's helping because you get that equipment and you use it for a while and then she grows out of it or she's done with it. Then we are able to take it back and replace it with something they think is going to be good for her right now. It's really great because we could use something for two months and then it goes back to somebody else to use.

It's not limited to medical equipment like you would expect. It's all kinds of toys and things that help them develop—wagons, music boxes, blocks, Rody this little bouncy donkey thing that has ears you can hold on to and it helps her leg muscles; she can sit on it and bounce and it works on her core.

If there's not a waiting list you can keep the item longer than a month. There's one singing toy that we still have because she plays with it all the time. She will just stare at it and hold it because it vibrates as it plays the music. I never would have thought to buy that toy for her.

They bring toys with lights because she is interested in lights. The PT wants her to keep her head up for as long as we can, so we bring all those incentives for her to keep it up. They have different kinds of toys with blocks, books that they want her to work on feeling and touch. When [CKF family specialist] comes, she looks at what I have and checks in to see if there [is] something to take away and replace. It's just amazing because [Name] needs a lot of stuff and I couldn't buy all that.

The other thing is that you can try it before you buy it. I have a lot of trouble with my son sleeping at night. I tried one of their weighted blankets before I got him one of his own, because you don't want to invest all that money and then it's something that is not even gonna work.

The CKF participants continually emphasized the individualized, family-centered approach CKF takes with regard to the equipment loan program.

They try to make them appropriate for your child. [Name] has a cortical visual impairment. He's got lots of issues, but cortical visual is our big window. And so they search for books that meet his needs. [CKF family specialist] is always pulling out shiny books; it's not just that they bring books, but they put thought into it.

Mostly it's learning equipment and different toys because [Name] has so many issues. We experiment with different things—sometimes we try to stimulate his vision. He's still on feeding tubes, so [the CKF family specialist] has brought things for the oral stimulation, little jigglers and things like that.

Of course, he can't sit up or walk. We borrowed this kind of a keyboard pad hoping as he made notes when he kicked that it might entice him to roll. It didn't work out, but we try a lot of different things.

At the end of the appointment [CKF family specialist] checks in about the toys, "Are these toys okay that we brought? Were there any troubles with the ones you had before?" [Name] likes puzzles, but some of them are too much for her or if they have sound she just makes the sound and drives the whole house crazy. Capable Kids gets it—no sound puzzles. They really listen and write it down so they don't forget. I mean when we switched coordinators, the new person had all the notes and knew everything from what [the previous CKF family specialist] had before.

The equipment loan program allows families to integrate their children's therapeutic work in their home environment, while reducing the financial burden often associated with developmental therapeutic equipment. As the CKF program manual makes clear, therapists are also able to review the catalog of equipment and make recommendations to meet children's therapeutic needs. This bolsters another support of the CKF model, coordination among service providers, which is discussed in the next section.

### **Coordination among Service Providers**

Families with children with special needs are often involved with a myriad of services, which can lead to feelings of being overwhelmed. Participants reported that having coordinated services and a sense that they and the providers are working together with shared information is a support that they value. One non-CKF respondent described the coordination among their service providers.

Right before [Name] got out of First Steps, she was getting OT, PT, and speech every week or every other week. They had joined together as a team, so [OT provider] would come out and then she would go relay back to the team what they worked on. The same went for [PT and speech providers], then they go over everybody's notes. That way when [any provider] would come out, she knew what to go over and then she'd go relay it back.

Another non-CKF focus group participant noted that the First Steps-referred therapists "all work within a group, which has proven to be just fine." In another non-CKF focus group 75 percent of the participants (3 out of the 4) indicated that they felt their First Steps-referred service providers did a good job of communicating to help them have integrated services. That group agreed that the service providers "talk among themselves and then get back with you as a focus for your child."

It was unclear from the non-CKF focus group discussions if the participants found that services they received outside of First Steps or through their early childhood system were coordinated. One participant did note that in her family's situation there was no information shared between a private program in which her child was involved and First Steps. Another non-CKF participant described feeling that she did not have a choice when it came time to choose her daughter's school placement.



When she was entering kindergarten, we had a group meeting and *I thought I had a choice* whether I could send her to the [local school] or to the state school for mentally and physically handicapped children. But then it was just decided that the state school was the spot for her. It's fine, but I just thought I had this big decision to make and it really wasn't my decision. [Emphasis added]

### **Coordination of CKF with Other Providers**

In contrast, CKF participants pointed to their involvement with CKF and the willingness of their CFK providers to work in concert with their other providers.

In my experience, I have found that Capable Kids is more than happy to collaborate with whoever is necessary to get the best care for my child, whatever it is. Unfortunately, I've found as well that other programs we're involved in are not as willing to collaborate or they have good intentions, but just don't follow through.

Because we are still in First Steps, a lot of times they'll [CKF] team up with either PT or OT. So they might come in for 15 or 20 minutes so they can see therapy and see what kind of needs we have.

Participants in one of the focus groups explained that some of their First Steps providers have a contract with the agency at the CKF site and some of their children attend day care at that same site, which allows for even more coordinated services. However, in each of the three CKF focus groups, participants spoke about the benefit and support they receive from the coordination between their CKF providers and their therapy providers.

Every time I have occupational or speech therapy or a special instructor from First Steps at the house, they will always say, "Here's something that [Name] could use if Capable Kids has something like XYZ." Then they'll give me a name of something I've never heard of and ask me to see if Capable Kids has that. And [CKF family specialist] will always look, or they might even e-mail each other without me being in the loop. And [CKF family specialist] also asks me if there is anything that First Steps says that [Name] could use or what his goals are right now? So she knows what kind of equipment, what kind of toys to bring, and they're really mindful.

The good thing is that her therapists come here [CKF site]. She sees the stuff they have and she knows [Name]. So she'll tell [CKF family specialist], "Okay, I need this for [Name] and I think I'm gonna use this." So when [CKF family specialist] comes to see us, she brings that stuff that the therapists said.

Sometimes because my house is right by [CKF site], the therapist stops by for things that she needs for—or things that she think [Name] will benefit from while they are doing their therapy session.

I have one therapist who works with the public schools. She knows she can stop and look through that [equipment] room to see if there's anything that she thinks will be beneficial to [Name]. It's nice because then she can say, "Hey, why don't you try to get this and then maybe you can bring it to therapy."

One participant compared her experience with a previous foster child without CKF to her current CKF experience with her preadoptive child.

We were getting First Steps with the previous foster care. We had a wonderful First Steps person; I loved her. But I know now that there were some things that I could have used from First Steps. I missed out by not having that personal person come into the house and just say, “Okay, what do we need to do to help this child?” We would have benefited from having Capable Kids’ services to have somebody in the house just working alongside of the First Steps coordinator. Without Capable Kids, you just miss that personal piece and just that knowledge of having somebody else to say, “Okay, here, what kind of things can we do to help strengthen the low muscle tone?”

Other CKF participants described a dynamic in which they served as the bridge between CKF and their other service providers.

I did not have much confidence in the person I had for First Steps physical therapy. So I had to ask what they were working on at the hospital and what I can work on at home. Then I bring that information to Capable Kids.

I serve as the bridge between services. I’ll ask a therapist if there is anything that [Name] could use that would help her at home. They’ll tell me, and then I go to Capable Kids and say, okay, here’s what we’re working on right now in therapy. What do you have that can help me with these things?

Some CKF participants also described how they utilized the CKF support as they transitioned from early childhood services to school-based services.

I was very frustrated at the first IEP meeting. Even though I had typed everything out and I gave it to the whole team, I needed to watch because I had a pretty rocky early childhood team. I wanted to watch the tone and the demeanor of the people, but I couldn’t do that and write at the same time. I wished I would have had [the CKF family specialist] with me. So the next time, she actually came in with me. So she was my note taker and I was able to really control the meeting. Then she typed it up for me in like a week or two, so then I had those notes.

I had everybody at my IEP. I called them all. Said, I need y’all there. Capable Kids was there. First Steps was there. My service coordinator from [Geographical Region] Department of Mental Health was there. They will be wherever you want them to be, because they know a lot more legally than we as parents do. We’re there more emotionally and physically, and they are there more in the books. And sometimes all you need is just that one phenomenal person on the team.

[Name] is actually the first child with autism that has been at that school. The school has made so many accommodations; teachers were sent to special training. But a lot of it was because of having [CKF providers] and First Steps there with me as my advocates, because we all had been working with her for three years now, so everybody knew what [Name] was going to need.

The issue of advocacy was raised in each of the six focus groups and is explored further in the following section.

### **Identifying Resources and Learning to Advocate**

Another way to gauge supports for families is through asking about advocacy efforts. How did they learn to advocate for their children and families? Did they have people or groups to turn to along the way? Some participants talked about using the internet and looking up resources, such as MyAutismTeam.org, for their children's specific diagnoses. One person mentioned becoming involved with Partners in Policymaking, a formal leadership training program for parents of children with developmental disabilities.<sup>19</sup> Others spoke about turning to their doctors for information, such as this parent.

I actually have the same pediatrician for my kids that I had when I was little. He's really great. If I ask him, "Hey, do you know about this?" or if there's a problem he's like, "I don't know, let me look that up," or, "Let me have you talk to someone else about that."

Other participants related having the opposite experience with their medical providers, as in the following example.

My pediatrician couldn't even direct me in a right path. I called the hospital because I thought they could refer me to a doctor or someone who had experience working with special needs children and they couldn't even find anyone on the roster. I talked to four different people at [Hospital] and I was like, "At this point I don't even care what the doctor does. I just want to speak to someone who has experience with being with another special needs child."

Some of the differences between the CKF and the non-CKF participants in response to the questions, "Do you feel confident that you know how to best advocate for yourselves and your families?" and "Do you feel that you have people that help you along the way?" were striking. The questions seemed to give pause to some of the non-CKF participants. One parent responded, "I would think if we had any help, it would have been through his pediatrician." Another said, "I don't know. We have a service coordinator through developmental services for [Geographical Area]." And according to a third parent, "I'm pretty much on my own. The doctor's office helped me with their part of IEP and when we started [local area] preschool I did have First Steps helping me with the IEP."

One mother who was relatively new to her area lamented about her frustration with her service coordinator's lack of efforts. She reported that she's been "waiting for almost six months trying to figure out what to do next, because now he's four and I can't figure out what to do with my son." In contrast, even though CKF participants shared frustrations and challenges in common with non-CKF participants,

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<sup>19</sup> See <http://www.moddcouncil.org/page.php?contentID=52> for more information.

they talked about feeling that they had someone in their corner. For example, one parent spoke about relying on her CKF provider as her “backbone” to help her advocate for more appropriate services as her daughter was presenting with more issues.

I used [CKF providers] as second eyes. [Name] started out just needing a PT for being premature. When [Name] just kept going downhill, no one knew why. [The CKF family specialist] was more eyes and ears for me because we just couldn’t put it together. So when First Steps came in I would always have [the CKF family specialist] come in. So that way they could work together. It was like having this backbone because I could tell everybody what was going on, but no one would believe me. That’s how it became for me. So I was like, “Oh okay, I got this backbone.”

Other CKF participants echoed these sentiments.

If you don’t have a good Department of Mental Health or regional office person when you transition out of First Steps, you’re on your own. Fortunately the ball seems to have been picked up since the Capable Kids program has come about.

We just went through an IEP transition and Capable Kids was the most beneficial. [The CKF family specialist] knew I had a lot of questions on this whole transition and she told me from the first about the IEP and what we were dealing with. So in that aspect, as a parent, I got the most information from Capable Kids going through that transition.

One mother described that she felt like she had to “fight” all the time for her daughter, but she did not feel that way about CKF.

Every month we have to fight to get [my daughter] a refill for her acid reflux medication. Each month we have to fight the doctor to call in to the insurance and explain why she is still on it. Same thing with WIC. She’s on special milk. I’ve been fighting since January to get her milk. They are telling me now she will have to have some special disease or something to keep getting it. She’s finally starting to feed herself and she’s gaining weight. I’m like, “You’re going to do this to me right now? Please don’t.” That’s why I think we love Capable Kids because we don’t have to fight here. You can sit back and be yourself.

While some comparison group participants shared that they would feel comfortable asking a service provider—such as their First Steps coordinator or a therapist—if they had a particular question, families still need to have enough knowledge to know what questions to ask. One participant’s response illustrates this.

I can always call on former therapists if I have a question. And [I learn] from word of mouth. I didn’t even know what an IEP was until a friend of mine was involved in the process for her daughter. I wouldn’t have even known where to start. *It was never brought up.* [Emphasis added]

Other examples of “word of mouth” were prevalent in the focus group discussions and support forums where families with similar issues can get together, such as the CKF playgroup goals.

What I found is that everything is word of mouth with having a child with just different needs. So really before Capable Kids and before the different programs and things that they attached on like music therapy, I had really nowhere to go. I had no other contacts, no other moms that could even get it or understand. Even talking with his primary physician, she didn’t really have that bedside manner because she didn’t know what was going on.

Once we got him into the neuropsychologist and found out his disabilities, that’s when I finally went back to the school and actually talked to other parents. I talked to some of the parents and learned about the IEP, that’s what got me started with the school to meet with them and figure out how we were going to teach [him].

Five participants at one of the CKF focus groups—more than half of the group— talked about CKF facilitating individual parent connections in their community by asking CKF families if they would be willing to speak to another family with a similar diagnosis. One mother shared, “I’ve done it with a couple of families now, one who just found out their daughter has cerebral palsy. My son has cerebral palsy. So [the CKF family specialist] says, ‘Hey [Name], do you mind if we give them your information?’” Another mother in the conversation added, “They bring families together, which is so great, and then we extend it out. We meet each other and then we’re like, ‘Oh hey, let’s get together another day.’ It’s like support, support, support.”

### **Social-emotional Support**

Having that “support, support, support” helps empower parents and families as they work to increase children’s developmental gains. It also helps reduce the factors associated with increased rates of child abuse and neglect by reducing stress, reducing financial hardships, and increasing parental competencies and support networks. The challenges and stressors confronting families with children in the program can be monumental. One mother in a comparison focus group explained that she was forced to resign from her job after she exhausted her FMLA time. She eventually declared bankruptcy. Though she receives nursing care, the nurses are prohibited from transporting her daughter. Thus, the mother had to take numerous days off from her subsequent jobs in order to take her daughter back and forth to the doctors. As a result, the mother lost those jobs.

Without a support network, daily life can become overwhelming. One participant stated, “If you don’t have family support, then you’re not going to be able to help your child, you just won’t.” But not everyone has equal access to that family or community support. We asked the focus group participants what they thought was the most helpful service they received. Most of the non-CKF participants named First Steps.

First Steps because [Name] was barely crawling up to the time he was two and a half years old. Now he stands up with no issues. He just has to hold on to something to keep his balance with his splints on and First Steps is who made it a fact that he needs to keep them on.

Without First Steps we would not have known really how to go on with her therapy and what to do.

I like First Steps's structure. I mean they tell you upfront the mile markers, what they're trying to achieve. Even though mine didn't meet the goals on the scheduled marks, we still achieved them. It may have been a month or two after, but we still achieved them. At least the structure of knowing what we were supposed to achieve is what I liked the best.

First Steps is great people. If I have any questions or if I'm questioning whether or not we need to add another thing, the coordinator is wonderful.

One non-CKF participant who never had First Steps services answered that Parents as Teachers (PAT) was her most helpful service. The home visiting model is similar to the home visiting aspect of CKF and that was what this participant appreciated.

PAT helped me personally. Yes, it helped my child, but I think it helped me understand what I can do to make things easier and better. It wasn't her just coming in and seeing him for an hour and then going away. She took the time and talked to me and my husband, when he was able to be there. It gave me the knowledge about what to do next.

CKF participants indicated in several ways that they felt strongly supported by the CKF program. The personal touch, in addition to the program's other components, is what endears the CKF program to its participants. CKF focus group participants repeatedly discussed the strong feelings of support they receive from being involved with the CKF program. We asked focus group participants to name the most helpful service they received, CKF participants repeatedly mentioned CKF.

It's the people at Capable Kids that come to your house that make the difference for me. I have [a CKF family specialist] and she is seriously the most concerned, sweet lady you will ever meet in your entire life. And that makes a difference to me more than anything. If I had somebody that was kind of just business-like and indifferent, I don't think I would enjoy—well, yes their loan program would be very beneficial—but I don't think I would have the warm fuzzies that I have now. I wouldn't be telling everybody who I find out has a disability with their kid about Capable Kids yet.

I just think this is a great program. When I heard about it, I couldn't believe something like this could happen. When we started I wasn't sure how much they can provide, but having that therapy work with you and them coming here and picking up the stuff, I think it's just a great thing. Your life is just different and you have a lot of different worries about a lot of different things when you have a special needs kid. Capable Kids just helps put things at ease for you.

They are there for you, like when [my son] was in the hospital and he missed two music therapies in a row. Everything's revolved around music from day one with him. We always get music toys from Capable Kids, it's his motivation. They videotaped a music therapy session, put it on a CD and brought it to us in the hospital so we could watch it there. It was amazing. [He] still watches it.

Capable Kids has been so helpful on so many levels. And with the money that they're given to do what they do, they stretch it so much further than other free programs.

[The CKF family specialist] has helped me a lot and my First Steps team, because they've all been a very strong support system morally, emotionally, socially, just in every way, shape, and form. I'm a very strong advocate vocally for when it comes time to talk to people about things for children's special needs, but I'm not a strong advocate for myself or a support system for myself. I tend to just kind of try and do everything myself and get used to it. But [the CKF family specialist] reaches out and encourages me all the time.

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## **Information Sharing and Parent Networking**

During the CKF focus groups, a few ideas were generated for how families could be even better supported through improved information sharing. At each focus group, including the comparison groups, participants commented that they had learned from each other during the group and there were discussions about how to continue this type of forum. A number of questions were raised regarding potential "parent forums": At what time of day would the forums occur? Would child care be provided? Would there be planned topic areas or would it just be free flowing? What would draw attendees who did not participate in the focus groups? Would it be facilitated or parent- or guardian-led? One of the CKF focus group participants noted that she hoped that a "parent forum" would yield more interaction from the parents than at the playgroups. She said, "an hour while watching your children isn't a situation where you can really talk." Other participants in the group followed up on that, noting, "We've had good conversations, but it's kind of getting to the point of being ready to put yourself out there." Another participant said she would like to have the opportunity to learn from other parents who have older children with similar issues "to give me a view of how this is going to be in the future. I want to hear how they went through this and this and that."

In one of the CKF focus groups, the discussion about parent groups became a discussion about having a current list of resources that is available to all CKF participants, like the catalog of equipment/toys. Participants spoke about their CKF family specialists sending out individual e-mails or e-mails to their entire caseload, but they did not believe the information was necessarily shared with the larger cohort of CKF families. For example, when they learned of the CKF family specialist who researched the temperatures of indoor pools (discussed earlier in this chapter), other participants were interested in having that information. That particular set of focus group participants talked about having the CKF

families maintain some sort of database or a shared Google spreadsheet that would include static information—such as IEP, housing, or nutrition assistance—and dynamic information, such as seasonal activities.

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## Summary of Findings

While our sample size was limited, the focus groups of CKF and non-CKF parents or legal guardians provided a rich understanding of the service experiences of families with children in a program. Parents in all three of the CKF focus groups enthusiastically described the program as supportive, family focused, and committed to helping them help their children learn and grow. CKF focus group participants commented on the relationship-based approach found within each of the program’s components: home visits, supportive group meetings and activities, and a comprehensive resource-lending program.

CKF home visits offer participants an opportunity to “vent” about their family’s struggles and frustrations, as well as extoll their family’s progress and success. Having that “personal connection” with their CKF specialist embeds service provision into a family’s support network. Learning about additional resources, such as the mother who recounted how her CKF specialist researched the temperatures of indoor pools in the area for aqua therapy, is another support families receive through their CKF home visits. Families appreciate having CKF as a reliable resource for learning about opportunities for their children to grow and develop. As reported earlier, some of the differences between the CKF and the non-CKF participants in response to the questions, “Do you feel confident that you know how to best advocate for yourselves and your families?” and “Do you feel that you have people that help you along the way?” were striking. While some comparison group participants identified family or service providers to whom they could turn, others verbalized a definite lack of support. In contrast, no one who participated in the CKF focus groups reported such a void of support. Indeed, some families were quick to point out their relief at having CKF staff accompany them to meetings that might prove challenging, such as IEPs, or at having CKF be their “backbone” to bolster their reports regarding their children’s behaviors or issues.

CKF families also appreciated the program’s inclusion of their entire family so that they could learn how to incorporate their child’s equipment, games, or toys into their regular routines. Participants from both the comparison and CKF groups described other services that focused solely on their children in the program, thereby isolating siblings and compartmentalizing families instead of helping families come together.

Playgroups and other group activities were also described as being supportive and helpful for families to learn about resources and ideas from other families, as well as to strengthen their network of friends. Several CKF participants described playgroups as being approachable and open. Approachability was a



characteristic that was also echoed with regard to the equipment loan program. Parents or legal guardians are encouraged to peruse the catalog of equipment, as are therapy providers. This increases the coordination of services and assists families in incorporating their children's therapeutic work into their home environment, while reducing the financial burden often associated with obtaining developmental therapeutic equipment.

CKF seeks to provide emotional, financial, and developmental supports for families with children with special needs. CKF focus group participants report that this goal is accomplished, at least in part, through

- the special relationship formed with CKF staff, which reduces isolation and increases awareness of community resources, and provides support when families face new experiences, such as IEP meetings;
- encouraging networking with other involved families through supportive group meetings and playgroups, which reduces isolation and strengthens support networks;
- providing therapeutically appropriate games, toys, and equipment at no cost to CKF families; and
- approaching the entire family unit by including the family members during home visits and providing the equipment loan program that enables families to engage more fully through therapy and play with their child involved in the program.

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# Conclusions

The Capable Kids and Families program (CKF) provides services in the state of Missouri to families of children with disabilities or developmental delays from birth to 6 years old. The goal of the program is to support family functioning and foster positive developmental outcomes for families raising children with special needs. One of the CKF program's distinctive features is that it provides families with a comprehensive resource-lending program where developmentally appropriate equipment and materials are placed in the child's home, at no expense to the family. The goals of this study and the report were to describe (a) key child disability types and household or family characteristics, (b) service usage patterns, (c) family outcomes and (d) parent-child interactions for two groups of families. These two groups consisted of families participating in the CKF program and a comparison group of families enrolled in other programs serving children with disabilities. Given that rural and urban population often have different challenges in accessing services, we also examined whether findings differed within and between rural and urban populations.

Overall, we found few differences between families in the CKF program group and families in the comparison group at all three time points in terms of their experiences and satisfaction with the services they received. There were few differences across the three data collection points for either group. For the most part, all of the families made sure that their child received the services they needed to succeed; the families were working hard to advocate for their child and their child's development; they enjoyed the time they spent with their children; and they appreciated the efforts made by the professionals in their lives and their children's lives.

However, CKF families reported higher levels of use of a range of therapeutic services compared to families in the comparison group. This could reflect the fact that children in the CKF families have more disabilities or diagnoses, and more severe ones, than do the children in the comparison families. (The findings also suggest that one of the benefits of the CKF program is its ability to link families to needed

resources, although we cannot determine from these data is whether the services were accessed directly through the CKF program or through other means.) In addition, CKF survey respondents also reported significantly higher levels of satisfaction with their relationships with their service professionals than comparison families do.

CKF home visits offer participants an opportunity to “vent” about their family’s struggles and frustrations, as well as extoll their family’s progress and success. Having a personal connection with their CKF specialist embeds the service provision into a family’s support network. Families appreciate having CKF as a reliable resource to learn about additional therapeutic equipment and opportunities for their children to grow and develop. All of the CKF families who participated in the focus groups expressed appreciation for both the material and the social-emotional support provided by their home visitor. In contrast, the comparison families who participated in the focus groups had more of a mix of perspectives. Some comparison group participants identified family or service providers to whom they could turn, but others verbalized a definite lack of support.

There were several other positive aspects of the CKF program mentioned by focus group participants. One was that, in contrast to other services, CKF includes all family members so they can all learn how to incorporate the equipment, games, or toys of the child in the program into their regular routines. Another was the monthly playgroups and other group activities, which were described as supportive and helpful for learning about resources and ideas from other families, as well as a way to strengthen their network of friends. Several CKF participants described the both the playgroups and the equipment loan program as being approachable and open. With respect to the loan program, parents or guardians as well as therapists are encouraged to peruse the catalog of equipment. The equipment is designed to improve service coordination and help families integrate their children’s therapeutic work into their home environment, while reducing the financial burden associated with purchasing such equipment.

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## **Study Limitations**

As an initial effort to evaluate the CKF program, our analyses provide important information about the service experiences of these two groups of families and indicated areas where the CKF program could potentially affect family well-being. The study findings are strengthened by the use of more than one data collection method: a survey of families administered at three points in time and focus groups to explore experiences with CKF and other services for children with disabilities in more detail.

At the same time, like any research study, this one has limitations. One limitation is that, as a quasi-experimental study, we could not randomly assign families to different program groups. Nor did we capture in the data collection all of the possible factors that might affect the responses of the families in

the two groups. Despite the effort to create a comparison group that was similar to the group of CKF families, there were a number of differences between the two groups in terms of family characteristics (e.g., income and employment) and children's disabilities. Additionally, we recently learned that the CKF program serves families at a military base, which means that families at one of the locations were more mobile than other families in the sample. This mobility likely affected our ability to locate families to participate in follow up surveys. In addition, the sample of families who responded to the survey at all three data collection points was relatively small; therefore, we could not conduct many subgroup analyses by, say, demographic characteristics or disability levels. The pattern of results related to the higher use of services by CKF families could be driven by the fact that CKF families report having children with more disabilities or diagnoses than do the comparison families. They also suggest that one of the benefits of the CKF program is its ability to link families to needed resources. We cannot determine from these data whether the services were accessed directly through the CKF program or through other means.

We also know that service duration, the dose, and the intensity are all likely to affect the outcomes of services. However, we do not know when our survey respondents began receiving services (only that it was prior to the first data collection point<sup>20</sup>) or how frequently they used them during the study period. Data such as these would have been relatively easy to obtain for the CKF families from service records, but would have been difficult to obtain for the comparison families. Thus, analyzing service information was beyond the resources and scope of this study. With respect to use of other services, we found that CKF families used considerably more services than comparison families. But we cannot determine the extent to which the CKF program (or other service providers) helped families access these additional services.

Finally, it is possible that the measures selected for this study were not sufficient to show change over time or other differences that could be attributed to the services and resources provided by the CKF program—that is, beyond the level of satisfaction with the provider-family relationship found with the Family-Professional Practices scale. Most of the outcome measures yielded high ratings at Time 1 and remained high over time. Thus, it would be difficult to detect change in the measures used in this study. A survey more tailored to the specific elements of the CKF program—the playgroups, the group meetings, and the therapy equipment—might have shown some differences.

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<sup>20</sup> Time 1 was not a true baseline point.

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## Recommendations

In conclusion, the CKF program provides emotional, financial, and developmental supports for families with children with special needs. Based on both survey and focus group findings, the program is accomplishing this goal, at least in part, through:

- the development of a special relationship with CKF staff, which reduces isolation, increases awareness of community resources, and provides support when families face new experiences such as IEP meetings;
- opportunities to network with other involved families through supportive group meetings and playgroups, which reduce isolation and strengthen support networks;
- therapeutically appropriate games, toys, and equipment offered at no cost to CKF families; and
- a family-centered approach that includes all family members in home visits and enables them to engage more fully with their involved child through therapy and play.

There were very few suggestions from parents in the CKF program of ways to improve the program, but parents who participated in focus groups—both those in the CKF group and in the comparison group—clearly valued the opportunity to talk about their children and services with other parents. They expressed a desire for more opportunities for networking and information sharing. Although parents in the CKF program appreciate the group activities offered by CKF, their general view was that these opportunities were still limited. One other suggestion that emerged during the focus group sessions was to more broadly share resources (e.g., through an online list serve or newsletter) that CKF family specialists currently share on an individual basis. This would allow the larger cohort of CKF families could receive the same information.

Given that comparison group families were, overall, positive about their service experiences and that ratings at Time 1 were fairly high, it was not surprising to find few differences between the CKF and comparison group and little change over time. At the same time, in light of the severity of the disabilities of the children whose families are in the CKF group as compared to those in the comparison group, we are encouraged by the fact that families in both groups rate their experiences with services and their levels of satisfaction, enjoyment, and stress with daily caregiving routines comparably. These findings suggest that the program is ready for a more comprehensive implementation and outcomes evaluation.

A future study should include the collection of administrative data as well as parental reports on services and therapies provided by the CKF program and other intervention. These data would help us to understand the differences between the CKF and comparison programs and perhaps mediate the relationship between program participation and outcomes. Systematic data on the number of CKF home visits that are scheduled, home visits that are completed, the duration of the home visit, who participated

in the home visit, and the topics covered would be very helpful for interpreting within- and between-group variations in service satisfaction and outcomes. We also recommend adding other measures pertinent to the goals and distinctive features of the CKF program. For example, in an effort to reduce the burden on families participating in this research study, we tried to limit the length of the survey. We used the Family Outcome Survey (FOS) as an overall indicator of family functioning because the scales aligned with the CKF logic model. Findings from baseline data collection suggest that there is little variation across participants on the majority of items on the FOS. We recommend adding measures of parental stress and family functioning to help determine the impact of participation in the CKF program. Finally, assuming random assignment to a program and comparison group would not be feasible, we believe it is important to more carefully match the characteristics of the two groups so that they are more comparable.

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# **Appendix A: Results for All Respondents at Each Time Point**

**Table A- 1. Characteristics of the Child**

	<b>Time 1</b> <i>N = 233</i>	<b>Time 2</b> <i>N = 234</i>	<b>Time 3</b> <i>N = 175</i>
<b>Program group (%)</b>			
Capable Kids and Families	37	50	47
Comparison	63	50	53
<b>Age at time of survey, years (mean, <i>sd</i>)</b>	3.2 ( <i>1.68</i> )	3.5 ( <i>1.81</i> )	3.8 ( <i>1.64</i> )
<b>Sex of child (%)</b>			
Male	58	61	58
Female	42	39	42
<b>Race/ethnicity of child (%)</b>			
White	76	76	81
Black	11	11	9
Hispanic	4	3	3
Other <sup>a</sup>	9	9	7
<b>Severity of disability (%)<sup>b</sup></b>			
Mild	39	39	43
Moderate	44	41	39
Severe	17	20	18
<b>Type of disability/diagnosis (%)</b>			
Language or speech delays	51	47	47
Developmental delays	42	40	46
Cognitive mental delay	12	14	16
Autism	14	15	15
Visual impairment	12	13	14
Cerebral palsy	9	10	13
Physical disability	10	10	13
Down syndrome	13	15	12
Hearing impairment	8	7	6
Traumatic brain injury	4	3	5
Spina bifida	2	2	2
Pervasive developmental delay	5	3	2
Muscular dystrophy	1	2	1
Fragile X	1	0	0
Other genetic disorder	11	12	15
Other health impairment	28	27	25
<b>Number of disabilities (mean, <i>sd</i>)</b>	2.2 ( <i>1.69</i> )	2.2 ( <i>1.76</i> )	2.3 ( <i>1.78</i> )
<b>More than one disability/diagnosis (%)</b>	52	48	51
<b>More than two disabilities/diagnoses (%)</b>	30	30	34

<sup>a</sup> Other race/ethnicity includes: Asian, American Indian/Alaskan Native and multiple races/ethnicity which includes quarter Pakistani, American Indian or Alaskan Native and white, Bi-racial, Black or African American; Hispanic or Latino and white, Black or African American and white; Hispanic or Latino and white, Mixed race, and white and Other (Italian).

<sup>b</sup> At Time 1, 207 of 233 provided this information. At Time 2, 203 of 234 provided this information. At Time 3, 161 of 175 provided this information.

**Table A- 2. Characteristics of Parent/Household**

<b>Characteristic</b>	<b>Time 1 N = 233</b>	<b>Time 2 N = 234</b>	<b>Time 3 N = 175</b>
<b>Parent aware of child's disability (%)</b>			
Before birth	13	17	17
At birth	33	41	36
<b>Marital status (%)</b>			
Married	75	78	79
Single	14	13	10
Live-in partner	4	3	4
Other	5	5	7
<b>Respondent relationship to child (%)</b>			
Mother	92	89	90
Father	3	4	4
Other	3	3	3
<b>Primary caregiver's education (%)</b>			
Did not complete high school	8	9	9
High school diploma/GED	9	13	10
Some college or technical school	33	30	26
College degree	36	36	38
Graduate degree	14	12	17
<b>Primary caregiver employment</b>			
Employed outside home (%)	41	43	46
Hours worked per week (mean, <i>sd</i> )	32.8 (12.01)	32.4 (12.17)	31.6 (12.95)
<b>Secondary caregiver employment</b>			
Employed outside home (%)	79	81	75
Hours worked per week (mean, <i>sd</i> )	41.9 (8.99)	42.9 (9.14)	41.9 (9.66)
<b>Household income (%)</b>			
Less than \$10,000	13	14	13
\$10,000–\$29,999	29	27	25
\$30,000–\$49,999	19	21	19
\$50,000–\$69,999	14	15	17
\$70,000 or more	25	24	26
<b>Household income not adequate (%)</b>	23	26	27
<b>Meets needs, but not wants (%)</b>	33	35	28
<b>Meets needs and at least some wants (%)</b>	44	39	45

**Table A- 3. Percent of Services Used by Family**

	<b>Time 1</b> <i>N</i> = 233	<b>Time 2</b> <i>N</i> = 234	<b>Time 3</b> <i>N</i> = 175
Speech therapy	73	72	70
Occupational therapy	61	65	62
Physical therapy	51	57	59
Preschool special education	30	30	33
Special education	19	25	29
Early Intervention services	31	34	27
Home visiting	30	28	27
Prekindergarten	16	15	17
Developmental therapy	13	14	11
Day care or child development center	12	12	10
Applied Behavioral Analysis	9	6	7
Vision therapy	7	9	7
Early Head Start	3	4	5
Head Start	3	2	3

**Table A- 4. Mean Scores for the Family Outcome Survey Measures**

	<b>Time 1</b> <i>N</i> = 232	<b>Time 2</b> <i>N</i> = 234	<b>Time 3</b> <i>N</i> = 174
Understanding child's strengths and needs (mean, <i>sd</i> )	4.4 (0.56)	4.4 (0.56)	4.4 (0.55)
Knowing rights and advocating for the child (mean, <i>sd</i> )	4.0 (0.80)	4.0 (0.80)	4.0 (0.83)
Helping child develop and learn (mean, <i>sd</i> )	4.4 (0.63)	4.3 (0.65)	4.2 (0.69)
Having support systems (mean, <i>sd</i> )	4.1 (0.76)	4.1 (0.84)	4.1 (0.81)
Accessing community resources (mean, <i>sd</i> )	4.3 (0.65)	4.3 (0.73)	4.2 (0.76)

Note: Outcomes are multi item factors representing and are mean scores ranging from 1 (not at all) to 5 (completely).

**Table A- 5. Mean Scores for the Parent-Child Interaction Questionnaire**

	<b>Time 1</b> <i>N</i> = 232	<b>Time 2</b> <i>N</i> = 234	<b>Time 3</b> <i>N</i> = 174
Mealtime (mean, <i>sd</i> )			
Enjoyable	3.8 (0.87)	3.8 (0.83)	3.7 (0.83)
Stressful	2.7 (1.02)	2.6 (0.99)	2.8 (0.96)
Satisfying	3.8 (0.92)	3.7 (0.93)	3.7 (0.89)
Getting dressed (mean, <i>sd</i> )			
Enjoyable	3.9 (0.97)	3.7 (0.90)	3.8 (0.90)
Stressful	2.5 (1.10)	2.4 (0.99)	2.5 (1.03)
Satisfying	3.9 (1.00)	3.8 (0.90)	3.8 (0.93)
Leaving the house (mean, <i>sd</i> )			
Enjoyable	3.9 (0.91)	3.9 (0.89)	3.8 (0.90)
Stressful	2.7 (1.07)	2.6 (1.07)	2.7 (1.09)
Satisfying	3.9 (0.93)	3.9 (0.91)	3.8 (0.90)
Bath time (mean, <i>sd</i> )			
Enjoyable	4.2 (0.95)	4.3 (0.78)	4.2 (0.83)
Stressful	2.3 (1.23)	2.2 (1.08)	2.2 (1.11)
Satisfying	4.2 (0.92)	4.3 (0.80)	4.2 (0.85)
Bedtime (mean, <i>sd</i> )			
Enjoyable	3.7 (1.01)	3.8 (0.99)	3.7 (0.96)
Stressful	2.7 (1.17)	2.5 (1.03)	2.7 (1.07)
Satisfying	3.8 (1.03)	3.9 (0.97)	3.7 (1.04)

Items are rated on a scale between 1 (never) and 5 (always).

**Table A- 6. Mean Scores for the Family-Professional Practices Scale**

Scale Item	Mean ( <i>sd</i> )	
	Time 2 <i>N</i> = 231	Time 3 <i>N</i> = 173
Really listens to my concerns and requests	4.8 (0.60)	4.7 (0.58)
Treats my family with dignity and respect	4.9 (0.50)	4.8 (0.56)
Sees my children in a positive and healthy way	4.9 (0.51)	4.8 (0.58)
Is sensitive to my family's cultural and ethnic background	4.8 (0.59)	4.7 (0.65)
Provides information I need to make good choices	4.8 (0.60)	4.7 (0.64)
Understands my children's and family's situation	4.8 (0.59)	4.7 (0.63)
Works with my family and me in a flexible and responsible manner	4.8 (0.58)	4.8 (0.58)
Helps me be an active part of getting desired resources and support	4.7 (0.65)	4.6 (0.70)
Presents options about the different kinds of supports and resources available for achieving what my family considers important	4.7 (0.66)	4.5 (0.80)
Is flexible when my family's situation changes	4.8 (0.56)	4.7 (0.69)
Builds on my children's and family's strengths and interests as the primary way of supporting my family	4.7 (0.68)	4.7 (0.68)
Does what they promised to do	4.8 (0.60)	4.7 (0.65)
Works together with my family and me based on mutual trust and respect	4.8 (0.58)	4.7 (0.60)
Recognizes the good things I do as a parent	4.8 (0.57)	4.7 (0.61)
Helps me accomplish my goals and priorities for my children	4.7 (0.61)	4.7 (0.62)
Helps me learn about things I am interested in	4.6 (0.76)	4.6 (0.74)
Supports me when I make a decision	4.7 (0.66)	4.7 (0.65)
Treats my children with dignity	4.9 (0.55)	4.8 (0.55)
Builds on my children's strength	4.9 (0.50)	4.8 (0.61)
Values my opinion about my children's needs	4.8 (0.58)	4.8 (0.61)

Items are rated on a scale between 1 (very dissatisfied) and 5 (very satisfied).

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# Appendix B: Family Outcomes Survey Results

**Table B- 1. Mean scores for all factors in the Family Outcomes Survey (Full Sample)**

	Mean ( <i>sd</i> )		
	Time 1 N = 232	Time 2 N = 234	Time 3 N = 174
<b>Outcome 1. Understanding Child’s Strengths/Needs</b>			
I know the next steps for my child’s growth and learning.	4.1 (0.82)	4.1 (0.86)	4.0 (0.87)
I understand my child’s strengths and abilities.	4.5 (0.70)	4.5 (0.69)	4.5 (0.63)
I understand my child’s delays and/or needs.	4.4 (0.72)	4.5 (0.69)	4.4 (0.70)
I am able to tell when my child is making progress.	4.6 (0.63)	4.6 (0.65)	4.6 (0.65)
<b>Outcome 2. Knowing Rights and Advocating for the Child</b>			
I am able to find/use the services and programs available to my family.	4.1 (0.86)	4.2 (0.92)	4.1 (0.93)
I know my rights related to my child’s special needs.	3.9 (1.15)	4.0 (1.08)	4.0 (1.02)
I know who to contact and what to do when I have questions or concerns.	4.2 (0.96)	4.3 (0.93)	4.2 (0.90)
I know what options are available when my child leaves the program.	3.5 (1.24)	3.4 (1.30)	3.5 (1.28)
I am comfortable asking for services & supports our child and family need.	4.3 (0.94)	4.3 (0.91)	4.3 (0.96)
<b>Outcome 3. Helping Child Learn and Develop</b>			
I am able to help my child get along with others.	4.2 (0.84)	4.3 (0.82)	4.1 (0.87)
I am able to help my child learn new skills.	4.4 (0.73)	4.4 (0.78)	4.2 (0.76)
I am able to help my child take care of his/her needs.	4.5 (0.77)	4.4 (0.86)	4.3 (0.84)
I am able to work on my child’s goals during every day routines.	4.3 (0.79)	4.3 (0.87)	4.2 (0.86)
<b>Outcome 4. Having Support Systems</b>			
I am comfortable talking to family and/or friends about my child’s needs.	4.5 (0.86)	4.5 (0.83)	4.4 (0.87)
I have friends or family members who listen and care.	4.6 (0.81)	4.6 (0.88)	4.5 (0.94)
I am able to talk with other families who have a child with similar needs.	3.4 (1.43)	3.5 (1.44)	3.6 (1.43)
I have friends or family members I can rely on when I need help.	4.2 (1.09)	4.2 (1.20)	4.3 (1.05)
I am able to take care of my own needs and do things I enjoy.	3.7 (1.17)	3.6 (1.25)	3.7 (1.22)
<b>Outcome 5. Accessing Community Resources</b>			
My child participates in social, recreational, religious activities we want.	3.8 (1.20)	3.8 (1.17)	3.8 (1.16)
My family is able to do things we enjoy together.	4.1 (0.99)	4.1 (0.98)	4.1 (1.02)
My family’s medical needs are met.	4.3 (0.93)	4.3 (1.01)	4.3 (0.94)
My family’s dental needs are met. <sup>a</sup>	4.1 (1.29)	4.4 (1.15)	4.0 (1.25)
My child care needs are met.	4.4 (0.96)	4.4 (1.00)	4.3 (1.06)
My family’s transportation needs are met.	4.6 (0.81)	4.5 (0.92)	4.5 (0.87)
My family’s food, clothing, and housing needs are met.	4.6 (0.80)	4.5 (0.90)	4.5 (0.87)

<sup>a</sup> At Time 1, just 28 individuals responded to this item, the *n* for all other items ranged from 229–232. At Time 2, just 18 individuals responded to this item, the *n* for all other items ranged from 229-234. At Time 3, 173 individuals responded to this item, the *n* for all other items ranged from 170–174. For the 5 factors, Cronbach’s  $\alpha$  ranged from 0.77 to 0.86.

**Table B- 2. Mean scores for all factors in the Family Outcomes Survey over Time (Limited Sample)**

	<b>Time 1</b> <i>N</i> = 113	<b>Mean (sd)</b> <b>Time 2</b> <i>N</i> = 113	<b>Time 3</b> <i>N</i> = 113
<b>Outcome 1. Understanding Child's Strengths/Needs</b>			
I know the next steps for my child's growth and learning.	4.0 (0.79)	4.1 (0.86)	4.0 (0.87)
I understand my child's strengths and abilities.	4.5 (0.68)	4.4 (0.74)	4.5 (0.63)
I understand my child's delays and/or needs.	4.4 (0.71)	4.4 (0.71)	4.4 (0.74)
I am able to tell when my child is making progress.	4.6 (0.68)	4.5 (0.74)	4.6 (0.62)
<b>Outcome 2. Knowing Rights and Advocating for the Child</b>			
I am able to find and use the services and programs available to my family.	4.1 (0.90)	4.1 (0.98)	4.1 (0.93)
I know my rights related to my child's special needs.	3.9 (1.07)	4.0 (1.02)	4.1 (0.95)
I know who to contact and what to do when I have questions or concerns.	4.3 (0.93)	4.4 (0.83)	4.3 (0.85)
I know what options are available when my child leaves the program.	3.5 (1.23)	3.6 (1.26)	3.6 (1.21)
I am comfortable asking for services & supports that our child and family need.	4.3 (0.89)	4.3 (0.92)	4.3 (1.02)
<b>Outcome 3. Helping Child Learn and Develop</b>			
I am able to help my child get along with others.	4.2 (0.86)	4.1 (0.87)	4.1 (0.87)
I am able to help my child learn new skills.	4.3 (0.77)	4.3 (0.79)	4.2 (0.78)
I am able to help my child take care of his/her needs.	4.4 (0.81)	4.3 (0.83)	4.3 (0.91)
I am able to work on my child's goals during every day routines.	4.4 (0.77)	4.2 (0.93)	4.2 (0.87)
<b>Outcome 4. Having Support Systems</b>			
I am comfortable talking to family and/or friends about my child's needs.	4.6 (0.79)	4.5 (0.78)	4.5 (0.82)
I have friends or family members who listen and care.	4.7 (0.72)	4.6 (0.83)	4.5 (0.94)
I am able to talk with other families who have a child with similar needs.**	3.5 (1.50)	3.6 (1.44)	3.9 (1.31)
I have friends or family members I can rely on when I need help.	4.3 (1.10)	4.2 (1.21)	4.2 (1.08)
I am able to take care of my own needs and do things I enjoy.**	3.7 (1.21)	3.5 (1.25)	3.8 (1.21)
<b>Outcome 5. Accessing Community Resources</b>			
My child participates in social, recreational, or religious activities that we want.	3.8 (1.23)	3.9 (1.09)	3.9 (1.18)
My family is able to do things we enjoy together.	4.1 (1.01)	4.0 (1.03)	4.2 (0.99)
My family's medical needs are met.	4.3 (0.93)	4.2 (1.08)	4.3 (0.94)
My family's dental needs are met. <sup>a</sup>	4.1 (1.38)	4.4 (0.92)	4.1 (1.18)
My child care needs are met.	4.4 (1.01)	4.3 (1.11)	4.4 (1.05)
My family's transportation needs are met.	4.6 (0.88)	4.5 (0.96)	4.5 (0.92)
My family's food, clothing, and housing needs are met.	4.6 (0.81)	4.5 (0.94)	4.5 (0.92)

<sup>a</sup> At Time 1, just 13 individuals responded to this item, the *n* for all other items ranged from 112-113. At Time 2, just 8 individuals responded to this item, the *n* for all other items ranged from 111-113. At Time 3, 112 individuals responded to this item, the *n* for all other items ranged from 110-113.

Note: Paired sample *t*-tests indicate that the following time-to-time differences are statistically significant at  $p < .05$  or less: Iknowmyrights...1 vs. Iknowmyrights...3; Iamabletowork...1 vs. Iamabletowork...2; Iamabletowork...1 vs. Iamabletowork...3; Iamabletotalk...1 vs. Iamabletotalk...3; Iamabletotalk...2 vs. Iamabletotalk...3; and Iamabletotakecare...2 vs. Iamabletotakecare...3. For the 5 factors, Cronbach's  $\alpha$  ranged from 0.76 to 0.88.

\*\*Additional analyses for the sample of families who responded at all three data collection points show that CKF families rated this item "I am able to talk with other families who have a child with similar needs" significantly higher than families in the comparison group at Times 2 and 3 ( $p < .05$ ). In contrast, comparison families responded significantly higher than CKF families to this item: "I am able to take care of my own needs and do things I enjoy" at Times 1 and 3 ( $p < .05$ ). (These results are available from Chapin Hall upon request.)



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# Appendix C: Survey Measures

## Family Outcome Survey; Section A: Family Outcomes

The following statements focus on the ways in which you support your child's needs. For each statement below, please select which option best describes your family right now: not at all, a little, somewhat, almost, or completely.

	Not at all	A little	Some-what	Almost	Completely
<b>Outcome 1. Understanding Child's Strengths/Needs</b>					
I know the next steps for my child's growth and learning.	1	2	3	4	5
I understand my child's strengths and abilities.	1	2	3	4	5
I understand my child's delays and/or needs.	1	2	3	4	5
I am able to tell when my child is making progress.	1	2	3	4	5
<b>Outcome 2. Knowing Rights and Advocating for the Child</b>					
I am able to find and use the services and programs available to my family.	1	2	3	4	5
I know my rights related to my child's special needs.	1	2	3	4	5
I know who to contact and what to do when I have questions or concerns.	1	2	3	4	5
I know what options are available when my child leaves the program.	1	2	3	4	5
I am comfortable asking for services & supports that our child and family need.	1	2	3	4	5
<b>Outcome 3. Helping Child Learn and Develop</b>					
I am able to help my child get along with others.	1	2	3	4	5
I am able to help my child learn new skills.	1	2	3	4	5
I am able to help my child take care of his/her needs.	1	2	3	4	5
I am able to work on my child's goals during every day routines.	1	2	3	4	5
<b>Outcome 4. Having Support Systems</b>					
I am comfortable talking to family and/or friends about my child's needs.	1	2	3	4	5
I have friends or family members who listen and care.	1	2	3	4	5
I am able to talk with other families who have a child with similar needs.	1	2	3	4	5
I have friends or family members I can rely on when I need help.	1	2	3	4	5
I am able to take care of my own needs and do things I enjoy.	1	2	3	4	5
<b>Outcome 5. Accessing Community Resources</b>					
My child participates in social, recreational, or religious activities that we want.	1	2	3	4	5
My family is able to do things we enjoy together.	1	2	3	4	5
My family's medical and dental needs are met.	1	2	3	4	5
My child care needs are met.	1	2	3	4	5
My family's transportation needs are met.	1	2	3	4	5
My family's food, clothing, and housing needs are met.	1	2	3	4	5

---

## Parent-Child Interaction Questionnaire

Today's Date \_\_\_ / \_\_\_ / \_\_\_

Please tell us about the following activities you may have participated in with your child during the past two weeks.

### Meal Time

In general, in the past two weeks, <i>Meal time</i> with my child has been...	Never	Rarely	Sometimes	Very often	Always
Enjoyable	1	2	3	4	5
Stressful	1	2	3	4	5
Satisfying	1	2	3	4	5

Other thoughts about Meal Time during the past two weeks:

### Getting Dressed

In general, in the past two weeks, getting my child dressed has been...	Never	Rarely	Sometimes	Very often	Always
Enjoyable	1	2	3	4	5
Stressful	1	2	3	4	5
Satisfying	1	2	3	4	5

Other thoughts about Getting Dressed during the past two weeks:

### Leaving the House

In general, in the past two weeks, leaving the house with my child has been...	Never	Rarely	Sometimes	Very often	Always
Enjoyable	1	2	3	4	5
Stressful	1	2	3	4	5
Satisfying	1	2	3	4	5

Other thoughts about Leaving the House during the past two weeks:

### Bath Time

In general, in the past two weeks, Bath time with my child has been...	Never	Rarely	Sometimes	Very often	Always
Enjoyable	1	2	3	4	5
Stressful	1	2	3	4	5
Satisfying	1	2	3	4	5

Other thoughts about Bath Time during the past two weeks:

Bed Time

In general, in the past two weeks, Bed time with my child has been...	Never	Rarely	Sometimes	Very often	Always
Enjoyable	1	2	3	4	5
Stressful	1	2	3	4	5
Satisfying	1	2	3	4	5

Other thoughts about Bed Time during the past two weeks:

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## Family-Professional Practices Scale

### Family-Professional Practices

#### CKF Participants Instructions

This survey is about how you feel about the Capable Kids and Families staff member who works the most with your child and you. Think about how satisfied you are with your CKF Specialist over **the last six months**

#### How satisfied are you that your CKF Specialist...

	Very dissatisfied	Dissatisfied	Neither	Satisfied	Very satisfied
1. Really listens to my concerns or requests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Treats my family and me with dignity and respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Sees my child(ren) in a positive healthy way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is sensitive to my family's cultural and ethnic background	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Provides me information I need to make good choices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Understands my child(ren) and family's situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Works with my family and me in a flexible and responsive manner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Helps me be an active part of getting desired resources and support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Presents options about different kinds of support and resources available for achieving what my family considers important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- |                                                                                                             |                          |                          |                          |                          |                          |
|-------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 10. Is flexible when my family situation changes                                                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Builds on my child(ren) and family's strengths and interests as the primary way of supporting my family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Does what they promise to do                                                                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Works together with my family and me based on mutual trust and respect                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Recognizes the good things I do as a parent                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Helps and me accomplish my goals and priorities for my child(ren)                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Helps me learn about things I am interested in                                                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Supports me when I make a decision                                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Treats my child with dignity                                                                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Builds on my child's strengths                                                                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Values my opinion about my child's needs                                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

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## Family Demographic Survey

We would like some information about your child who is currently receiving service, you and your family. Please complete the sections below by either filling in the blank space or circling your choice.

### ABOUT YOUR CHILD

Birth date of child receiving services \_\_\_/\_\_\_/\_\_\_

Gender of child with disability (please circle)      \_\_\_Female      \_\_\_Male

How do you describe the child? (Check all that apply)

- \_\_\_ American Indian or Alaska Native
- \_\_\_ Asian
- \_\_\_ Black or African American
- \_\_\_ Hispanic or Latino
- \_\_\_ Native Hawaiian or Other Pacific Islander
- \_\_\_ White
- \_\_\_ Other (please specify): \_\_\_\_\_

Has your child been diagnosed?

- \_\_\_ Yes
- \_\_\_ No (If no, go to question # 7)

Were you aware of your child's diagnosis with a disability prior to his/her birth?

- \_\_\_ Yes
- \_\_\_ No

Was your child's diagnosis made at birth?

- \_\_\_ Yes
- \_\_\_ No. If no, how old was your child when he/she was diagnosed with a disability?

Child's age \_\_\_\_\_

Please CHECK the item(s) that most accurately describes your child (Please check all that apply)

- \_\_\_ Down syndrome
- \_\_\_ Autism
- \_\_\_ Cerebral Palsy
- \_\_\_ Hearing Impairment
- \_\_\_ Developmental delay
- \_\_\_ Muscular Dystrophy
- \_\_\_ Traumatic Brain Injury
- \_\_\_ Other Genetic Disorder (please describe) \_\_\_\_\_
- \_\_\_ Other (please describe) \_\_\_\_\_
- \_\_\_ Language/Speech delay
- \_\_\_ Fragile X
- \_\_\_ Visual Impairment
- \_\_\_ Physical Disability
- \_\_\_ Cognitive/Mental delay
- \_\_\_ Spina Bifida
- \_\_\_ Pervasive Developmental Delay (PDD)

Have professionals described your child's delay or disability as

- \_\_\_ Mild
- \_\_\_ Moderate
- \_\_\_ Severe

9. Which of the following is your child involved in? (Please check all that apply)

- |                                               |                                                               |
|-----------------------------------------------|---------------------------------------------------------------|
| <input type="checkbox"/> Early Head Start     | <input type="checkbox"/> Early Intervention Services          |
| <input type="checkbox"/> Pre-K                | <input type="checkbox"/> Special Education                    |
| <input type="checkbox"/> Head Start           | <input type="checkbox"/> Preschool Special Education          |
| <input type="checkbox"/> Home Visiting        | <input type="checkbox"/> Day Care or Child Development Center |
| <input type="checkbox"/> Speech Therapy       | <input type="checkbox"/> Developmental Therapy                |
| <input type="checkbox"/> Physical Therapy     | <input type="checkbox"/> Vision Therapy                       |
| <input type="checkbox"/> Occupational Therapy | <input type="checkbox"/> Applied Behavioral Analysis          |

10. What other services does your child receive?

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#### ABOUT YOU AND YOUR FAMILY

11. What is your relationship to the child that is currently receiving services?

- Mother  
 Father  
 Grandmother  
 Grandfather  
 Other adult relative (please specify) \_\_\_\_\_  
 Other (please specify): \_\_\_\_\_

12. Please think of all of the people who currently live in your home (spouse, partner, relatives, friends, children, etc. ). Please list below the first initial of each of these people and their relationship to you.

First initial	Relationship to you	First initial	Relationship to you
1.		6.	
2.		7.	
3.		8.	
4.		9.	
5.		10.	

13. Your Marital Status:

- Single  
 Married  
 Live-in Partner  
 Separated  
 Divorced  
 Widowed

14. Are you currently employed outside your home?

- Yes . If yes, how many hours per week do you typically work? \_\_\_\_\_ hours/week  
 No

15. Can you easily take time off during the day or rearrange you work schedule to attend to the needs of your child with a disability?

Yes

No

16. Is your child's other primary caregiver employed outside the home?

Yes. If yes, how many hours per week does he/she typically work? \_\_\_\_\_ hours/week

No

17. Can he/she easily take time off during the day or rearrange his/her work schedule to attend to the needs of your child with a disability?

Yes

No

18. My family's total income is between:

Under \$10,000

\$10,000-\$29,000

\$30,000-\$49,000

\$50,000-\$69,000

\$70,000 and over

19. How adequate do you feel your family's income is in meeting the needs of your family? (Place a check next to the statement that best describes your situation. )

More than adequate to meet all of our needs and wants

More than adequate to meet our needs and some of our wants

Adequate to meet our needs, but no wants

Not adequate to meet all of our needs

Much less than adequate to meet even our basic needs

20. Your highest educational level:

Less than 8th grade

Less than 12th grade

High School diploma or GED

Some College or Technical school

College degree

Graduate degree

21. Child's other primary caregiver's highest educational level:

Less than 8th grade

Less than 12th grade

High School diploma or GED

Some College or Technical school

College degree

Graduate degree



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## CKF Focus Group Guide

### THE COMMUNITY PARTNERSHIP GROUP INTERVIEW GUIDE Parents/Guardians of Children with Disabilities

We really appreciate your taking time to talk with us.

Before we get started I must get your agreement to participate in the study and make sure you understand your role in the study.

[READ OVER CONSENT FORM CHECKLIST. REVIEW CHECKLIST ON 2<sup>nd</sup> PAGE AND ANSWER ANY QUESTIONS.]

HAVE **ALL** RESPONDENTS PROVIDED VERBAL CONSENT?

YES ⇒ GO TO NEXT BOX

NO ⇒ ANY INDIVIDUAL WHO DOES NOT CONSENT WILL BE  
ASKED TO LEAVE THE GROUP

RECORD THE FOLLOWING INFORMATION:

DATE: \_\_\_\_\_

LOCATION: \_\_\_\_\_

NUMBER OF PARENTS/GUARDIANS PRESENT: \_\_\_\_\_

MALES: \_\_\_\_\_

FEMALES: \_\_\_\_\_

OTHER PEOPLE PRESENT: \_\_\_\_\_

DID **ALL** RESPONDENTS CONSENT TO AUDIO RECORDING?

YES ⇒ START INTERVIEW AND RECORDING

NO ⇒ START INTERVIEW WITHOUT RECORDING

## **Focus Group Interview Guide Capable Kids and Families**

Thank you for participating in our study through this focus group. This study is being done to learn more about the service experiences of parents of young children with disabilities, including Early Intervention, the Capable Kids and Families Program (CKF), and other services. We are conducting focus groups with family members in three different regions of Missouri.

Today I would like to speak with you about how your family takes care of your CKF-enrolled child, how you use services to help care for your child(ren), if you have unmet service needs, and how services might be improved for you and your family. We want to make sure we cover specific topics and give all of you the opportunity to share your opinions; consequently, we may need to cut short some answers or topics in order to finish the discussion in our allotted time.

Possible Focus Group Questions:

1. To begin, we would just like to know a little about you and your family. Let's go around the room and have each of you tell us what you would like to be called, how many children you have, and the age of your child(ren) with disabilities.
2. Now can you briefly describe a typical day with your child who is receiving services? What is it like to take care of him or her and what services do you use to help with his or her care?
  - Of those services, which do you find the most helpful/enjoyable for your family?
  - Is there a service you wish your family had to make it easier to take care of your child?
3. Let's talk about your experiences with the CKF program. First, how did you learn about the CKF program.
  - How long have you been involved with the program?
4. Why did you and your family decide to work with CKF?
  - What did you expect from being involved with the program?
  - Has the program been different from what you expected? If so how?
  - Is there something that you and your family especially like or value about the program? Dislike about the program?
5. I'd like to hear about your child's experiences with CFK.
  - What does your child like best about the program?
  - Has your child had any problems in the program?
  - What is your child learning? What changes do you see in his/her development?
6. There are 3 main components of the CKF program, Home Visiting, Therapy Equipment Loan Program, and Connections to Other Families. I'd like to learn about your experiences with each of these program components.
  - **Home Visiting:** What are your perceptions about this service? Is this something you would have without CKF? How do you feel when the home visitor is in your home? What happens during home visits? Describe the relationship (if applicable) your child has with your home visitor? How are they scheduled? How often do they occur? Is that frequency comfortable for you and your family? Does the frequency meet your family's needs? What is the impact of having the home visiting service for you, your child, and your family? Do you have any recommendations for changes to home visits?

- **Therapy Equipment:** What are your perceptions about this service? Is this something you would have without CKF? What is the impact of being able to have therapy equipment remain in your home for you, your child, and your family? (Probe – Do you find this allows you to incorporate therapy activities into daily life? Do you feel like a more active partner with your child’s therapists as a result of having therapy equipment in your home? Do you have any recommendations for changes to the equipment loan program?)
  - **Connections/Playgroups:** *[Note for interviewer: Socialization activities allow families opportunities to provide information, resources and emotional support to new parents looking for answers and solutions to rearing a child with a disability. They also provide a safe forum for discussing common fears and concerns. The playroom has been designed to offer opportunities for children of all abilities. The Somotron ball pool has soothing vibrations and soft lights that provide a relaxing experience. The Equipony simulates therapeutic horseback riding. The toys provide play activities on many levels.]* How many of you participate in this service? Why or why not? What are your perceptions about this service? Do you connect with (find comfort in) the other families that you meet through CKF? Has anyone met with CKF families outside of the CKF-sponsored activities (i.e. Playgroups)? Do you have any recommendations for changes to the CKF groups?
7. Have your expectations about the program changed since you first started?
    - What would you like to get out of the program going forward?
    - Is it easy to remain involved with CFK?
    - What is the communication like with CFK staff?
    - Are there any changes you would recommend for the program?
  8. Now I’d like to find out more about your other supports and services. First, who/what do you consider as part of your social/emotional support system? (Probe: Extended family, friends, faith-based communities, service providers, other parents with children with disabilities.)
    - Do you feel that you have people to turn to when you need a break or need some back-up?
  9. With what other types of services are you and your family involved? (Probe: EI, physical therapies, occupational therapies, speech therapies, social services, community services (day care or child development center), or health care services, etc.)
    - How did you find out about these services?
    - How easy or difficult was it to access these services?
  10. What was your experience like with (name of service)?
    - Did you find them helpful? If so, how? Please provide examples.
    - What, if anything, could have made them more helpful?
    - Would you use them if you needed again in the future?
  11. Do these services you use help your child meet his/her specific IFSP goals? If so, how (and which services)?
    - Overall, do you feel your child is meeting his/her specific IFSP goals as fast as you expected? What contributes to meeting or not meeting goals?
  12. Do the services you and your family receive work together?
    - Do they work well together and build upon each other – are they complementary? If so, please provide examples.

- Are the service providers able to communicate with each other? If so, do they? Is this helpful? If not, would you like them to? What are any barriers to communication?
  - Are they duplicative or cumbersome? If so, please provide examples.
  - Do they contradict each other? If so, please provide examples.
13. Do you feel confident that you understand your child's strengths and needs?
- How do you stay on top of your child's changing needs/strengths?
  - Do you look to any particular service providers for assistance/guidance?
14. Are there other services that would benefit you, your child, or your family? (Probe: Are there gaps in service?) If so, what types of services would you seek and what are the barriers for you to these services? (Probe: cost, work schedules; transportation; waiting lists; language barriers; immigration status; awareness.)
15. Did you have any concerns about your child in the past year that you didn't seek assistance for?
- If yes, what were they?
  - Can you share why you didn't seek help?
16. Do you feel that you are able to access the resources you and your family need?
- How do you learn about resources?
  - Do you feel that this is sufficient? What, if anything, would you suggest as a way to learn about more resources?
17. Do you feel that confident that you know how best to advocate yourself and your family?
- If yes, what are some ways that you have learned how to advocate and what are some examples of your advocacy efforts?
  - If no, would you like to learn how to be a more effective advocate? Is there a service provider you would turn to for that?

I can't thank you enough for spending time with me today and sharing such personal aspects of your lives. Your experiences really add to our understanding of the challenges families with children in services face and what you need to succeed. As a result, we can help improve existing services and give more families access to those services.

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## Comparison Group Focus Group Guide

### THE COMMUNITY PARTNERSHIP GROUP INTERVIEW GUIDE Parents/Guardians of Children with Disabilities

We really appreciate your taking time to talk with us.

Before we get started I must get your agreement to participate in the study and make sure you understand your role in the study.

[READ OVER CONSENT FORM CHECKLIST. REVIEW CHECKLIST ON 2<sup>nd</sup> PAGE AND ANSWER ANY QUESTIONS.]

HAVE ALL RESPONDENTS PROVIDED VERBAL CONSENT?

YES ⇒ GO TO NEXT BOX

NO ⇒ ANY INDIVIDUAL WHO DOES NOT CONSENT WILL BE  
ASKED TO LEAVE THE GROUP

RECORD THE FOLLOWING INFORMATION:

DATE: \_\_\_\_\_

LOCATION: \_\_\_\_\_

NUMBER OF PARENTS/GUARDIANS PRESENT: \_\_\_\_\_

MALES: \_\_\_\_\_ FEMALES: \_\_\_\_\_

OTHER PEOPLE PRESENT: \_\_\_\_\_

DID ALL RESPONDENTS CONSENT TO AUDIO RECORDING?

YES ⇒ START INTERVIEW AND RECORDING

NO ⇒ START INTERVIEW WITHOUT RECORDING

## Focus Group Interview Guide

Thank you for participating in our study through this focus group. This study is being done to learn more about the service experiences of parents of young children with disabilities, including Early Intervention and other services. We are conducting focus groups with family members in three different regions of Missouri.

Today I would like to speak with you about how your family takes care of your EI-involved child, how you use services to help care for your child(ren), if you have unmet service needs, and how services might be improved for you and your family. We want to make sure we cover specific topics and give all of you the opportunity to share your opinions; consequently, we may need to cut short some answers or topics in order to finish the discussion in our allotted time.

### Possible Focus Group Questions:

1. To begin, we would just like to know a little about you and your family. Let's go around the room and have each of you tell us what you would like to be called, how many children you have, and the age of your child(ren) with disabilities.
2. Now can you briefly describe a typical day with your child who is receiving services? What is it like to take care of him or her and what services do you use to help with his or her care?
  - Of those services, which do you find the most helpful/enjoyable for your family?
  - Is there a service you wish your family had to make it easier to take care of your child?
3. Let's talk about your experiences with EI services. First, How did you learn about the EI services?
  - How long have you been involved with EI services?
4. Why did you and your family decide to work with EI?
  - What did you expect from being involved with EI?
  - Have the services been different from what you expected? If so how?
  - Is there something that you and your family especially like or value about the services? Dislike about the services?
5. Does anyone receive home visiting services through EI or a different service (note service provider)?
  - If no, is this a service you would like to have? If you would like to have this service, what would you hope to gain from a home visiting service?
  - If yes, what are your perceptions about this service? How do you feel when the home visitor is in your home? What happens during home visits? How are they scheduled? How often do they occur? Is that frequency comfortable for you and your family? Does the frequency meet your family's needs? What is the impact of having the home visiting service for you, your child, and your family? Do you have any recommendations for changes to home visits?

6. Have your expectations about EI changed since you first started?
  - What would you like to get out of the program going forward?
  - Is it easy to remain involved with EI?
  - What is the communication like with EI staff?
  
7. Now I'd like to find out more about your other supports and services. First, who/what do you consider as part of your social/emotional support system? (Probe: Extended family, friends, faith-based communities, service providers, other parents with children with disabilities.)
  - Do you feel that you have people to turn to when you need a break or need some back-up?
  
8. With what other types of services are you and your family involved? (Probe: physical therapies, occupational therapies, speech therapies, social services, community services (day care or child development center), or health care services, etc.)
  - How did you find out about these services?
  - How easy or difficult was it to access these services?
  
9. What was your experience like with (name of service)?
  - Did you find them helpful? If so, how? Please provide examples.
  - What, if anything, could have made them more helpful?
  - Would you use them if you needed again in the future?
  
10. During any therapies, does the provider bring equipment? If yes:
  - If the service is home-based, can the equipment stay at your home between appointments? If the service is center-based, can you borrow the equipment for your child's use at home?
    - i. If no, how do you integrate the therapies between sessions? Is that easy/difficult? What would having regular access to therapeutic equipment mean to your child/family?
    - ii. If yes, what is the impact of being able to have therapy equipment remain in your home for you, your child, and your family? (Probe - Do you find this allows you to incorporate therapy activities into daily life? Do you feel like a more active partner with your child's therapists as a result of having therapy equipment in your home?)
  
11. I'd like to hear more about your child's experiences his/her services.
  - What does your child like best about the services s/he is involved in?
  - Has your child had any problems in the program(s)?
  - What is your child learning? What changes do you see in his/her development?
  
12. Do the services you and your family receive have work together?
  - Do they work well together and build upon each other – are they complementary? If so, please provide examples.

- Are the service providers able to communicate with each other? If so, do they? Is this helpful? If not, would you like them to? What are any barriers to communication?
  - Are they duplicative or cumbersome? If so, please provide examples.
  - Do they contradict each other? If so, please provide examples.
13. Do these services you use help your child meet his/her specific IFSP goals? If so, how (and which services)?
- Overall, do you feel your child is meeting his/her specific IFSP goals as fast as you expected? What contributes to meeting or not meeting goals?
14. Do you have the opportunity to receive information, resources and emotional support as a parent looking for answers, ideas, and solutions about having child with a disability? If yes, please provide examples? If no, is this something you would like to have?
- Do you have access to and make use of a safe forum for discussing common fears and concerns? If yes, please provide examples? If no, is this something you would like to have?
  - Does your child have the ability to interact with other children with disabilities in a safe, nurturing environment? If yes, please provide examples? If no, is this something you would like to have?
15. Do you feel confident that you understand your child's strengths and needs?
- How do you stay on top of your child's changing needs/strengths?
  - Do you look to any particular service providers for assistance/guidance?
16. Are there other services that would benefit you, your child, or your family? (Probe: Are there gaps in service?) If so, what types of services would you seek and what are the barriers for you to these services? (Probe: cost, work schedules; transportation; waiting lists; language barriers; immigration status; awareness.)
17. Did you have any concerns about your child in the past year that you didn't seek assistance for?
- If yes, what were they?
  - Can you share why you didn't seek help?
18. Do you feel that you are able to access the resources you and your family need?
- How do you learn about resources?
  - Do you feel that this is sufficient? What, if anything, would you suggest as a way to learn about more resources?
19. Do you feel that confident that you know how best to advocate yourself and your family?
- If yes, what are some ways that you have learned how to advocate and what are some examples of your advocacy efforts?
  - If no, would you like to learn how to be a more effective advocate? Is there a service provider you would turn to for that?

I can't thank you enough for spending time with me today and sharing such personal aspects of your lives. Your experiences really add to our understanding of the challenges families with children in services face and what you need to succeed. As a result, we can help improve existing services and give more families access to those services.



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# **Appendix D: Focus Group Recruitment and Consent Materials**

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## Comparison Family Letter of Invitation—Focus Group

Letterhead

Dear Parent,

Thank you for participating in our survey process to learn more about programs and services for families and children with disabilities. We are writing to ask you to participate in a focus group on this topic in a small group with other parents. The focus group meeting will take about 90 minutes and it is completely voluntary. Whether or not you participate will have no effect on current or future receipt of services. It will be held from 1:30 pm to 3:00 pm on Saturday, March 9, 2013 at the Arc's Family Center. The Arc's Family Center is located at 1177 N. Warson Road, St. Louis, MO. We will provide a \$25 gift card to thank you for your time.

We have asked Chapin Hall at the University of Chicago to lead the focus groups. Chapin Hall is an independent research organization that does research in order to improve policies and programs for children. The focus groups will be audio taped for research purposes, provided all members of the group consent to the taping otherwise the researchers will take notes on the conversation.

We believe that parents are critical in helping children develop and get ready for school. We are interested in parents experiences with the programs and services that are available for children with disabilities and how to improve them to better meet the needs of children and families.

Results of the conversations with parents will be included in a final report written by Chapin Hall to the Community Partnership. No parent or children's names will be included in the report. Nothing that is said in these discussions will ever be linked to the name of the person who said it in any report. Additionally, your name, child's name, or any other identifiable information will not be shared by Chapin Hall with The Community Partnership.

We hope you will consider participating in this opportunity to share your views. Parents often enjoy the chance to share their joys and concerns with fellow parents, and to know that they are being listened to as a part of a process to understand and change how things are working.

Please call or email Jean Darnell or return the enclosed self-addressed, postage-paid postcard if you are willing to participate. You may also send an email to the address below. If you do not wish to participate in the focus group, please call or email Jean Darnell and she will take your name off of the list

If you agree to participate, someone will call you a few days before the focus group happens to make sure you can still participate, and answer any questions you may have. If you have any questions at this time, please contact Jean Darnell at 888-541-4636 or [jean.darnell@thecommunitypartnership.org](mailto:jean.darnell@thecommunitypartnership.org)

Thank you,

Jean Darnell  
Research Coordinator  
The Community Partnership

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## Comparison Family Consent Form—Focus Group

# ChapinHall

at the University of Chicago

Policy research that benefits children, families, and their communities

### Services for Children with Disabilities

#### Informed Verbal Consent for Family Members

Chapin Hall at the University of Chicago is an independent policy research center whose mission is to build knowledge that improves policies and programs for children, youth, families, and their communities. Researchers at Chapin Hall are conducting this study for The Community Partnership to learn more about the service experiences of parents of young children with disabilities, including Early Intervention and other services that are received. We are conducting focus groups with family members in three different regions of Missouri. A focus group is a small group of people brought together to participate in a guided discussion of a specific topic. Before we begin, I need to provide you with information about the study and obtain your consent to be interviewed. This process is called informed consent. You may ask questions about the study or process at any point.

This study is being conducted to help us learn about how families take care of their children, how they use services to help care for their children, unmet needs for services, and how services could be improved. We are conducting six voluntary focus groups with 8 to 10 family members in each of three areas of the state, two rural areas and one urban area. The focus group will include questions about you and your child and your experiences with services for children with disabilities. Potential questions include the following:

- • Now can you briefly describe a typical day with your child who is receiving services? What is it like to take care of him or her and what services do you use to help with his or her care?
- • What kinds of services are you currently using for your child? How did you find out about these services? How easy or difficult was it to access them?
- • What was your experience like with the Early Intervention program?
- • Are there other services that would benefit you or your child?

The only risk to you for participating in the focus group is the possibility that someone outside of this group will learn what you have told us. However, to prevent this from happening, we will take the following steps. If you agree to participate in the focus group, we will keep all of your answers private and confidential. We also ask you not to share today's discussion with others. We will not share your name or other identifying information with The Community Partnership, other agency staff or use it in any communication or written reports about the study. The information we collect from you and other parents will be used to write reports for The Community Partnership, in which we will summarize responses from many people. General things we learn from the study may also be presented at conferences or professional meetings, and in written articles.

It is possible in these reports and data presentations that we will use quotes from the focus group to illustrate common themes in the information from the focus groups. If we choose to quote from a focus group participant, we will not include any information such as name, age, race, or location that could be

used to identify you. If you tell us something and we write it in a report, no one will know that you were the person who said it.

The focus group will last for about 90 minutes. We would like to audiotape the discussion to provide a more accurate record. If everyone in the group does not agree to the recording of the discussion, we will not record the discussion but take notes instead. If we do record, the recording will be erased one year after we complete our transcript and analysis of the focus group.

Your participation in the focus group is voluntary. Whether or not you choose to participate will have no impact on the services you receive. To thank you for your time, we will provide you with a Wal-Mart gift card for \$25.

Now I will review each of these conditions and answer any questions you may have.

- Chapin Hall researchers will be conducting six focus groups with parents of young children with disabilities. You will be one of 8 to 10 participants in one of these six focus groups.
- You are agreeing to participate in an approximately 90 minute discussion that will be completed now.
- Whether or not you choose to participate will have no impact on the services you receive.
- Your participation is voluntary and refusing to participate or to answer any question will not result in any consequences or penalties.
- What you say in the focus group may be quoted in a report or presentation. However, the researchers will keep everything you say in the focus group confidential and will not share it with anyone outside the research team. Your name and other identifying information will not be used in any report or presentation and will be destroyed at the end of the study.
- You agree not to share comments of other parents in the focus group with others.
- The information collected for the study will be destroyed in 5 years after the study is completed.
- You are being asked to consent to the focus group being audio recorded. If you do not agree to be audio-taped, the focus group will be conducted without audiotaping. If the discussion is recorded, the audio recording will be erased within one year of transcription.
- You may refuse to answer any question during the focus group or leave the group at any time without consequences.
- You will receive a \$25 gift card to thank you for participating in the focus group.
- You understand that you will get a \$25 gift card even if you do not answer all the questions or leave the group at any time.
- If you have any questions about the study, contact the study director, Julie Spielberger, at Chapin Hall at the University of Chicago, 1313 East 60th Street, Chicago, IL 60637; 773-256-5187 or 1(800) 508-6023, [jspielberger@chapinhall.org](mailto:jspielberger@chapinhall.org).
- If you have any questions about your rights or are upset in anyway about the study, you may contact the IRB Coordinator at SSA/Chapin Hall IRB Director, University of Chicago, 969 East 60th Street, Chicago, IL 60637, 773-834-0402, [ssairb@uchicago.edu](mailto:ssairb@uchicago.edu).

Please circle “YES” or “NO” to indicate whether you understand each of the following statements:

- |        |                                              |
|--------|----------------------------------------------|
| YES NO | All of your questions have been answered.    |
| YES NO | You agree to participate in this study.      |
| YES NO | You agree to have the discussion audiotaped. |

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## CKF Letter of Invitation—Focus Groups

Letterhead

Dear Parent,

Thank you for participating in our survey process to learn more about programs and services for families and children with disabilities. We are writing to ask you to participate in a focus group on this topic in a small group with other parents. The focus group meeting will take about 90 minutes and it is completely voluntary. Whether or not you participate will have no effect on current or future receipt of services. It will be held from 10:30am to 12:00 noon on Saturday, March 9, 2013 at the Arc's Family Center. The Arc's Family Center is located at 1177 N. Warson Road, St. Louis, MO. We will provide a \$15 gift card to thank you for your time.

We have asked Chapin Hall at the University of Chicago to lead the focus groups. Chapin Hall is an independent research organization that does research in order to improve policies and programs for children. The focus groups will be audio taped for research purposes, provided all members of the group consent to the taping otherwise the researchers will take notes on the conversation.

We believe that parents are critical in helping children develop and get ready for school. We are interested in parents experiences with the programs and services that are available for children with disabilities and how to improve them to better meet the needs of children and families.

Results of the conversations with parents will be included in a final report written by Chapin Hall to the Community Partnership. No parent or children's names will be included in the report. Nothing that is said in these discussions will ever be linked to the name of the person who said it in any report. Additionally, your name, child's name, or any other identifiable information will not be shared by Chapin Hall with The Community Partnership. We hope you will consider participating in this opportunity to share your views. Parents often enjoy the chance to share their joys and concerns with fellow parents, and to know that they are being listened to as a part of a process to understand and change how things are working.

Please let your CKF home visitor know if you are willing to participate call or email Jean Darnell. If you do not wish to participate in the focus group, please call or email Jean Darnell and she will take your name off of the list.

If you agree to participate, someone will call you a few days before the focus group happens to make sure you can still participate, and answer any questions you may have. If you have any questions at this time, please contact Jean Darnell at 888-541-4636 or [jean.darnell@thecommunitypartnership.org](mailto:jean.darnell@thecommunitypartnership.org)

Thank you,

Jean Darnell  
Research Coordinator  
The Community Partnership

# **ChapinHall** at the University of Chicago

Policy research that benefits children, families, and their communities

## **Services for Children with Disabilities**

### **Informed Verbal Consent for Family Members**

Chapin Hall at the University of Chicago is an independent policy research center whose mission is to build knowledge that improves policies and programs for children, youth, families, and their communities. Researchers at Chapin Hall are conducting this study for The Community Partnership to learn more about the service experiences of parents of young children with disabilities, including Early Intervention and other services that are received. We are conducting focus groups with family members in three different regions of Missouri. A focus group is a small group of people brought together to participate in a guided discussion of a specific topic. Before we begin, I need to provide you with information about the study and obtain your consent to be interviewed. This process is called informed consent. You may ask questions about the study or process at any point.

This study is being conducted to help us learn about how families take care of their children, how they use services to help care for their children, unmet needs for services, and how services could be improved. We are conducting six voluntary focus groups with 8 to 10 family members in each of three areas of the state, two rural areas and one urban area. The focus group will include questions about you and your child and your experiences with services for children with disabilities. Potential questions include the following:

- • Now can you briefly describe a typical day with your child who is receiving services? What is it like to take care of him or her and what services do you use to help with his or her care?
- • What kinds of services are you currently using for your child? How did you find out about these services? How easy or difficult was it to access them?
- • What was your experience like with the Early Intervention program?
- • Are there other services that would benefit you or your child?

The only risk to you for participating in the focus group is the possibility that someone outside of this group will learn what you have told us. However, to prevent this from happening, we will take the following steps. If you agree to participate in the focus group, we will keep all of your answers private and confidential. We also ask you not to share today's discussion with others. We will not share your name or other identifying information with The Community Partnership, other agency staff or use it in any communication or written reports about the study. The information we collect from you and other parents will be used to write reports for The Community Partnership, in which we will summarize responses from many people. General things we learn from the study may also be presented at conferences or professional meetings, and in written articles.

It is possible in these reports and data presentations that we will use quotes from the focus group to illustrate common themes in the information from the focus groups. If we choose to quote from a focus group participant, we will not include any information such as name, age, race, or location that could be used to identify you. If you tell us something and we write it in a report, no one will know that you were the person who said it.

The focus group will last for about 90 minutes. We would like to audiotape the discussion to provide a more accurate record. If everyone in the group does not agree to the recording of the discussion, we will not record the discussion but take notes instead. If we do record, the recording will be erased one year after we complete our transcript and analysis of the focus group.

Your participation in the focus group is voluntary. Whether or not you choose to participate will have no impact on the services you receive. To thank you for your time, we will provide you with a Wal-Mart gift card for \$15.

Now I will review each of these conditions and answer any questions you may have.

- Chapin Hall researchers will be conducting six focus groups with parents of young children with disabilities. You will be one of 8 to 10 participants in one of these six focus groups.
- You are agreeing to participate in an approximately 90 minute discussion that will be completed now.
- Whether or not you choose to participate will have no impact on the services you receive.
- Your participation is voluntary and refusing to participate or to answer any question will not result in any consequences or penalties.
- What you say in the focus group may be quoted in a report or presentation. However, the researchers will keep everything you say in the focus group confidential and will not share it with anyone outside the research team. Your name and other identifying information will not be used in any report or presentation and will be destroyed at the end of the study.
- You agree not to share comments of other parents in the focus group with others.
- The information collected for the study will be destroyed in 5 years after the study is completed.
- You are being asked to consent to the focus group being audio recorded. If you do not agree to be audio-taped, the focus group will be conducted without audiotaping. If the discussion is recorded, the audio recording will be erased within one year of transcription.
- You may refuse to answer any question during the focus group or leave the group at any time without consequences.
- You will receive a \$15 gift card to thank you for participating in the focus group.
- You understand that you will get a \$15 gift card even if you do not answer all the questions or leave the group at any time.
- If you have any questions about the study, contact the study director, Julie Spielberger, at Chapin Hall at the University of Chicago, 1313 East 60th Street, Chicago, IL 60637; 773-256-5187 or 1(800) 508-6023, [jspielberger@chapinhall.org](mailto:jspielberger@chapinhall.org).
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Please circle “YES” or “NO” to indicate whether you understand each of the following statements:

- YES NO      All of your questions have been answered.
- YES NO      You agree to participate in this study.
- YES NO      You agree to have the discussion audiotaped.