



## **Family Support Services for Grandparents and Other Relatives Providing Care for Children of Women Who Are Substance Abusing and HIV Positive**

By

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### **TABLE OF CONTENTS**

<b>I. INTRODUCTION .....</b>	<b>5</b>
A. PROGRAM HISTORY .....	5
B. THE INSTITUTE.....	5
C. THE PROBLEM.....	5
1. <i>Number of Clients to be Served</i> .....	7
2. <i>Social Service Privatization</i> .....	7
D. INTERVENTION .....	7
1. <i>Kinship Collaborative Intervention</i> .....	7
<b>II. GOALS &amp; OBJECTIVES .....</b>	<b>9</b>
<b>III. EVALUATION POPULATION.....</b>	<b>11</b>
<b>IV. EVALUATION DESIGN AND METHODS.....</b>	<b>11</b>
A. OUTCOME MEASURES .....	11
B. RESEARCH DESIGN.....	12
C. SAMPLE GROUPS .....	12
D. SCHEDULE OF MEASUREMENT.....	12
E. DURATION OF THE EVALUATION .....	12

<b>V. EVALUATION PROCEDURES .....</b>	<b>13</b>
A. INTRODUCTION .....	13
B. REFERRAL PROCESS & CASE FLOW .....	13
C. INTERVIEW PROCEDURE FOR EVALUATION MEASURES .....	15
<b>VI. DATA MANAGEMENT .....</b>	<b>15</b>
<b>VII. .... STATISTICAL ANALYSIS</b>	<b>16</b>
<b>VIII. .... OBLIGATIONS OF THE PROJECT</b>	<b>16</b>
A. INFORMED CONSENT .....	16
B. CONFIDENTIALITY .....	16
C. RETENTION OF DATA .....	16
D. WITHDRAWAL OF FAMILIES .....	16
<b>IX. ASSESSMENT TECHNIQUES .....</b>	<b>17</b>
A. THE INTERVIEW .....	17
1. <i>Introductory Comments for the Interview</i>	17
2. <i>Provisions for Caregivers Experiencing Problems</i>	18
B. ADMINISTRATION OF QUESTIONS FOR CAREGIVERS .....	18
1. <i>General Considerations</i>	18
2. <i>Order of Presentation of Materials</i>	18
3. <i>Comments for the Caregiver</i>	18
<b>X. REFERENCES .....</b>	<b>22</b>
<b>XI. APPENDICES .....</b>	<b>23</b>
<b>X. APPENDICES</b>	
A. Measures	
• Family Needs Scale	
• SF-12 V2 Physical and Mental Health Scales	
• Child Questionnaire V2	

## SYNOPSIS

**Title:** Family Support Services for Grandparents and Other Relatives Providing Care for Children of Women Who Are Substance Abusing and HIV Positive

**Objectives:** The **Kinship Collaborative** (four kinship-serving agencies who formed a collaborative in January, 2001) proposes to implement a program to provide **integrated legal and social services** to the families of relative caregivers. This project is based on research and data on: grandparents as caregivers; children of substance abusing and/or HIV-positive women; family systems; and family support services. The proposed services build on the well-researched and successful Kinship Supportive Services Program (KSSP) model currently being replicated in eleven California counties. The Kinship Collaborative is adapting this model to address the particular concerns of the local Alameda County community. Through the Alameda County KSSP, grandparents and relative caregivers were offered a broad selection of services to choose from in order to assist them in the care of their kin children: legal services; intensive family support services (including informal counseling, advocacy, resource brokerage, transportation, assistance with housing, budgeting, education and respite care); peer support groups; and educational forums.

**Results & Benefits:** Through the provision of comprehensive services, including integrated legal and social work services, the Kinship Collaborative projects the following benefits to children and caregivers:

- Improved family functioning
- Increased family stability
- Attention to children's safety
- Increased socialization opportunities for children
- Improved children's health and well-being
- Improved caregivers' health and well-being
- Decreased isolation of the caregivers
- Keeping kinship families intact
- Increased permanency planning
- Maintaining children in their extended family and community
- Increasing children's likelihood for long-term health and self-reliance
- Reducing the drain on public systems such as foster care, child protective services and the juvenile court.
- More efficient and effective services to kinship families due to cross-training of legal staff and social work staff.

**Evaluation:** Family Support Services of the Bay Area (FSSBA) has contracted with Edgewood Center for Children and Families' Institute for the Study of Community-Based Services (Institute) to conduct the evaluation of the proposed project. FSSBA's decision to sole source the evaluation component to the Institute is based upon its eight-year history of designing, conducting and disseminating research efforts of kinship children and their relative caregivers. The Institute has accomplished this as part of Edgewood Center's evolving national model for serving Kinship families. The Institute's director and staff work closely with FSSBA staff to develop both formative and summative evaluation processes based upon the Institute's experience.

- **Formative:** Records were maintained of case files, supervisory records, and staff meetings and contain detailed records of the type and amount of services as well as contacts between family advocates and families. These records provide a measure of the extent to which the policies and procedures of the model are implemented. These formative processes track attainment of project objectives within specified time frames. Institute staff and FSSBA staff note discrepancies from the original plan, provide performance feedback, and make recommendations for adjusting the program to better achieve the intended outcomes (See pgs. 13 & 14 Referral Process and Case Flow).
- **Summative:** Summative evaluation examines the permanency outcomes for children in the kinship families served by FSSBA during the project period. In addition to permanency outcomes for children, FSSBA utilized a 31-item Family Needs Scale instrument adapted by Edgewood's Institute from Dunst, Trivette and Deal's Family Needs Scale (1988) and used in other kinship caregiver evaluation studies since 1993. Because health has been noted as a significant factor affecting the lives of caregivers and families (Cohon & Cooper 1999; Cohon, Hines, Cooper, Packman & Siggins 2003), the project used the SF-12v2 General Health Survey (Ware, Kisinski, Turner-Bowker & Gandek 2002) to measure health concerns. After consultation with the author, Institute staff selected 10 items from the Child Health Questionnaire-PF50 (Landgraf, Abetz & Ware 1996).

## I. INTRODUCTION

### A. Program History

The Kinship Collaborative, of which the applicant, Family Support Services of the Bay Area, is the lead agency, was formed to provide comprehensive, effective and accessible services to kinship families. The collaborative has received seed money from Alameda County and the State of California to establish a Kinship Supportive Services Program, one of eleven county pilot programs funded across the state. The four agencies of the collaborative, respected providers of kinship services, have been meeting since January 2001 to establish linkages, integrate and expand services, ensure conformance to the statewide KSSP data system, raise funds and develop the new Kinship Center.

The Kinship Collaborative agencies are listed below, along with the services they provide to the Kinship Supportive Services Program (KSSP):

- **Family Support Services of the Bay Area (FSSBA)** provides individualized, intensive home-based services; respite care; summer camperships; and management of the new Kinship Center. It is currently fundraising to expand these services and to offer additional youth services and transportation assistance.
- **Legal Assistance for Seniors (LAS)** provides legal advice and representation in custody matters; guardianship; restraining orders; housing issues; planning for incapacity; and public benefits including income and health care. It also assists clients in multiple languages, which will be available to kinship families as needed.
- **Grandparents and Relatives as Second Parents (GRP)** provides grandparent and relative caregiver support groups; a telephone WarmLine for callers to speak with a peer counselor who provides information, referrals and emotional support; crisis counseling; kinship education and health-focused workshops; intergenerational activities; and a teen club.
- **A Grandparents Awareness and Information Network (AGAIN)** provides grandparent and relative caregiver support groups; education; a kinship library; and advocacy.

### B. The Institute

The Institute for the Study of Community-Based Services (Institute) is the research arm of Edgewood. The goal of the Institute is to make use of Edgewood's numerous clinical settings to conduct evaluative research of program effects and provide useful data to Edgewood program staff and a variety of audiences including families, community leaders, professionals, policy makers, and administrators.

### C. The Problem

According to the U.S. Census Bureau (1998) there are more than 3.7 million grandparent-headed households in the United States. This number has grown by more than 75% since 1970. In the State of California, approximately 500,000 children are living in

grandparent-headed households. And in Alameda County, recent figures show that there are 22,783 children less than 18 years of age in the county who are living in households headed by grandparents. This rate of 7.5% of all children under the age of 18 exceeds the national average of 5.5%. (California Agriculture, March-April 2001.)

Kinship families offer a time-honored, culturally respected solution to unfortunate, but not uncommon, family problems such as substance abuse and child neglect. Kinship families, however, cannot function effectively without community and public support. They are typically headed by older women with limited financial means, caring for children who have suffered from trauma or neglect. Caregivers' needs may be as basic as obtaining health care for the children or themselves; as technical as legal assistance to make proper custody arrangements; or as emotional as a chance to connect with other grandparents in the same situation. In some cases multiple and complex issues warrant the more intensive attention of a case manager (e.g. schooling for children with special needs; financial management; access to health and mental health services; court-mandated requirements; and logistics of keeping multiple appointments).

Children who have lived with substance-abusing parents are likely to have suffered neglect, if not direct abuse, and show the effects of living in a continually chaotic, unpredictable environment. If the parent is also HIV-positive, her health deterioration not only adds to the child's needs, but makes permanency planning all the more urgent. To help children recover from trauma and develop positively, caregivers are often required to coordinate multiple medical and mental health appointments and assessments each week. Their legal responsibilities not only include arranging for custody, but accounting for the children's needs in their plans for managing personal and financial matters in case of incapacity, as well as for distributing their estates after death. In many cases, for instance, a substance-abusing parent needs to be prevented from inheriting the caregiver's estate at the expense of the children. Such matters are not only a cause for worry, but require a high level of expertise to resolve.

Substance abuse and AIDS/HIV infection are two critical problems that prevent parents from either directly providing care for children or creating the safe, nurturing environment children need for their healthy development. The federal General Accounting Office (1998) estimated that two-thirds of all children in foster care had a substance-abusing mother. Many of these (80%) had been using drugs or alcohol for at least five years and consequently had a greater risk of HIV exposure. Women now represent 30% of new HIV infections and constitute an increasing share of full-blown AIDS cases, according to the Centers for Disease Control and Prevention; most of these new cases are African American women. While African American women make up just 13% of the U.S. female population, they represent 63% of cases of women with AIDS as of 1999. AIDS is the second leading cause of death among African American women ages 25-44 (CDC, 1999). An estimated 7,300 children were orphaned as the result of HIV / AIDS, and it was estimated that the overall number of motherless children and adolescents will be exponentially increasing each year so that numbers in the range of 80,000-125,000 are likely.

Grandparents and relative caregivers actually have a triple challenge in bringing up young children. They must provide for the needs of the children's immediate needs, which as

noted above, can be intense; they must surmount legal and financial hurdles to obtain the legal ability and resources to meet these needs; and finally they have important, numerous needs of their own: health concerns, lack of emotional and peer support, and inadequate experience or training on raising children with special needs.

### **1. Number of Clients to be Served**

It is estimated that each year:

- At least 100 families received legal services and social services assessments.
- Of these 100 families receiving legal services, at least 70 families received referrals to KSSP services and non-KSSP services.
- Of these 100 families receiving legal services, at least 30 families received individualized case management via home-based and community-based services, including advocacy and linkages with educational, health and mental health services.
- At least 50 relative caregivers received legal information via LAS educational sessions.

### **2. Social Service Privatization**

The recent implementation of Welfare Reform has challenged policymakers to create programs that cut costs and address new service demands imposed by the kinship placement phenomenon (Gleeson 1996). States and localities contract out social services for a variety of reasons, but these decisions are based primarily on the belief that higher quality services can be delivered more cost-effectively by private providers. “Privatization is commonly defined as any process aimed at shifting functions and responsibilities, in whole or in part, from the government to the private sector” (U.S. General Accounting Office [GAO] 1997a). The GAO (1997b) cites results from a Child Welfare League of America survey that found thirty-one states planning or already implementing managed care approaches in the management and delivery of child welfare services. This transition is likely to continue, as Congress has shown greater interest in privatizing social services programs, even though there have been few empirical studies comparing the quality of publicly and privately provided services (GAO 1997b).

## **D. Intervention**

### **1. Kinship Collaborative Intervention**

It is important to acknowledge that intervention models written in response to an RFP are idealized designs that are conceived by professionals with experience in the field, but that unanticipated external changes require modification of initial intervention processes. This was the case with the Kinship Collaborative project and details of these changes are reported in this Manual beginning on page 12, Referral Process and Case Flow. While features of the model changed, the basic concept of

offering comprehensive services by combining different components particularly legal representation and consultation did not change. The processes described in the Case Flow section were not written with the idea to set forth a definitive program for other agencies wanting to implement a similar array of services. Agencies and clients at different locations have their own unique requirements, politics and external factors that will affect the implementation of program processes. We recommend that any site implementing a similar service intervention conduct periodic formative evaluation of their processes to refine and improve their program model and address site-specific requirements. The FSSBA Kinship Collaborative has used this program Manual as a tool to review, document and change our service delivery processes during the life of this project.

The core of the Kinship Collaborative model serves kinship families through the provision of comprehensive services, including integrated legal and social work services, including training, social and peer support, formal and informal advocacy, case management, and legal representation. Numerous surveys and studies of grandparents and relative caregivers cite caregivers' needs for social support and training, respite care to give the caregivers a break, legal and financial assistance services for their children and transportation. The Kinship Center, as a component of the Kinship Support Services Program (KSSP) opened in the Fall of 2001 and began to provide all of these services in a convenient, one-stop location. If families preferred, KSSP is structured so they can take advantage of these same services in their local neighborhoods or in their homes.

**a.) Social Services:** Social Workers are available to meet with kinship families to assess their needs and assist them in working their way through the complex systems that impact their kin children. They are trained in a strength-based, culturally-sensitive approach to working with families. Specifically, they:

- secure needed community resources, including financial resources,
- provide practical guidance,
- provide counseling and emotional support,
- access health and mental health services,
- train in household management and budgeting,
- assist in locating adequate and affordable housing,
- assist with educational issues,
- assist families with self-advocacy,
- provide parenting training, when appropriate,
- monitor the well being and safety of the children,
- coordinate services with other service providers, and
- provide transportation assistance.

**b.) Legal Services:** Relative caregivers face numerous legal issues in caring for their kin children: guardianship and custody issues, securing economic and healthcare benefits for which they are eligible, medical and educational authority, restraining orders to prevent or stop abuse of the children or

caregiver, and housing problems, such as eviction notices. All of these legal services were made easily accessible to caregivers.

- c.) **Support Groups:** Support groups provide a much-needed place for grandparents to air their concerns and receive support and guidance from other caregivers. They also provide a forum for training to occur. When grandparents feel supported and listened to by peers, they gain strength to continue addressing the many challenges that face them as caregivers. They may be more open to developing new skills and approaches in meeting these challenges.
- d.) **Respite:** The provision of respite services provides relative caregivers and their families a much-needed break from their full-time caregiving responsibilities. Respite providers available through this Collaborative are specially trained to provide a nurturing and safe experience for the children. Respite recipients may choose to have care provided in the family's home, in a certified daycare site, or at a community site, such as a family resource center or a medical clinic. Group respite care, provided on-site while caregivers attend support groups or other appointments, also provide positive social experiences for children.

## II. GOALS & OBJECTIVES

The program is designed to serve the special needs of families who are caring for minors because of the incapacity or inability of the parents to do so, particularly because of the parent's substance abuse or HIV infection. The goals and objectives are designed with these factors in mind.

- a.) **Goal:** *Identify the variety of individual needs of relative caregivers and their families, to tailor services to meet these needs, and to develop a better understanding of community needs to aid in future planning.*
  - Objective:** To conduct pre and post assessments of families using the Family Needs Scale and the SF-12 Health Survey. We also included a brief 10-item child health questionnaire based on the Child Health Questionnaire-PF50 and developed in collaboration with the primary author of the original scale, Jeanne Landgraf.
  - Objective:** To administer a client survey that rate services received as well as list services still needed.
- b.) **Goal:** *Provide a comprehensive system of services to relative caregivers and their families, including integrated legal and social services.*
  - Objective:** To provide a legal/social work team assessment for all kinship families referred for legal services.
  - Objective:** To provide referrals to KSSP services and other appropriate services to kinship families who are receiving legal services.
  - Objective:** To provide individualized case management via home-based and community-based services, including advocacy and linkages with educational, health and mental health services.

- c.) **Goal:** *To increase the knowledge of relative caregivers regarding legal issues that impact their families.*  
**Objective:** To produce four community sessions per year on legal issues for caregivers.
- d.) **Goal:** *To increase the knowledge of KSSP staff regarding legal issues that impact their families.*  
**Objective:** To produce two staff sessions per year on legal issues for staff.
- e.) **Goal:** *To determine the effectiveness of the new service model.*  
**Objective:** To collect pre and post tests on evaluation measures to determine the effectiveness of the services for kinship families.
- f.) **Goal:** *To disseminate information for program replication.*  
**Objective:** To produce materials to enable replication of the successful aspects of the program.

### III. EVALUATION POPULATION

This project served Northern Alameda County families in which children (ages 0-18 years) are being raised by relatives. Most are grandparent-headed, but other relatives are also represented. While some kinship families were under the auspices of the County child welfare system, many others have not interacted with it. However, in all cases, without the availability of a kinship caregiver, the children would be placed in foster care, with strangers who may not represent their culture or live in their community. All new referrals to the FSSBA Kinship Collaborative program that do receive services were asked to participate in the evaluation. With expectable non-participation and attrition, we anticipated recruiting approximately one hundred non-duplicated kinship families during the project period.

### IV. EVALUATION DESIGN AND METHODS

#### A. Outcome Measures

Summative evaluation examined the permanency outcomes for children in the kinship families served by FSSBA during the project period. The majority of kinship caregivers are grandparents unfamiliar with social science questionnaire requirements, therefore the evaluation measures have been selected to reduce respondent burden.

In addition to permanency outcomes for children, FSSBA utilized a 31-item Family Needs Scale instrument adapted by Edgewood's Institute from Dunst, Trivette and Deal's Family Needs Scale (1988) and used in other kinship caregiver evaluation studies since 1993. This measure taps specific areas of importance to kinship families including financial, legal, educational, respite and recreation, health and mental health, and special services for children. The measure was used as part of the FSSBA intake (T1) and can be given in about 20 minutes by caseworkers. The measure can also be used to develop a case plan for each family. The measure was given again when a family completed their case plan (T2), providing a pre-treatment / post-treatment assessment of families' needs.

Because health has been noted as a significant factor affecting the lives of caregivers and families (Cohon & Cooper 1999; Cohon, Hines, Cooper, Packman & Siggins 2000), the project used the SF-12 V2 Physical and Mental Health Summary Scales to measure health concerns. The Institute has effectively utilized a longer measure of health, the SF-36 General Health Survey with kinship caregivers since 1993, but because we wanted to reduce the burden of assessment for caregivers, we decided to use the shorter SF-12 measure. Rather than relying on individuals to complete measurement schedules independently, a higher response rate and greater accuracy in completion is achieved by having face-to-face interviews between social workers and kinship caregivers. The SF-12 v2 was given at intake (T1) and completion of the case plan (T2).

Lastly, after discussions with the author of the measure, we have selected several items from the Child Health Questionnaire-PF 50 (CHQ-PF50) for use with caregivers to provide an understanding of the global health status of the children ages 7-18 in their

care. This adapted measure contains only ten items, again with the aim of reducing caregiver burden.

## B. Research Design

The design for the quantitative component of the evaluation is a correlational approach using within-groups, pre-test and post-test standardized measurements. The within subjects factor is time, with two levels: 1) baseline (T1), and 2) follow-up (T2). Analysis of the score data was conducted using parametric t-tests and nonparametric tests on ranks to examine differences between appropriate normative samples and the subjects in the present evaluation. In addition, changes were examined from T1 to T2. The Institute is working with Edgewood to develop a database written in Microsoft Access for entering data from the Family Needs Scale and SF-12 measures and trained FSSBA staff to perform this data entry. Completed databases were sent to the Institute periodically. Copies of all assessment forms were sent to the Institute and staff conducted periodic auditing of data entry to insure accuracy. Statistical analyses were conducted annually, and interim reports given to FSSBA staff as well as provided to the Children's Bureau.

## C. Sample Groups

The sample groups were drawn from all kinship client families referred to the Kin Collaborative groups and receiving LAS and FSSBA services through KSSP. We anticipated that there would be three sample groups: 1) KSSP services only received T1 and T2 assessments; 2) KSSP services and subsequently referred to family re-claim after receiving *more than* 90 days of KSSP services received T1 and T2 assessments; and 3) KSSP assessment services only and referred to family re-claim receiving *less than* 90 days of KSSP services received only the T1 assessment.

## D. Schedule of Measurement

Quantitative assessment measures for each participant was conducted when they entered the program (T1). The second assessment (T2) occurred either at graduation/closing or the 12-month anniversary of enrollment

### Time 1/Baseline

Enrollment in Kin Collaborative

### Time 2/Follow-up

Graduation/Closing, or 9 Months

Referral to family re-claim if >90 days service

## E. Duration of the Evaluation

The evaluation took place over the grant period with formative evaluation beginning as the grant starts and the summative evaluation measures beginning with the first referrals.

## F. Qualitative Interviews

The Institute has consistently utilized mixed methods evaluation designs incorporating qualitative and quantitative findings (Cohon et al 2000). Institute staff includes doctoral level psychologists and anthropologists experienced with ethnographic techniques and qualitative interviewing. Institute staff consulted with FSSBA project staff to randomly identify a number of FSSBA clients to interview. The Institute was contacted by Jill Messing, a graduate student from the University of California Berkeley's School of Social Welfare. Ms. Messing and the Institute agreed that she would conduct qualitative focus groups with a number of children in kinship homes. Ms. Messing completed seven focus groups with a total of 40 children from different kinship projects including the FSSBA Kinship Collaborative. Her findings were published by the National Abandoned Infants Assistance Resource Center, School of Social Welfare, University of California Berkeley in September 2004 in a report entitled "*Focusing on the Needs of Youth in Kinship Care.*" A copy of this publication is included with the FSSBA Kinship Collaborative Final Report.

## V. EVALUATION PROCEDURES

### A. Introduction

These case processes are not written as definitive for a program design for an agency choosing to implement a similar model. Participating agencies and clients at each site will have their own unique requirements that will influence the design and implementation of program. We recommend that each site conduct periodic formative evaluation of their service delivery processes to refine and improve their program model to address site-specific issues. This FSSBA project has made use of this Program Manual as part of our formative evaluation process tool to review, change and document our own service delivery and implementation processes. Some replication sites may wish to adopt a similar strategy for their own program development process.

### B. Referral Process & Case Flow

*Initial Design:* The original model had the Legal Assistance for Seniors (LAS) attorney and the FSSBA Social Worker jointly interviewing families at the LAS site. This proved awkward for clients as the questions posed by two different professionals required shifting back and forth. Subsequently, the FSSBA Social Worker saw the clients after they had been interviewed by the LAS attorney, but still at the LAS site. Finally, the FSSBA Social Worker moved back to the FSSBA site and contact was done via telephone and email.

For families who enter this project through LAS, the Intake Specialist, a Paralegal, obtains information on the phone from the relative caregiver. This information is given to the kinship Staff Attorney. As soon as a Staff Attorney receives the case, they have their Paralegal send out a packet of information along with a kinship services brochure to be completed before the relative caregiver's meeting with the Staff Attorney and the FSSBA Social Worker. A cover letter enclosed with this packet explains the availability of kinship supportive services to clients. If the Paralegal assesses that the family may have difficulty

completing the forms, she lets the Staff Attorney know that this family should be contacted directly and will probably need a face-to-face meeting to complete the forms.

The Staff Attorney contacts each new client to conduct an initial assessment with the client and identifies potential service needs in addition to legal services. If appropriate non-legal needs are identified, a referral is made to the FSSBA Social Worker, not using the professional title "Social Worker", but giving the individual's name and identifying them as "someone who works with kinship families." This is done in an effort to establish a more personal relationship between client and staff. We have found that non-legal needs are often not raised by clients in their initial discussions with the Staff Attorney, but emerge later in the process after a level of trust has been established. At this time, a referral to the kinship support staff is made. Most contact between the Senior Attorney and the FSSBA Social Worker is done by telephone and email. Referrals may also come from FSSBA to LAS. The Senior Attorney then notes this so that there is not a need to refer back to FSSBA for social services. In sum, this intake process remains open and flexible to address the individual characteristics and preferences for each client.

Once the referral has been made to the FSSBA Social Worker, this worker then contacts the kin family to explain the supportive services available and to assess the family's resources. An effort is made to understand each family's situation without forcing a family to accept services, but allowing the family to understand that there are possibilities for them to selectively choose services. The emphasis is placed on relationship-building and establishing trust as a way to engage families. At the end of each meeting and as each case evolves, a follow-up plan is jointly developed by the family and staff. In February 2002, our formative evaluation of this referral process noted that obtaining Informed Consents took more time than anticipated so that there was a one to two week lag between the referral to FSSBA and the initial meeting with a client. There was consideration of having the FSSBA social worker meet clients even before meeting the LAS Staff Attorney, but this was not done because clients were usually calling for legal assistance, not social services.

In March 2002 there were staff changes at FSSBA and LAS that briefly disrupted the referral process. In April of 2003 the Executive Director of LAS left, and one of the FSSBA Social Worker's also left. In May 2003, budget uncertainty in Alameda County led to LAS needing to turn away clients, as they were not sure how much staff would be available in the next two months when the new County budget took effect. In June 2003 Alameda County announced that Kinship Supportive Services Program (KSSP) dollars were reduced by 50% and LAS had to reduce their staffing on the project utilizing a law clerk instead of a full time professional attorney. In September 2003 LAS determined that their staff could no longer represent all families at their hearings, but could help them with paperwork and coach them up to the court hearing. At this time LAS was receiving two to three guardianship calls per week. LAS hired a new Executive Director in October, and the decision was made that all referrals to FSSBA would be FAXed over using a standardized referral form to insure that information was not lost, which could happen with telephone referrals. Formative review of the process in January 2004 found

that the FAX method was working well and allowed for ease of record keeping. In August 2004 a new law clerk was hired for the project at LAS.

If the majority of the issues seem to be more legal in nature, the LAS staff member becomes the main contact for the family. If the issues seem to be more psychosocial in nature, then the FSSBA Social Worker becomes the main contact for the family. In either case, the family may feel free to contact either worker at any time. Examples of non-legal issues that clients have presented to LAS and FSSBA include budgeting, nutrition, household management, need for childcare or respite, health and mental health needs, counseling, navigating the school system and linking families with resources.

Intensive home-based services were offered to those kinship families with the greatest needs. These include such risk factors as serious illness, extreme poverty, mental health problems, chronic neglect, physical abuse, emotional or sexual abuse, HIV, or substance abuse. Although these problems may not be occurring in the kinship caregiver's home, their occurrence in the child or the parent of the child is also a risk factor, likely to affect the kinship family's ability to function.

The FSSBA Administrative Assistant enters data for all new client families. Informed Consent forms giving permission to be interviewed are obtained from clients during the intake process.

### **C. Interview Procedure for Evaluation Measures**

1) Because this is a project with the goal of demonstrating the effectiveness of a new service model, primary importance is given to the provision of services to clients. Secondly, administration of the evaluation measures is considered. LAS or FSSBA staff explain the need for evaluation to clients at an appropriate time during the intake process. Initial (T1) interviews are conducted within the first three visits, or as soon as is deemed appropriate, after the intake process.

#### Follow-Up Interviews

A follow-up interview is conducted with the clients once after the initial interview. The follow-up interview (T2) occurs at closing/graduation/referral to family re-claim or ninth months after the initial interview. When a family has received more than 90 days of service from FSSBA and then is referred to family re-claim, a T2 interview with the Family Needs Scale, SF-12V2, and Child Questionnaire was completed.

## **VI. DATA MANAGEMENT**

The Institute has databases written in Microsoft Access for entering data from the Family Needs Scale and developed data fields for the SF-12 Health Survey and Child Questionnaire measures. Edgewood staff trained FSSBA staff to perform data entry. Completed databases were sent to the Institute via email. Additionally, copies of all assessment forms were sent to the Institute, where staff conducted periodic auditing of data entry to insure accuracy. Analyses were conducted annually, and interim reports given to FSSBA staff.

Qualitative data analyses were conducted by Jill Messing from the University of California Berkeley.

## **VII. STATISTICAL ANALYSIS**

The design for the evaluation is a correlational approach using within-groups, pre-test and post-test standardized measurements. The within subjects factor is time, with two levels: 1) baseline (T1), and 2) follow-up (T2). Analysis of the score data were conducted using parametric t-tests and nonparametric tests on ranks to examine differences between appropriate normative samples and the subjects in the present evaluation. In addition, changes will be examined from T1 to T2.

## **VIII. OBLIGATIONS OF THE PROJECT**

### **A. Informed Consent**

All participating families must sign informed consent before entering the evaluation. By signing the informed consent forms, caregivers agree that they will complete all evaluations required, unless they withdraw voluntarily or are terminated from the study for any reason.

### **B. Confidentiality**

The study protocol, documentation, data and all other information generated are held in strict confidence.

### **C. Retention of Data**

The investigator maintains all records pertaining to this study for a minimum of two years.

### **D. Withdrawal of Families**

The attrition rate was monitored and clients who drop out of the program followed-up with telephone calls, or, when possible, face-to-face visits. We attempted to conduct interviews with these caregivers to determine their reasons for leaving, without encouraging or influencing them to return. A significant number of families did not withdraw, and therefore this group was not compared with persons who remained in the program. Participants were informed that any individual may choose to withdraw from the study for any reason and at any time.

## ASSESSMENT TECHNIQUES

### E. The Interview

#### 1. Introductory Comments for the Interview

When giving an assessment to caregivers, the interviewer begins by introducing themselves. The caregiver is then informed of how the interview will proceed and given a brief explanation of the assessment measures. The following guidance is provided solely to assist the person conducting an interview and is not to be followed literally. The person conducting the assessment interview should rely on their clinical judgment and their relationship with the caregiver.

*“We want to talk to you in order to help programs like ours improve services to children and caregivers.” This interview will include several sets of questions; some about your family’s needs, some about your health and lastly regarding your child’s health. We may not be able to finish all of these today, but if we don’t, that will be fine and we can complete them at another time very soon.”*

*“This interview is voluntary and your responses will be kept confidential. The information collected is identified with a number, and your responses to the questions are grouped with other caregivers’ answers. You may ask me to repeat a question if you don’t understand what I’ve asked, or tell me if you don’t know the answer to a question. You should also know that the questions are of a personal nature and you may decline to answer or end the interview at any time if you have any concerns or feel uncomfortable.”*

*“If you should become upset during the interview, I will stop the interview and talk with you about what happened. People rarely become upset or uncomfortable by the interview, but we have a procedure that I will follow and discuss with you if this should happen.*

*“You should also know that I am a mandated reporter which means that I am required by law to report to Child Protective Services if you tell me that you have abused a child in your care in any way. I will also inform you before I report the incident. Do you have any questions regarding what I have said?”*

## 2. Provisions for Caregivers Experiencing Problems

If a caregiver participant becomes visibly upset at any point during the interview, the interview is stopped and the following steps are taken:

- The interviewer first discusses the situation with the caregiver and determines if the problem requires a follow-up with a therapist.
- If it is decided that the caregiver needs to see a therapist the interviewer asks the caregiver if the family has one and asks the caregiver for permission to contact that therapist.
- If the caregiver does not have a therapist, he or she is referred to a follow-up with a community agency therapist known to FSSBA. The FSSBA Project Director of the Kinship Collaborative is also informed of the nature of the problem and the referral.
- A note is placed in the case file.

If the interviewer believes that the caregiver may have been upset, but not shown visible signs of this, the interviewer discusses the situation with their supervisor and asks them to follow-up with the client to provide a chance for the participants to discuss any reactions that they may have had to the interview process.

## F. Administration of Questions for Caregivers

### 1. General Considerations

Caregivers are not required to answer the questionnaires. If they decline to participate, they are told that their participation is voluntary and they can decide to end the interview.

Emphasize that all responses are kept confidential. Point out that individual names are not linked with their answers and that the results will be identified only by a number and compiled with other caregiver responses.

In order to maintain consistency in test administration, all caregiver questionnaires should be read aloud to the caregiver and responses recorded by the interviewer.

### 2. Order of Presentation of Materials

1. If not already signed, caregiver informed consent (general consent)
2. Family Needs Scale (31 items)
3. SF-12-V2-Physical and Mental Health Summary Scales
4. Child Questionnaire (10 items)

### 3. Comments for the Caregiver

*“The interview will begin with some questions about your family background. Please let me know if you don’t understand the question, or if you don’t know the answer to a question. There are no right or wrong answers. You should also know that some of the questions are of a personal*

*nature and you may decline to answer or end the interview at any time if you feel uncomfortable or have any concerns. Do you have any questions before we begin?"*

The interviewer presents as follows:

- Administration of the family origin questions.

*"First, I want to ask you some questions about your family background. We are collecting this information so that we can include in our research report some general information about the families we serve."*

The interviewer then reads the family origin questions and records the responses on the question sheet.

- Administration of the Family Needs Scale

The following script may be used to introduce the Family Needs Scale.

*"The Family Needs Scale was designed to provide reliable information about the needs of kinship families. The questionnaire asks questions about different types of needs that you may or may not have. There are no right or wrong answers."*

The interviewer hands the caregiver a copy of the Family Needs Scale to use as a visual cue and administers the measure by reading aloud each item and recording their verbal responses on another copy of the Family Needs Scale.

*Note: The use of the Response Card instead of a copy of the measure may be used as a visual cue.*

The interviewer says, *"Because there are different response options for each item, please take your time before answering a question."*

- Administration of the SF-12V2 Physical and Mental Health Summary Scales

The interviewer presents as follows:

*"This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Here is a copy of the questionnaire for you to follow along with as I read the questions aloud."*

The interviewer hands the caregiver a copy of the twelve-item SF-12 V2 to use as a visual cue and administers the measures by recording their verbal responses on another copy.

- Administration of the child questionnaire.

*“These questions are about the children you are caring for in order to help us understand their health and the affect that their health and behavior has on you. I will ask you the same group of questions for each of the children you are caring for.”*

The interviewer hands the caregiver a copy of the 10-item child questionnaire to use as a visual cue and for each child in the family asks the questions and records the verbal responses on another copy.

### Caregiver Questionnaire Administration Do's and Don'ts

**Do** request and encourage the caregiver to answer

**Do not force** or command the caregiver to answer

**Do** read and repeat a question **verbatim** for the caregiver

**Do not interpret** a question

**Do** tell the caregiver to answer a question based on what they think the question means

**Do not accept** an incomplete questionnaire without first encouraging the caregiver to provide responses to unanswered questions

**Do** have the caregiver answer the questions **by themselves**

**Do not** allow spouses or family members to help the caregiver answer the questions

**Do** encourage the caregiver to complete all questions

**Do not** force or command the caregiver to complete a particular question

### Addressing Problems and Questions

- What to do if the caregiver doesn't want to complete a questionnaire.

A caregiver is not required to answer the questionnaire. If the caregiver declines to participate, tell them that their participation is voluntary. Tell them that they are being asked to complete the questionnaire so that we can better understand kinship families like theirs. Tell them that responses are needed so that a complete picture may be obtained. If the caregiver still declines, record the reason for the decline and go on to the next measure.

- What to do if the caregivers are concerned that someone will look at their answers.

Emphasize that all responses to the questionnaires are to be kept confidential. Point out that their names do not appear anywhere on the questionnaire, so that their results will be linked with an ID

number and not their name. Explain that their answers to the questionnaire will be pooled with other grandparents and that they will be analyzed as a group rather than as individuals.

- What to do if the caregiver asks you the meaning of an item.

Some caregivers might ask the meaning of specific items so that they can better understand the response. If this happens, you can assist them by rereading the question for them verbatim. If they ask you to interpret the meaning of an item, do not try to explain it, but suggest that he/she use his/her own interpretation of the question. All participants should answer the question based on what they think the questions mean. They should be encouraged to answer all of the questions.

Sometimes caregivers may have trouble with the response choices. They may say “I don’t know” or something different than what is stated in the questionnaire. In this circumstance, gently guide them to respond in one of the pre-set categories by saying something like:

*“I know that it may be hard for you to think this way, but which of these responses most closely expresses what you are thinking or feeling?”*

If the caregiver does not like a question, or thinks it is unnecessary or inappropriate, state that they may refuse to answer any item(s).

Rewording items, paraphrasing or interpreting items for the caregiver can bias results. Thus, it is important that differences in answers due to rewording of items be minimized.

If the caregiver has difficulty completing the questionnaires and you feel you cannot address their concerns adequately with the instructions and guidance provided, thank them, and discontinue the measure and record the difficulty on a blank sheet of paper.

- What to do if the caregiver wants to know the meaning of their answers.

If a caregiver asks you to interpret responses or asks for a “score”, tell him/her that you are not trained in interpreting or scoring the information. Emphasize that their responses are to be kept confidential. Tell caregivers that their answers to the questionnaire will be pooled with other caregivers’ answers and that they will be analyzed as a group rather than as individuals.

- What to do if the caregivers asks why they have to complete the questionnaires additional times in the future.

Explain to the caregiver that they must complete the questionnaires at different times to test whether their responses change. This will give a more complete representation of their needs, their health, and their child’s health over the course of time.

## IX. REFERENCES

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## **X. APPENDICES**

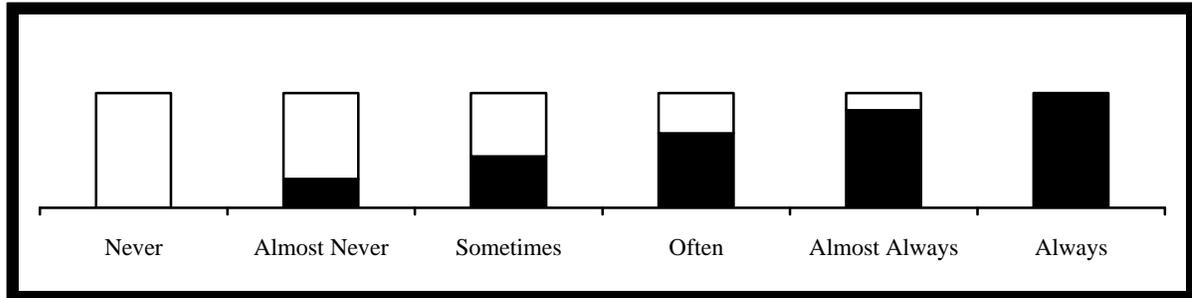
### A. Measures

- Family Needs Scale
- SF12-v2 General Health Survey
- 10-Item Child Health Questionnaire

**APPENDIX**

**FAMILY SUPPORT SERVICES OF THE BAY AREA  
Family Needs Scale**

Family Name: \_\_\_\_\_ KSN I.D.#: \_\_\_\_\_ Type of Interview:  Intake  
 Graduation  
 Worker Name: \_\_\_\_\_ Date \_\_\_\_\_  Closing  
 Other \_\_\_\_\_



<i>How frequently do you need:</i>	<i>Never</i>	<i>Almost Never</i>	<i>Some-times</i>	<i>Often</i>	<i>Almost Always</i>	<i>Always</i>	<i>Notes: Use other sheet if needed</i>
1. Extra money to buy necessities and pay bills.	1	2	3	4	5	6	
2. Help budgeting money	1	2	3	4	5	6	
3. Legal assistance.	1	2	3	4	5	6	
4. Help getting enough food daily for two meals for your family.	1	2	3	4	5	6	
5. Help learning to cook nutritious meals for your family.	1	2	3	4	5	6	
6. Having a telephone or access to one.	1	2	3	4	5	6	
7. Help getting a place to live.	1	2	3	4	5	6	
8. Plumbing, lighting, or heat.	1	2	3	4	5	6	
9. Help getting furniture, clothes, toys.	1	2	3	4	5	6	
10. Help completing chores, repairs, home improvements.	1	2	3	4	5	6	
11. Help adapting your house to meet your child's needs.	1	2	3	4	5	6	
12. Help getting a job.	1	2	3	4	5	6	
13. Help getting places you need to go for yourself.	1	2	3	4	5	6	

14. Help transporting my child places, including appointments.	1	2	3	4	5	6	
15. Travel equipment for your child's needs (e.g a baby seat).	1	2	3	4	5	6	
<i>How frequently do you need:</i>	<i>Never</i>	<i>Almost Never</i>	<i>Sometimes</i>	<i>Often</i>	<i>Almost Always</i>	<i>Always</i>	<i>Notes: Use other sheet if needed</i>
16. Someone to talk to about your child (-ren).	1	2	3	4	5	6	
17. Someone to talk to about how things are going for you.	1	2	3	4	5	6	
18. Medical and dental care for your family.	1	2	3	4	5	6	
19. Time to do things for yourself.	1	2	3	4	5	6	
20. Emergency health care for your family.	1	2	3	4	5	6	
21. Help planning for your own future health needs.	1	2	3	4	5	6	
22. Help managing the daily needs of my child at home.	1	2	3	4	5	6	
23. Emergency child care.	1	2	3	4	5	6	
24. Respite care.	1	2	3	4	5	6	
25. Special services for your child such as counseling, special education, vocational training.	1	2	3	4	5	6	
26. Time to do fun things with your family.	1	2	3	4	5	6	
27. To belong to parent groups or clubs.	1	2	3	4	5	6	
28. Help learning how to be a more effective parent.	1	2	3	4	5	6	
29. Assistance with alcohol or other substance abuse problems either for myself or family member (specify).	1	2	3	4	5	6	
30. Protection for yourself and your family from violence in your neighborhood.	1	2	3	4	5	6	

31. Protection for yourself and your family from violence in your home.	1	2	3	4	5	6	
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(Adapted 9/95 by D. Cohon. From: C.J. Dunst, C.M. Trivette, and A.G. Deal, 1988, *Enabling and Empowering Families: Principles and Guidelines for Practice*, Cambridge, MA: Brookline Books.) D. Cohon modified item #1 to the adaptation of scale on 12/10/01.

rev. 12/10/01

# The SF-12v2↔ Health Survey

## Instructions for Completing the Questionnaire

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

### EXAMPLE

**This is for your review.** Do not answer this question. The questionnaire begins with the section **Your Health in General** below.

For each question you will be asked to fill in a bubble in each line:

1. How strongly do you agree or disagree with each of the following statements?

**Strongly agree**

**Agree Uncertain Disagree Strongly disagree**

a) I enjoy listening to music. ! " ! ! !

b) I enjoy reading magazines. " ! ! ! !

Please begin answering the questions now.

## Your Health in General

1. In general, would you say your health is:

**Excellent Very good Good Fair Poor**  
! ! ! ! !

2. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

**Yes, Limited a lot**

**Yes, limited a little**

**No, not limited at all**

a) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf ! ! !

b) Climbing **several** flights of stairs ! ! !

3. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

**All of the time**

**Most of the time**

**Some of the time**

**A little of the time**

**None of the time**

a) **Accomplished less** than you would like !!!!!

b) Were limited in the **kind** of work or other activities !!!!!

4. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

**All of the time**

**Most of the time**

**Some of the time**

**A little of the time**

**None of the time**

a) **Accomplished less** than you would like !!!!!

b) Did work or other activities **less carefully than usual**

!!!!!!

5. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

**Not at all A little bit Moderately Quite a bit Extremely**

!!!!!!

6. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**...

**All of the time**

**Most of the time**

**Some of the time**

**A little of the time**

**None of the time**

**All of the time**

**Most of the time**

**Some of the time**

a) have you felt calm and peaceful? !!!!!

b) did you have a lot of energy? !!!!!

c) have you felt downhearted and depressed? !!!!!

7. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

**All of the time**

**Most of the time**

**Some of the time**

**A little of the**

**time**

**None of the**

**time**

**!!!!!**

***THANK YOU* FOR COMPLETING THIS QUESTIONNAIRE!**

**CHILD HEALTH QUESTIONNAIRE CAREGIVER FORM – V2 REVISED**

Child Last Name \_\_\_\_\_ First Name: \_\_\_\_\_ Type interview  Intake  
 DOB: \_\_\_\_\_  Annual  
 KSN I.D. # \_\_\_\_\_  Graduation  
 Date \_\_\_\_\_  Closing

1) In general, would you say your child’s health is:

**XI.**    **Excellent**                      **Very Good**                      **Good**                      **Fair**                      **Poor**  
                                                                                                                                                       

2) {ASK ONLY AT INTAKE} Compared to a year ago, how would you rate your child’s health now:

**XII.**    **Excellent**                      **Very Good**                      **Good**                      **Fair**                      **Poor**  
                                                                                                                                                       

3) During the past 4 weeks, how often has your child’s health or behavior:

	<b>A lot</b>	<b>Somewhat</b>	<b>Very Little</b>	<b>Never</b>
a. limited the types of activities you could do as a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. interrupted various everyday activities (eating meals, watching T.V. )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. limited your ability as a family to “pick up and go” on a moments notice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. caused tension or conflict in your home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. been a source of disagreements or arguments in your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. caused you to cancel or change plans (personal or work) at the last minute?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4) During the past 4 weeks were you limited in the amount of time YOU had for your own needs because of your child’s

a. physical health:

<b>Limited a lot</b>	<b>Limited somewhat</b>	<b>Limited Very little</b>	<b>Not limited</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b. emotional well being or behaviors:

<b>Limited a lot</b>	<b>Limited somewhat</b>	<b>Limited Very little</b>	<b>Not limited</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>