CHAPIN HALL
CENTER FOR CHILDREN
AT THE UNIVERSITY OF CHICAGO

Caring for their Children's Children

Assessing the Mental Health Needs and Service Experiences of Grandparent Caregiver Families

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INTRODUCTION

Nationwide, the number of grandparents caring for their grandchildren has increased dramatically over the last two decades (Harden, Clark, & Maguire, 1997; Casper & Bryson, 1998), and according to recent census data for Illinois, over 100,000 grandparents are responsible for grandchildren under 18 years of age who are living with them (U.S. Census Bureau, 2001 Supplementary Survey Summary Tables).

Having relatives care for a child in need, either with or without involvement by the public child welfare agency, is believed to promote or sustain cultural heritage and support continuity in the child's environment. However, a growing body of research indicates that a significant proportion of these children exhibit emotional or behavioral problems – problems that can place additional strains on the caregivers and their interactions with the child. (Goodman, Potts, Pasztor & Scorzo, 2004; Lawrence-Webb, Okundaye, & Hafner, 2003). In one study, approximately one-third of the grandchildren exceeded the clinical cutoff for behavioral problems on the behavior rating index for children (BRIC), and approximately one-quarter of the grandchildren had a school or learning problem (Goodman et al., 2004). Lai and Yuan (1994) found that 70 percent of grandparents in their study reported caring for a child with one or more medical, psychological, or behavioral problems.

Ehrle, Geen, and Clark (2001) report that about one-third of the relative caregivers in their study had less than a high school degree, over half were not married, one-fifth of the households had four or more children, and two-fifths of the households had a family income below the federal poverty level. Grandparent-caregivers were even more likely than other relative caregivers to be older, have less than a high school diploma, be in poor health or have a limiting condition, and be living in poverty (Scarcella, Ehrle, & Geen, 2003). Many

grandparent-caregivers have been found to suffer from such health problems as hypertension, arthritis, and diabetes (Grant, 2000) or such mental health problems as psychological distress in general (Mills, Gomez-Smith, & De Leon, 2005) and depression in particular (Fuller-Thomson, Minkler, & Driver, 1997; Kolomer, McCallion, & Janicki, 2002). Less is known, however about how caregivers' health and mental health directly or indirectly impact their grandchildren's well-being and their likelihood of obtaining needed services.

Utilization of mental health services is a significant concern among relative caregiver families. Many children in the care of relatives (including those arranged through the formal child welfare system *and* those arranged privately) are reportedly not accessing mental health services despite a demonstrated need (Ehrle & Geen, 2002; Leslie et al., 2000). These families may not be using services for a variety of reasons, including the caregiver's perception of the child's needs, the caregiver's own physical or mental health, total family burden and caregiving responsibilities, previous experiences with and cultural attitudes toward service providers, household income, insurance coverage, and such other barriers as childcare or transportation.

The purpose of this study was to explore needs, utilization patterns, and barriers to utilization of mental health services among families in which grandparents are caring for their grandchildren. The research questions for this study include:

- How are children in their grandparents' care doing, and what do grandparents see as their service needs?
- How might caregivers' needs – particularly unmet health or mental health needs – impact children's mental health and service utilization?
- What, if any, barriers to mental health service utilization have grandparent-caregivers encountered?

Developing knowledge that addresses these questions will facilitate improvements in the availability of mental health services that are appropriately targeted to families in which grandparents bear the primary responsibility for raising their grandchildren.

For the most part, the findings in this study are consistent with prior research on grandparents' caregiving experiences. This is significant because of the distinct nature of this sample. Whereas many previously published qualitative studies have recruited caregivers and children from a formal service system (either public child welfare samples or interventions targeting grandparents), many of the families in this study have had no current ties to services. In this sample, half of the families had no involvement with a child welfare agency, and fewer than a third of the grandchildren and only a handful of the grandmothers were currently receiving mental health services.

Beyond confirming prior research, this study provides a rich portrait of these caregivers' experiences that draws on a family perspective and further underscores a number of service-utilization issues. The interviews reveal the existence of current, unmet mental health needs – among both grandparents and their grandchildren – and the concluding section of this report will highlight implications for practitioners and advocates interested in meeting the service needs of grandparent-caregiver families.

DISTRIBUTION OF GRANDPARENT-CAREGIVER HOUSEHOLDS IN ILLINOIS

According to 2000 Census data, there are over 100,000 households in Illinois in which a grandparent reported having primary responsibility for grandchildren living in the home – households we refer to in this report as *grandparent-caregiver households*. In order to assess the distribution of these households across the state, we mapped the number and proportion of households per census tract. The maps, coupled with information gathered about number of social service providers across the state, were used to identify and select two geographic areas with a higher concentration of grandparents and seemingly fewer social service providers. We conducted the interviews and administered the surveys within the two selected geographic areas in order to maximize the likelihood of successfully recruiting grandparents and of reaching service providers who have worked with this target population.

The data used to identify and map grandparent-caregiver households was extracted from the 2000 Decennial Census Summary File (STF 3). Question PCT8_3 identifies households in which the grandparent reported having "primary responsibility" for grandchildren residing in the home. Because this variable does not indicate the presence or absence of the biological parent, the maps may include grandparent-caregiver families in which a parent resides. Figure 1 shows the distribution of grandparent-caregiver households across the State of Illinois. Almost 1,500 census tracts – representing 50 percent of all census tracts in Illinois – have between 20 and 100 grandparent-caregiver households. Thus, the formation and well-being of these families is a relevant topic across many areas of the state. There are also geographic areas with a much higher concentration of grandparent-caregiver families. In fact, there are over 72,500 grandparent-caregiver households in the Cook and collar county region (see Figure 2).

Figure 1. Number of households where grandparent reports responsibility for grandchildren under age 18 in the home - Illinois
(2000 Census data, by census tract)

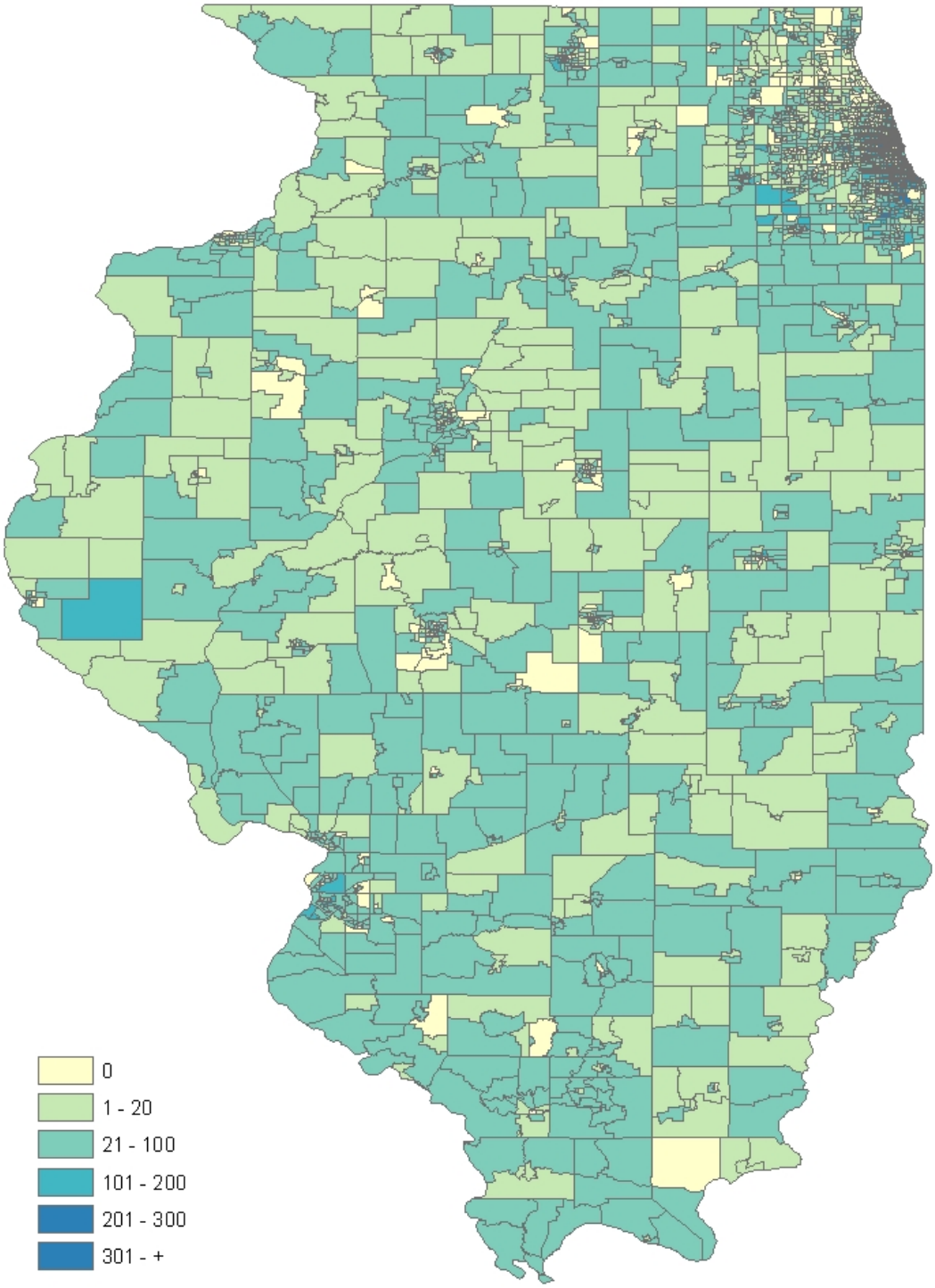
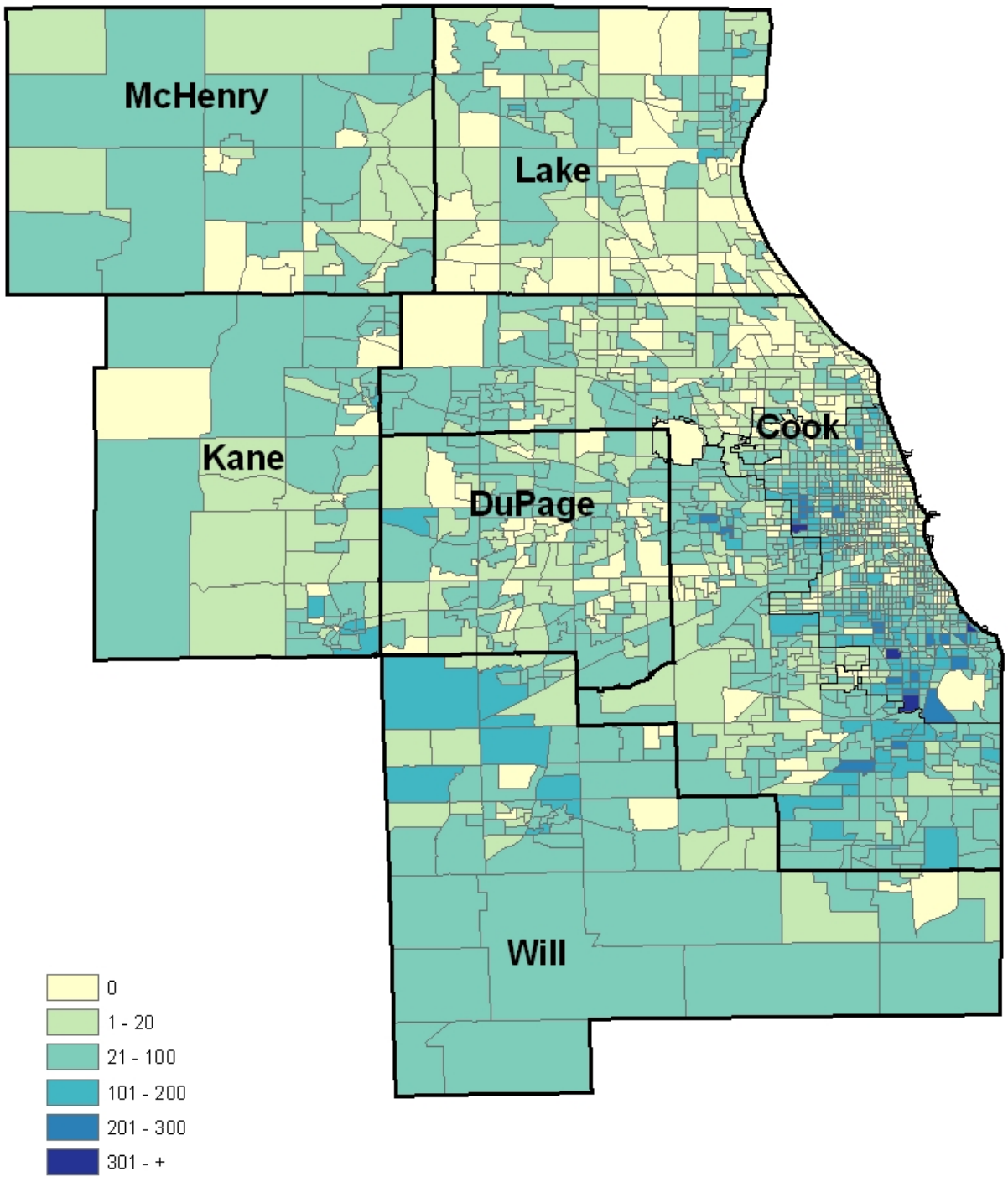


Figure 2. Number of households where grandparent reports responsibility for grandchildren under age 18 in the home - Six-County Chicago area (2000 Census data, by census tract)



Selection of Target Areas for Interview and Survey Data Collection

Cook and Will counties have the highest number of grandparent-caregiver households (58,833 and 3,560 respectively). However, for the purposes of this study, we were also interested in targeting areas that might have fewer mental health and social service providers. According to a 2004 report by the Brookings Institute, suburban census tracts in Chicago are not as close to social service providers as urban census tracts, and access is lowest within high-poverty census tracts (Allard, 2004). Therefore, the South Cook County suburbs and the Joliet/Northeast Will County areas were selected as the two areas with a significant number of grandparent-caregiver households (7,083 and 3,560 households respectively) and fewer mental health service providers.[1]

[1] See Appendix A for a map depicting the boundaries drawn for the South Suburban Cook County area.

METHODS

This study was conducted in three stages. In the first stage, we conducted a secondary analysis of census data in order to select two target study areas in Illinois with a high number of grandparent-caregiver households. Next, grandparent-caregivers and mental health providers from the two target areas were recruited for participation; grandparents were interviewed and mental health providers were administered a survey. In the third and final stage, workshops were offered in each of the target areas for study participants – grandparents and service providers – providing a forum for discussion and dissemination of the findings.

This section of the report provides detailed methodological information on the interview and survey components of the study, including sampling approaches, recruitment procedures, interview or survey protocols, and any standardized measures incorporated into these components (see Appendix B for a copy of the data collection instruments). The University of Chicago IRB approved the study protocol and procedures.

Interviews with Grandparent-Caregivers

Recruitment

In order to recruit interview participants, a flyer was created advertising the study – including the $20 compensation for a 1½-hour interview – with a toll-free number to call for more information about participating. Table 1 provides information on the two different approaches taken for distributing these flyers throughout the target areas: mailing them to professionals and community leaders, and posting them at various public places throughout the areas.

Table 1. Subject Recruitment Efforts, by Method and Target Area

	Cook County	Will County
Number of Packets Mailed to:		
Daycare/Head Starts	20	47
School Social Workers	76	67
Pastors/Churches	25	58
Community Centers	18	2
AARP Chapters	7	0
Grandparent Support Groups	10	1
Number of Flyers posted at:		
Grocery Stores	2	1
Laundromats	6	11
Pay Day Loan / Check Cashing / Currency Exchanges	11	13
Post Offices	1	0
Department of Health / Circuit Courts	1	0
Libraries	0	1
Train Stations	3	1

Note: Table numbers reflect number of different locations or persons receiving packets, not number of flyers posted at or mailed to each location.

Screening

A member of the research team provided prospective study participants who called the toll-free phone number with a brief description of the study and the option of answering eight questions that assessed whether they were eligible to participate in an interview. In order to qualify for the study, grandparents had to reside in the target area zip codes and currently be the primary caregiver, for at least 6 months, of one or more grandchildren between the ages of 2 and 18 years. The biological parents could not reside in the grandparent's home at the time of the interview, and the study was restricted to grandparents whose primary language was English.

Between March and November of 2005, sixty-five grandparents called the screening line to express an interest in the study. Approximately half (n=33) of the prospective participants indicated that they "saw a flyer" advertising the study, and another seventeen said they were referred by a professional. Most of the calls that were excluded were due to a parent living in the

home (14), a caller who resided outside the target area (5), or grandchildren being cared for who were not between the ages of 2 and 18 (4).

Of the forty qualified participants, thirty-two provided more specific information on how they found out about the study: twelve saw a flyer in the community, twelve saw a flyer at a child's school, and four received the flyer directly from the child's school social worker. Only one participant indicated she had heard about the study from another participant. Two of the forty qualified participants failed to complete the interview process. One never participated in the interview due to scheduling difficulties, and eventually a disconnected phone number and unanswered mail correspondence made it impossible to contact her. A second participant experienced an interruption half-way through the interview, and despite repeated efforts, the interviewer was unable to schedule another appointment to complete it. Thus, a total of thirty-nine grandparent-caregivers participated in the study with complete interview data gathered for thirty-eight participants.

Interview Protocol

Grandparent-caregivers participated in a semi-structured in-person interview approximately 1 hour in duration that included quantitative measures and open-ended questions regarding 1) household configuration, 2) the care situation, 3) the caregiver's physical and mental health, 4) the children's physical and mental health, and 5) the caregiver's and children's use of mental health services.

Measures

Caregiver depression. Caregiver depression was measured using the Center for Epidemiologic Studies Depression Scale (CES-D), developed by L.S. Radloff and first published

in *Applied Psychological Measurement*. [2]The CES-D is a twenty-item instrument developed to detect depression in the general population. Respondents rate the frequency or duration of time in the past week during which they have experienced a number of feelings or situations on a scale from 0 to 3; 0 indicating *some or a little of the time* (1 or 2 days), and 3 indicating *most or all of the time* (5 to 7 days). Possible scores range from 0 to 60, with higher scores indicating greater symptoms of depression, and a suggested cutoff of 16 to indicate depression. Because the CES-D does not assess the full range of depression, symptoms and uses the previous week as a time frame, its recommended use is as an indicator of symptoms of depression, not as a means to clinically diagnose depression.

Caregiver health distress. Caregiver perception of health distress was measured using a version of the Medical Outcomes Study health distress scale modified by the Stanford Patient Education Research Center. The modified health distress scale is a four-item instrument developed to measure respondents' feelings about the state of their health. Respondents rate the amount of time in the past month that they experienced a number of feelings—e.g., discouraged, worried, fearful, frustrated, on a scale from 0 to 5; 0 indicating *None of the time*, and 5 indicating *All of the time*. The scale score is the mean of the four items with a total score range of 0 to 5.

Child's behavior. Achenbach's Child Behavior Checklist (CBCL) is a 113-item assessment instrument designed and frequently used to obtain standardized measures of a child's behavior as reported by a caregiver (Achenbach & Rescorla, 2001). The pre-school form was used for children ages 2 to 5, and the school-age form was used for children ages 6 to 18. For each family, the CBCL was administered after selecting the child about whom the grandparent-caregiver had reported an emotional/behavioral problem and, if multiple children fit that

[2] Accessed through the Stanford Patient Education Research Center at: http://patienteducation.stanford.edu/research/cesd.html

criterion, the grandparent-caregiver was asked to select the child about whom he or she was most concerned. If only one child was being cared for, the grandparent completed the CBCL for that child. Each grandparent was provided a response card and asked to respond to each item using a 0-1-2 scale that represents *not or never true*, *somewhat or sometimes true*, and *very or often true*.

The CBCL was scored using Assessment Data Manager version 6.0 software provided by Achenbach System of Empirically Based Assessment (ASEBA). T-scores and indicators of borderline/clinical presentation were produced for eight syndrome scales: withdrawn, somatic complaints, anxious/depressed, aggressive behavior, delinquent behavior, thought problems, attention problems, and social problems. From these syndrome scales, three composite scales are calculated: internalizing (from the withdrawn, somatic complaints, and anxious/depressed scales), externalizing (from the aggressive and delinquent behavior scales), and total problems (incorporates all items).

A licensed clinician and member of the research team reviewed the CBCL scoring sheets and transcripts to assess consistency between numerical responses and open-ended responses (see Achenbach & Rescorla, 2001). If the explanation or example given by the grandparent was not illustrative of the numerical response, that response was changed for the final data analysis. For example, a grandparent indicated her grandson had obsessive thoughts sometimes. When asked to elaborate, the grandparent recounted the time when her grandson asked repeatedly for a video-game. The clinician/coder determined that the child's behavior was normative rather than obsessive, and the response was changed to *never*. In other instances, the grandparent used the same behavior to exemplify two different items. Per Achenbach & Rescorla (2001), a behavior should only be accounted for under one item. The clinician/coder made a decision about which item was most appropriate and adjusted the CBCL responses accordingly.

Analyses

Quantitative data about persons in the household and scores from all three standardized measures were entered in SPSS v.12.0 for further analysis. All interview tapes were transcribed. For the first level of qualitative coding, three members of the research team reviewed six transcripts and labeled units, such as a phrase, sentence, or paragraph, with a descriptive code of the unit's content. The data analysis team reviewed the descriptors together for reliability; where differences occurred they were discussed and clarified until a consensus emerged. The descriptors were then sorted into broad, non-mutually exclusive categories or themes. These themes comprised the coding scheme for analysis of the interview transcripts. Using Atlas.TI, each transcript was coded by one member of the research team. Periodically, during the analysis process, the team members met to discuss reliability in coding and to refine the coding scheme as new themes or variations on themes emerged.

Survey of Mental Health Providers

Sample

Of the 185 providers to whom surveys were sent, 36 were subsequently excluded because they either no longer existed or did not provide outpatient mental health services, and 4 were found to be duplicate listings for the same provider. Of the remaining 145 providers, 50 (34%) completed the survey. Almost three-quarters (73%) of providers who participated in the survey reported that they had either worked with grandchildren being raised by grandparents or grandparents who were raising their grandchildren. Therefore, it is highly probable that participation in the survey was largely driven by the perceived relevance of the substantive topic. This is further supported by notes taken during the follow-up phone calls in which at least three

providers indicated they did not work with “that population” and therefore would not be returning the mail survey.

Procedures

Each provider in the target sample was sent an introductory letter accompanied by a four page hard copy of the survey, a postage-paid return envelope, and instructions on how to complete the survey on-line if preferred. Only three providers completed the survey on-line. The remainder of the sample completed the survey by mail or by phone during a follow-up call placed by a member of the research team.

FINDINGS

The primary goal of this study was to increase our understanding of the need for and use of mental health services among grandparent-caregiver families. Interviews with grandparent-caregivers provided insights into grandparents' perspectives on the physical and emotional well-being of family members, their thoughts on their family's service needs, and their experiences with or perceptions of mental health services for both themselves and their grandchildren. Gathering data from those providing the services allowed for a brief examination of how service providers' and grandparent's perspectives aligned. Juxtaposed, the findings often verified each other but also pointed out gaps in understanding that may facilitate a better understanding of service needs and experiences and barriers to service delivery or utilization of services.

Interviews with Grandparent-caregivers

Description of the Grandparent-Caregivers and Their Families

Table 2 provides some descriptive information about the thirty-nine grandparent-caregivers we interviewed. Although all of the interview participants were women, slightly over half were raising their grandchildren with a spouse. The majority (77%) of the grandmothers were African American, and over half were between 50 and 59 years of age. Approximately one-quarter of the grandmothers were employed and another 26 percent quit working when they assumed care of the grandchildren. Almost two-thirds had annual household incomes less than $30,000, and although health insurance coverage varied, about one-half of the grandmothers relied on publicly funded programs for their health insurance.

Table 2. Description of Grandparent-Caregivers (*N* = 39)

	%
Primary Caregiver's Gender	
Female	100.0
Primary Caregiver's relationship to grandchildren	
Maternal grandmother	64.1
Paternal grandmother	30.8
Other (step-grandmother; cousin of mother)	5.1
Primary Caregiver's age	
40-49	10.3
50-59	58.9
60-69	23.1
70-74	7.7
Primary Caregiver's race	
African-American	76.9
Caucasian	15.4
Hispanic	5.2
Multi-racial	2.6
Primary Caregiver's marital status	
Married	54.0
Primary Caregiver's employment status	
Employed	26.3
Stopped working to assume care of grandchildren	26.0
Annual household income	
$0-10,000	15.4
10,000-20,000	25.6
20,000-30,000	23.1
30,000-40,000	5.1
40,000-50,000	20.5
Over 50,000	10.3
Primary Caregiver's Health Insurance Coverage	
Private Insurance	38.5
Medicaid	10.3
Medicare	23.1
No insurance	5.1
Medicaid and Medicare	15.4
Other (1 VA, 1 Medicare and Private)	5.1

Table 3 provides a snapshot of the families of the thirty-nine grandmothers who participated in the study. Across the thirty-nine families, a total of ninety-one grandchildren were represented, with the number of grandchildren being cared for per family ranging from one to seven. A significant proportion (77%) of grandparents reported that at least one grandchild in their home

had siblings who were living elsewhere. Approximately half of the families had no involvement with the public child welfare system. In many of these cases, the grandmothers reported that the biological mother had gone on to have more children who either remained with the mother or went to live with other relatives. Among those children in the grandmothers' care, the average age was about 10 years and the average length of time in their care was just under 7 years. The majority of grandchildren relied on a public health insurance program.

Table 3. Description of Grandparent-Caregiver Families

Family-Level Variables (*N* = 39)	**Mean**
Total number of adults in the home (includes caregiver)	2.1
Total number of children in the home	3.0
Number of grandchildren in the home	2.3
	%
Families in which grandchild has sibling outside the home	76.9
Families with no public child welfare involvement for any grandchild in the home	48.7
Child-Level Variables (*N* = 91)	**Mean**
Age of grandchildren in the home	10.3
Number of years grandchild has been in Caregiver's home	6.8
Grandchild's Health Insurance Coverage	**%**
Private Insurance	12.1
Medicaid/Public Aid/SCHIP	71.4
No insurance	3.3
Other (combination of public aid and private insurance or VA coverage)	6.6

Prevalence of Health Problems Among Family Members

Table 4 shows the prevalence of health problems among the grandmothers, their spouses, and the grandchildren in their care. Nearly four-fifths (79%) of the grandmothers reported having at least one health problem, and many had three or more health problems. Much like the grandmothers, the majority of their spouses (81%) also reported health problems, although a smaller proportion suffered from three or more problems. The three most-frequently reported health problems were the same for both the caregivers and their spouses – arthritis, high blood

pressure, and diabetes. A smaller but still sizeable proportion (57%) of grandchildren was reported to have at least one health problem. Emotional or behavioral concerns were most frequently reported, along with learning or developmental disabilities and asthma.

Table 4. Health Problems Among Family Members

	Respondent (*N*=39)	**Spouse (*N*=21)**	**At least one grandchild in the home has… (*N*=39)**
	%	**%**	**%**
Total Health Problems Reported			
None	21	19	43
Three or more health problems	44	21	12
Health Problems Reported by Type			
Arthritis	56	33	0
Asthma	21	10	31
Cancer	3	5	3
Diabetes	26	33	0
Heart Disease	8	24	0
High Blood Pressure	46	38	0
HIV or AIDS	0	0	0
Learning/Developmental Disability	0	0	41
Memory Problems	3	5	21
Substance Abuse Problems	0	0	0
Emotional or Behavior Concern	21	0	56
Other Health Problems**	5	10	21

** Health problems listed under other were speech/stutters (3), seizures (2), cerebral palsy (1), and eating disorder (1) for children; bad back (1), and menopause (1) for respondents; and emphysema (1) and stroke (1) for spouses.

Custody Arrangements and Legal Status

Although data show dramatic increases in the number of grandparent-caregiver households, many of these grandparents are caring for their grandchildren without legal standing. The legal status of grandparents who are raising their grandchildren has been discussed in the media, the research literature, and in legislative and advocacy arenas (Glass & Huneycutt, 2002; McLean & Thomas, 1996; Stowell-Ritter, 2004; Washington, 2006; Testa, 2005). Legal status is a significant issue for grandparents, practitioners who work with them, and policy makers

because it may determine what services and supports can be accessed, especially for grandchildren in "informal" arrangements. Challenges to accessing services for grandchildren and guidance and supports for caregivers are even greater among families who have had no involvement with the public child welfare system, as is the case for about half of the families in this study.

As part of the descriptive information gathered for this study, grandmothers were asked about the legal status of the child's custody. In the absence of a clear response, grandmothers were given response options of adoption, guardianship, subsidized guardianship, or the biological parents still retained custody.[3] In coding the transcripts, the project team found it difficult to definitively code the legal status of the current custody arrangement as many grandmothers used language that was vague relative to our research categories or legal definitions.

For about 16 percent of the 91 children, the biological parent appeared to still have custody. Regardless of custody arrangement, grandmothers used language that emphasized what was most salient to them, saying "He's just our grandchild. We have no…we haven't gone through any legal …none of that." They also emphasized which parts of the arrangement were most important to them, saying "I forgot what you call it, well they're assigned to me…I make all the decisions and everything, he's mine." or "We've got guardianship…and custody or whatever, you know we own them, they own us." Though the families' understanding of the relationship and its stability was often prioritized in their discussion over the child's legal status, this is not to say that some of the grandmothers did not realize the potential risks of not having

[3] Since 1997, Illinois has offered assisted or "subsidized" guardianship to children for whom reunification and adoption are not options, most of whom are relative caregivers. In addition to some services, the State provides monthly subsidy payments equal to the State's adoption assistance payments. See http://www.acf.hhs.gov/programs/cb/programs_fund/cwwaiver/2005/illinois2.htm for more detailed information.

established a legal arrangement:

> Waiting on a court date…Well the best I can tell you is DCFS is aware that the children are here…. [Interviewer: But their mother still has custody?] If she walks up today…She can probably take them away.

In addition, these families may be more likely to encounter problems registering for school, obtaining financial supports, and accessing health and mental health services for the children.

To the best of the research team's determination, just over half (54%) of the children were in some sort of guardianship arrangement, although it was not always clear whether the caregiver had filed for guardianship on their own or whether they had accepted the subsidized guardianship option through DCFS. In many of these cases, grandmothers responded by describing who was involved or the process they went through to complete and file paperwork:

> I have guardianship…I went down to the children's court at I guess that's what it is...and I petitioned for guardianship. They put several letters in the Minnesota newspaper for her to have a chance to contest it…and she didn't show up.
>
> [Interviewer: What's the legal custody status of [child] with you now?] Just grandmother…Guardian…It wasn't DCFS it was like a program that helped parents get guardianship of the kids. They had me do a lot of legal work.
>
> They referred me to an agency and the agency helped me with the papers, they got, gave me a little stipend… Like $200 for the kids or something [Interviewer: You have guardianship over her?] Yes I do.

Finally, just under a third (29%) of the children had been adopted by their grandparent(s). In many of these cases, the grandparent cited the desire to add the child to their health insurance as a motivating factor for seeking adoption. There were others; however, who were clearly opposed to adoption:

> They ask me did I want to adopt her…I told them no…I say that's my granddaughter. I don't need to adopt her. She's already related to me. I said I only need legal guardianship so I can take care of her…So I can take her to the

doctor. So that you know if anything happen, you know, I'm responsible.

Such sentiments toward adoption have been documented in other studies of kinship care (see McLean & Thomas, 1996). This has been a contributing factor in some states' consideration of such legal alternatives as subsidized guardianship.

Reasons Grandmothers Assumed Care of their Grandchildren

During the interviews, each grandmother was asked to describe how she came to care for her grandchildren. Responses to this question fell into two thematic categories, emotional ties and the biological parents' circumstances.

In a majority of these families, the decision to assume care of the grandchildren was influenced by the circumstances of the biological parent or parents and their ability to care for the grandchildren themselves. Just under half (49%) of the grandmothers reported that one or both of the biological parents were unable to care for the children due to having been involved with drugs or alcohol. Interestingly, this was the only statistically significant factor that differentiated DCFS-involved families from those who were not. A significantly larger proportion of families with reported parental substance use had one or more children who had current or previous involvement with DCFS (74% vs. 30%, $p<.01$).

Another circumstance leading grandparents to assume care was incarceration, with approximately one-fifth of the grandmothers reporting that one or both of the biological parents had been incarcerated. In a small proportion of families (15%), the grandmothers reported that one of the biological parents was deceased; however, this was the primary reason for assuming care of the grandchildren in only two families.[4]

[4] In the other 4 families, the deceased parent was either a non-custodial parent or the death occurred after the grandparent had already assumed custody for other reasons.

In the category of emotional ties, grandmothers spoke of their relationship with the grandchildren and/or the biological parents:

> Your grandkids are special…so I opened my doors to him.

> I said we should be there for our daughter…and we decided to go ahead and take care of him.

Several grandmothers expressed concerns over what they perceived to be the alternative – the children entering the foster care system:

> I didn't want to see them go into the system…I'm living and got my health and strength and I wanted to, I wanted them.

Changes Associated with Assuming Care of Grandchildren

Employment

As indicated in Table 2, about a quarter of the grandmothers interviewed were currently employed, and another 26 percent stopped working when they assumed care of their grandchildren. Several others reported that they had been attending school at the time and had to stop in order to care for the grandchildren. As the following quotations indicate, many of those who continued working – about a quarter of the respondents – talked of needing to rearrange their work schedule, change jobs, or make other special accommodations to continue to care for their grandchildren:

> So it was quite difficult. I had a babysitter at first. I would have to take him into the city, drop him off at the babysitter, go to work, and then I didn't get off until six. And you know day care centers close at six, so I'd be sneaking from work, or trying to talk somebody into [signing] me out so I could leave at say twenty minutes to six to get out here, to pick up the kids by six because they charge you a dollar a minute for being late, you know it was just—it was like there was nobody else who could do anything for me.

> I used to work for [company name] and that job I left because I didn't have anyone to care for him. So then I went to _____ Corporation, which I liked that job, and I had to leave…the hours that they was giving me I wasn't going

> to be able to maneuver and take care of him so I just went on and left that job. … And then I would take him to my [next] job …I was working out of the school district and I would hide him in my, because I had my own area see, and I hid him up and away until there was none of the school staff there and then he would come out and … it's kind of hard for me to imagine how did I do that? …When he got in school all day that was a big help.

Other research on women who have taken on an additional caregiver role suggests that although the decision to take on that responsibility was made independent of employment status, employment status was more likely to change among those who did decide to provide care for a family member (Pavalko & Artix, 1997, as cited in Pruchno & McKenney, 2006).

The impact of caregiving responsibilities on employment may be complex. Unemployment or a reduction in work hours may have not only economic implications – particularly closer to retirement age – but those changes also have social network implications as grandmothers lose a potential source of social support while going through dramatic changes in their and their families' lives. Of course, this must be weighed against the amount of stress encountered in efforts to balance work and childcare schedules among other things.

Marriage

As already mentioned, slightly more than half of the grandmothers were married at the time of the interview (see Table 2). However, through a series of questions about how their decision to care for their grandchildren affected family relationships, we learned that several other grandmothers had been married at the time they started caring for their grandchildren but were no longer married. Overall, twelve of the thirty-nine grandmothers (31%) discussed ways in which their decision to care for their grandchildren affected their marriages.

Three of the grandmothers spoke of previous marriages that ended in divorce after their grandchildren came to live with them; however, two of the three indicated there were marital difficulties already present before the added responsibility of raising grandchildren:

> Well I did have a husband, well, well for 33 years and he just left in February because he couldn't take the stress of the kids. …Well he said that it's, it's interfering with the travel and stuff like that basically, but it was just an excuse. I doubt if that really had anything to do with it.
>
> I think part of the reason why we're getting a divorce is because of [my granddaughter] being in the house … the marriage dissolved the following year. I won't say that taking the children had anything to do with the marriage; the marriage was in trouble already. But they are my grandchildren and the spouse was, it's not really his grandchildren.

Six of the grandmothers discussed ways in which raising their grandchildren placed additional strains on their marriage; four of these grandmothers felt that they were caught between their spouse (who was not the children's grandfather in all cases) and their grandchildren:

> [My husband] He's not much of a big help with the problems. I have to be the problem solver and because of that I think him and I argue a lot more. You know it's like OK, I didn't ask to be in this position you know … And it's like, "Help me with this." …if I get upset and I lose it about something you know, and I tell him that I'm upset and I'm losing it and I feel like I'm going nuts today he, instead of coping with it, will go to the person and start yelling at them, "look what you did to your grandmother."
>
> But [my grandchild] challenges my husband practically on a daily basis and I feel bad for him, my husband, because these really, these are my grandchildren, he is my husband, he is my second marriage. … And so I feel very upset that he has to be so upset.
>
> [My husband] loves them as much as I do but he doesn't know how to deal with it so I take a whipping from him too, because he loves me. He loves me and he loves the children. … my husband get mad at me [and say], "They don't appreciate what you're doing."
>
> So, and the thing of it is, is I feel bad that I'm imposing this on my husband. …Don't tell me that because this man is married to me that he's financially obligated to take care of these kids because it's not fair to him. I should not have to choose between my marriage and raising my grandchildren, but there have been times when it's been that way.

Not all of the grandmothers reported strains on the marriage; in fact, three grandmothers said that caring for their grandchildren strengthened the marriage, or that the marriage provided a significant source of support for them, saying "We've only gotten stronger together" or

> It drew my husband and I closer together … it gave us more reasons to stay together you know, just trying to help raise him and we bonded again …we've been married for 38 years.

Grandmothers' Role Loss

About one-fifth of the grandmothers (21%) discussed their feelings about taking on the parenting role instead of doing things they thought they might do as a grandparent. For many, this was a significant emotional loss, and they struggled with their new identity and role:

> I don't quite feel like a grandparent to them. I'm a parent. It's like psychologically I know that I'm their grandmother, but I'm not their grandmother because I would be a different type person only as a grandmother.
>
> This is not what I envisioned, believe me. I thought we would be taking trips you know, taking them to museums, doing things like that which would expand their minds. Things they would never have a chance to do. It's sad.
>
> What I had told my son was that I wanted to be a normal grandparent. I want to come pick her up on the weekends, spoil her rotten and send her back. Because that's what my mom did to me.

The role change had implications not only for the grandmothers, but also for the grandchildren and other family members:

> I think the hardest part with the children is them trying to get it in their heads that I can't just be Grandma anymore. … if I get upset or come down on them about anything they're just like, 'Grandma was never like this before.' And it's hard for me too because I don't like having to play mom but I have to. That's the hardest part of the whole thing. I like the role of Grandma. I think every woman likes the role of Grandma. You love being able to spoil them and play with them and send them back home. But when they stay you can't be Grandma anymore.

Another grandmother explained that one of her other children – not the biological parent of the grandchildren she was raising – was concerned that in raising one set of grandchildren the grandmother would not have the time or resources to be the more typical grandparent to the grandchildren not residing in the home.

Lifestyle Changes

About half of the grandmothers (49%) told us that assuming care of their grandchildren meant making changes to their lifestyle. For a few, the changes discussed were material – moving to a bigger house or apartment or buying a bigger car. For many, though, the changes largely involved loss of freedom:

> It's a freedom thing. I know I've got to be here at 2:30 pm because the youngest gets out of school at 2:30 p.m. I got to make sure I'm home at a certain time to get them bathed and fed and in bed and make sure their homework's done. Whereas before I got them I could come and go the way I pleased. Without having to worry about a time clock…[It's] a big burden. It's like it cut down my freedom.
>
> Our friends are all in their 60s where they can you know [say], "Let's go to dinner," and you can go to dinner. We can't do that. We have one couple that we see. Now we see them only every 6 months or so because we have to find a babysitter.
>
> When I got stuck with her, I don't mean stuck like in bad way. In a way I am happy, and in a way I feel like, "But when do I get my freedom to be to jump up and run out of the house like I want to, when I want to?" I got this responsibility. … I enjoy the company. Kids keep you young. But I be like wanting to go out sometime by myself. I want to mingle with other adults.

Another theme that permeated the discussions of how their lives changed was the sacrifices made in order to meet the children's needs. These sacrifices were not just of a financial nature, but often had implications for the extent to which the grandmothers were taking care of themselves.

> For me sometimes I just need the time for myself. I stopped doing certain things for myself in order to have money for them. You know I used to go to the beauty shop every week, just get my nails every two weeks or every week. I don't do that now. So, it's just, it did a whole lot in my life. I did 360 degrees in my life.
>
> Never been anywhere, done anything. I just went back to school 2 years ago you know, it was one of those things where I waited until my kids were grown. And I'm like OK, I've been doing for other people now I want to do something for me. And I even managed to, for the first time in my life, take a couple of vacations. I'd never been anywhere, so it was like just when I was starting to enjoy my life the most, bam, here I am with these kids again. So, I think I took

> it harder than any of the family members, because I really, I went into a real deep depression when I first got these kids. I mean I couldn't, I cried until I couldn't see straight.

Enjoyment Despite Stress

It is important to note – and it came through in several quotations already presented – that often, the grandmothers wanted to make sure that we knew there were also good moments or positive changes that accompanied the strains. More specifically, many of the grandmothers commented spontaneously about the joy that raising their grandchildren has brought them:

> I would say my life has been enriched by having them in my life.

> …it's kind of put a damper on my travel and those kinds of things, but that's okay because for some strange reason she is such a joy to just be around. You know we can go on a shopping trip like two old women and already she knows how to get the bargains. So it's okay.

> There are days when I feel they've picked the last ounce of everything out of me, and then there days that are wonderful. I love that and we have a good time.

Although researchers and service providers tend to focus on feelings of stress and change, it is absolutely critical – for the grandparents and those working with them – that these feelings of enjoyment not be lost among comments about stress and change. Maintaining a focus on positive aspects of the caregiving responsibilities promotes a mindset and intervention framework that is more consistent with strengths-based approaches, resilience, and "successful" aging (Sands, Goldberg-Glen, & Thornton, 2005).

Caregiver Well-Being

Grandparent-caregivers either have or experience many risk factors that may impact their well-being – older age, health problems, and changes in lifestyle, employment, and family

relationships, to name just a few. This section presents findings on grandmothers' reports of their physical and emotional well-being.

Physical Health and Well-Being

As mentioned earlier, nearly four-fifths of the grandparents reported one or more health problems. In response to a standardized measure gauging how much time someone has been worried, frustrated, fearful, or discouraged by their health, almost a quarter (23.7%) of the grandmothers in this study reported above average levels of distress relative to a chronically ill population.[5]

Many of the grandmothers talked about how their health had changed since they began caring for their grandchildren, with just over a third reporting that their health had worsened or that they were, at a minimum, increasingly tired as a result of caring for their grandchildren. In several cases, the grandmothers recognized ways in which their health limited their interactions with their grandchildren.

> My physical fitness you know, my high blood pressure and my diabetes both has not allowed me to be as active. Like they might want to go to see the school parade or whatever, I don't always feel up to it. I force myself to go, but I don't be feeling it. My balance be off a lot you know. So I have a lot of health issues and some days--well like anything--you might feel well today and tomorrow just don't even feel like doing anything. And I think that deters me from doing a lot of things with them that I would love to do.

Getting their grandchildren to and from school and extracurricular activities was mentioned several times as being exhausting, some discontinued the children's participation in after-school programs.

[5] The health distress instrument reportedly yielded a mean of 2.04 when tested on 1,130 subjects with chronic diseases, thus scores over 2.0 were considered indicative of above average levels of distress (Stanford Patient Education Research Center; http://patienteducation.stanford.edu/research/healthdistress.pdf).

Emotional Health and Well-Being

Depression. In talking about their experiences caring for their grandchildren, many of the grandmothers mentioned being depressed at some point. Based on scores from the standardized measure of depression that was administered during the interview, just over a third (36.8%) of the grandmothers scored above the clinical cutoff for the CES-D scale. Another five grandmothers did not score as being depressed, but talked about being depressed sometimes or having been depressed when they assumed care of their grandchildren.

Table 5 shows three factors that were found to be significantly associated with the grandmothers' CES-D depression scores. There were significantly higher mean health distress scores among those grandmothers whose CES-D scores indicated clinical depression; however, the total number of health problems grandmothers self-reported was not significantly associated with grandmothers' CES-D depression scores. It may be that depression affects grandmothers' perceptions of their health and functioning, or it may be that severity of health problems has a greater bearing on psychological distress picked up in the CES-D measure. Grandmothers' CES-D scores were also found to be significantly associated with parental incarceration and the average number of grandchildren for whom the caregiver reported emotional behavioral concerns. Among those grandmothers whose CES-D scores indicated depression, the proportion caring for a child whose parent was incarcerated was higher and the average number of children for whom the caregivers reported emotional behavioral concerns was significantly higher. Pruchno & McKenney (2002) also found an association between grandchildren's behaviors. They found not only a direct effect of grandchild behaviors (as measured with the CBCL) on grandmothers' negative affect, but an indirect effect as well by means of impacting grandmothers' assessment of caregiver burden.

Table 5. Factors associated with Grandmothers' Depression

	Grandmothers' CESD sum score exceeds cutoff for depression		***p*-value**
	No (N = 24)	**Yes** (N = 14)	
Grandmothers' average health distress score	.71	2.00	.000
Average number of children in home with reported emotional or behavior concern	.54	1.14	.041
Percent of families in which biological parent is or has been incarcerated	29%	71%	.036

No statistically significant association was found between grandmothers' CES-D depression scores and caregiver age, race, marital or employment status, household income, or substance use by a biological parent. It may be that the ability to detect statistically significant associations with some of these factors is limited by the small sample size represented here. Other studies have documented statistically significant associations between higher levels of grandparent-caregiver depression and younger age, how recently they assumed caregiving responsibilities, and marital status or co-residence; however, among non-white grandparent-caregivers, marital status did not moderate elevated depression levels (Blustein, Chan, & Guanais, 2004; Kolomer, McCallion, & Janicki, 2002; Thomas, Sperry, & Yarbrough, 2000).

Grandmothers' Reflections on the Children's Biological Parents. As noted in the description of sample selection, all of the families participating in the study were screened to ensure that neither of the biological parents was residing in the home with the grandmothers and grandchildren. Yet, it was striking how much the biological parents were at the heart of the discussion, and those discussions were often very emotional for the grandmothers.

Jackson (1996) cautions practitioners that parent-caregiver conflict is common among relative caregivers, and she recommends that practitioners acknowledge the "kinship triad" and

develop skills to include that triad in all components of any service delivery model. Assessment of relationships needs to be viewed in the context of that triad even when it is the grandparent-grandchild dyad presenting for assessment and/or treatment.

Several of the grandmothers struggled with thoughts of what led to the current caregiving arrangement and how they might have played a role:

> Everybody have to blame somebody. And I think I was blaming me for agreeing to help with the children. … And I blame me for my son because he didn't do what I thought he should have done. So it was like, I kept asking why? And I would say, "Why me?" …So it took me three years to get over the madness because I was mad. I don't know who I was mad at but I know I was mad. I was mad at me, and I guess I was really mad at the system.
>
> I sit and I try to figure out what I did wrong but I don't think I did it. I have two other children that are fine. But you do, you go through that.

In some cases, the grandmothers talked about how the children understood the grandparent's role in the events that led to the current caregiving situation. One grandmother said, "In his mind he thinks that I'm the reason that his mother's not with him."

On the other hand, another grandmother reported that her grandson held them accountable for not intervening sooner:

> [Our older grandchild] told us a lot of times, 'You didn't care about me because you didn't get me from my mom earlier-when I was little.' That kind of broke my heart. I was trying to explain to him that we couldn't just pick up and take him.

Some grandmothers appeared to be caught in the middle – between their biological children and the grandchildren – a position that clearly took an emotional toll. Overall, about one-third of grandmothers discussed the difficulties and stresses involved in dealing with their grandchildren's feelings toward their biological parents.

Hopes for parents' rehabilitation. Another theme that surfaced in the grandmothers' discussions about the biological parents was the lingering hope and/or uncertainty around

whether, when, and how the biological parents might resume caring for the grandchildren. Slightly over a quarter of the grandmothers made specific comments about their children coming back and taking on the parenting role again.

> I was taking them to see her because I was under the impression that she was gonna get her children back…and so I was taking them to see her. I was participating in the [rehabilitation] program and everything to help her get better and when she got out, she just decided she, just left.
>
> My son just showed up but he's been homeless for seven years and I, I didn't want to take him back but he just got a good job and we thought we would give him a chance.
>
> I don't know, I , I, I would love to see her make it. I don't know if she will…she thinks she's going to get out of there [the rehab center] and get the kids back but she's not. …I sit sometimes and I think well you know, what if she really does straighten herself out, how am I going to know, how am I going to ever trust her again to take these kids?

As these quotations demonstrate, some grandmothers' faced this issue in the beginning of the caregiving process; some faced it when the parent resurfaced after a period of time; and for others, it is an ongoing dilemma as the biological parent has continued some level of involvement in the family.

Handling the Stress, Coping Strategies

Forty-four percent of grandmothers (with varying levels of self-reported stress) seemed to have adopted an attitude of acceptance – perhaps as a means of moving beyond the questioning and the blaming. The grandmothers frequently made statements such as "You just got to do what you got to do and it works out" and "These are the cards I was dealt for life. So I have to play 'em the best way I know how."

On the other hand, some grandmothers described in more detail how they coped with the stresses and strains of raising grandchildren. The most frequently discussed coping mechanism

was drawing on faith or faith-based networks; 41 percent of the grandmothers said their faith, going to church, and praying helps them cope with raising their grandchildren. Several grandmothers (13%) said that they involve their grandchildren in activities to keep them busy and to give themselves a break. Others said that having a supportive circle of friends (15%) or family (10%) helps in raising their grandchildren. Finally, about one-fifth of the grandmothers turned to more formal sources of support – coping with the stresses of caring for their grandchildren by getting counseling for themselves, for their grandchildren, or for both themselves and their grandchildren. The use of and experiences with clinical services are discussed in more detail in a later section.

Well-Being of the Grandchildren

Although clinical information on the grandchildren in these families was not gathered directly from the children, it was gathered from the perspective of the grandmothers caring for the children. In this section, we present the results of the standardized assessment of the children's behaviors as well as thematically coded material from the interviews with the grandmothers.

Standardized Assessment of Behavior

As explained in the methodology section, each grandmother completed the Child Behavior Checklist (CBCL) for *one* child in each family. The child for whom the CBCL was completed – sometimes referred to in this report as the *target child* – was selected primarily based on grandmothers' reports regarding which child most concerned them with respect to emotional or behavioral well-being. Per recommendations in the Manual for the CBCL, results presented in this section are restricted to scores on eight syndrome scales and three composite scales (as opposed to the DSM scales) (Achenbach & Rescorla, 2001). The syndrome scales are

recommended for use in research identifying problem patterns or groups of children scoring high on a particular syndrome. The three composite scales – internalizing, externalizing, and total problems – have been found useful in differentiating children who need clinical services from those who do not need clinical services.

The prevalence and type of school-related problems reported among this sample is consistent with findings reported in other studies of children in kinship care (Goodman et al, 2004; Dubowitz & Sawyer, 1994; Edwards, 1998). In over two-thirds (69%) of the families, the grandchild's CBCL results indicated the presence of a clinical and/or borderline score on either one of the eight syndrome scales or on one of the three composite scales. It is worth noting that eleven of these children with a clinical or borderline score were currently receiving services. An additional four children whose scores were *not* in the borderline or clinical range were currently participating in services – two in educational services, one in a mentoring program, and one receiving medications with no additional counseling. Thus, it is possible that current receipt of services was influencing their current clinical presentation in a way that would underestimate the prevalence of syndromes or the need for services. Table 6 provides a more specific breakdown of the proportion of children scoring in the borderline or clinical range by type of scale.

Table 6. Prevalence of Clinical and Borderline CBCL Scores Among Grandchildren (*N* = 35)

		Clinical Scores	Borderline Scores
Syndrome Scales		%	%
	Anxious/Depressed	2.9	5.7
	Withdrawn/ Depressed	17.1	2.9
	Somatic Complaints	11.4	5.7
	Social Problems	8.6	22.9
	Thought Problems	14.3	5.7
	Attention Problems	22.9	11.4
	Rule-breaking behavior	11.4	14.3
	Aggressive behavior	17.1	11.4
Internalizing Problems		22.9	11.4
Externalizing Problems		31.4	14.3
Total Problems		31.4	14.3

These syndrome scale sores suggest that approximately one-fifth of the grandchildren for whom the CBCL was completed exhibit attention problems in the clinical range, and that figure rises to one-third when including children in the borderline range. Other types of problems reported with greater frequency in either the borderline or clinical range were social problems (31.5%), aggressive behaviors (28.5%), and rule-breaking behaviors (25.7%). Each of these types of problems has implications for the grandchildren's functioning, not only at home but also at school. In fact, some of the grandmothers responded to questions about emotional or behavioral problems in the context of school even if they did not observed the behavior at home, making comments such as, "One teacher told me that she thought he might have some anger management problems but he does that at school, I never see it" or "He do sometimes act out when at school…he burst out, holler across his class you know like emotionally." A few other grandmothers reported problematic behaviors at school such as cutting classes, arguing with teachers, or having trouble with peers.

Grandchildren Struggle with Thoughts of Their Parents

Children develop an understanding of their world through relationships, and relationships with parents are a significant influence, regardless of whether the parent is the primary caregiver. Thus, inconsistent parental contact or contact that is unpredictable in nature and/or frequency can have a significant impact on the child's emotional well-being, and may reveal itself through behavioral problems. For grandparents raising their grandchildren, there are tensions inherent in decisions about whether and when to allow contact between the grandchildren and the biological parents. Grandparents may be concerned about the child's emotional or behavioral reactions; yet, they may also want to sustain a connection between the grandchild and his or her parents. For some grandparents the desire to sustain a grandchild-parent connection may be out of hopes that the parent will resume their responsibilities, and for others it may be out of an effort to provide the child with a sense of the parent and/or the circumstances as many children question what led to circumstances or they fantasize about their parents in the absence of contact.

Just as thoughts about the biological parents of the children were emotionally draining for the grandmothers, the grandmothers also reported that these types of thoughts significantly impacted the grandchildren's well-being. Approximately one-third of the grandmothers discussed the emotional well-being of the children in terms of the impact the biological parents had on them. As evidenced in the following quotations, the grandmothers frequently described the children as being emotionally preoccupied with thoughts about the biological parents:

> That's why they are so angry with their mother and father. They want to know why they didn't keep them, why they didn't raise them?
>
> And [my grandson] worries about his mom all the time and he's not happy with his father… He's cried like a baby, yes he found out about [his mother stealing]. He went and stayed with his other grandmother. While he was there she went out stealing and he comes home crying. …he worries about his mom all the time. Only thing he wants to do is get grown and try to do something for her. All his life she been on drugs and in the

> hospital. Now she check herself in the hospital all the time… and when his dad call he's so drunk you don't understand what he's talking about. And I can take them to school, I can feed them; clothe them, and their mind's on their parents.
>
> She'll wake up in the middle of the night crying you know, wants to know what did she do wrong, why does her momma hate her so bad, you know stuff like that. Other than that she sleeps good you know and then she'll wake up some nights, "why did my momma throw me away," "what did I do to her, I didn't ask to be born."

According to the grandmothers' accounts, it was particularly traumatic for the children when the biological parents were a sporadic presence in the home and/or family:

> She came back to, occasionally to visit him but then she didn't really stay any more so I ended up with him…and it was very hard, very, very hard on him because he felt abandoned; he went through 6, yeah 6 months with his crying every night.
>
> These kids love their mother, they miss their mother, they're hurting for their mother…as soon as they get stable she would walk in and take them. And every time she did this I saw that it affected them you know, which is why I don't even want her here now. …You know I've just gotten these kids where they're not crying every day about her, so I'm not going to have her waltzing her ass up here when she needs to clear her conscience and then not care about how it's going to make them feel.

Caregiver Depression and Child CBCL

Although some studies address the mental health concerns among grandparents and grandchildren, less is known about the relationship between the mental health of caregiver and child. Results from this study suggest that there is a relationship, as evidenced by a statistically significant association between caregivers' depression scores and certain CBCL scores for the grandchildren. More specifically, higher CES-D scores for the grandmothers were found to be significantly correlated with higher t-scores on the internalizing scale ($r = .413$, $p \leq .01$) and the total problems scale ($r = .356$, $p \leq .05$), but not for the externalizing scale ($r = .222$, $p = .19$). Thus, caregiver depression was found to be related to children's internalizing problems and total problems.

The prevalence of depression among the grandmothers in this study and the reliance on grandmothers' reports of grandchildren's behavior in the CBCL raises questions about the interpretation of the CBCL scores. One concern is that the problem behaviors reported by grandparents are more reflective of the grandparents' emotional state than of the children's actual behaviors. However, other cross-informant studies on children in kinship care suggest that kinship caregivers might under-report problem behaviors (Dubowitz & Sawyer, 1994; Keller et al., 2001).

Need for, Use of, and Experiences with Mental Health Services

As noted in the introduction, one of the main goals of this study was to develop further our understanding of the complex dynamics underlying kinship caregiver families' apparent underutilization of mental health services. Thus, after assessing the families' needs and experiences, the conversations with grandparents focused on their need for or interactions with mental health services.

Perceived Need for Mental Health Services

Taking into account the CBCL scores of the thirty-five target grandchildren and whether they were currently engaged in services, we examined grandmothers' responses to questions about whether the child needed or could benefit from mental health services. Among those grandchildren whose CBCL scores were in the normative range, about one-third of the grandmothers said there was no need for services, and the others were open to services or would consider them, but they did not feel strongly that services were needed. A couple of grandmothers failed to differentiate between mental health services and educational services, expressing an interest in the latter.

Of the twenty-four children who scored in the borderline or clinical range on the syndrome or composite scales, half were perceived by their grandmothers as needing services. More specifically, the grandmothers spoke of the children needing services that would help in "dealing with her emotions, how she feels," provide "support…for uh, losing her mother…she need to get it out," or "rebuild his confidence, his self-esteem." However, in several instances, the conversation shifted to a discussion of needed educational services, rather than mental health services; one grandmother made comments such as, "he need…to talk to somebody…the older he gets the worse he gets…he's going on 9 years old and he doesn't speak well at all."

Of the other twelve children who scored in the borderline or clinical range on the syndrome or composite scales, but whose caregivers did not indicate a need for services, eleven were currently receiving services. Those current services included medications, a hospitalization, weekly outpatient counseling, and services through the school. These grandchildren's current participation in services likely decreased or negated the grandmothers' perceived need for services. Again, several of the grandmothers did not differentiate between mental health services and educational services and responded that the grandchild needed more special education services or increased tutoring.

For the grandmothers, perceived need for services was evaluated in light of whether they were currently participating in services, which only a few (4) were doing. Of the thirty-four grandmothers who were not currently receiving services, almost half said that they need or could benefit from mental health services, and another 15 percent said they "might need" or "maybe could benefit" from mental health services.

> Me and the children need help—any counseling, like, therapy to mediate some of the problems we have. I would love that.

> [I'm] a grandmother that just wants some relief… I don't just want relief physically from him; I want the mental stress up off me.
>
> Counseling would be good you know, for, for me because I want, I can talk and express my feelings of whatever came, is happening in my life that particular time. Once I get it out on the table and express myself and then I can go on, you know… sometimes you just need to you know, have somebody I guess to talk to so that they can tell you that whatever you're doing is right, you know.

Some of the grandmothers thought of counseling as a source of support and perhaps validation; others thought they might find support and validation by other means.

> I just wish more than anything…that there was somewhere that I could go that I, even if it's not at a therapy level – [to] sit and talk with other people that are raising their grandchildren. And see what they're feeling and see what they, I mean I can get better advice from them than I could from any shrink out there. You know, what have you done with this situation? Or if they ask me what did I do with the situation. Or how do you handle this, how do you handle that? You know, do you think this is a problem with the kid? Are you experiencing this or is this something really different that I need to look at?

Support groups for grandparents raising grandchildren appear to be one type of intervention that is experiencing rapid growth, moderate policy support, and success – as determined primarily through non-experimental evaluations (Cuddeback, 2004; Hayslip & Kaminski, 2005). In many states, foundations, the Department of Aging, or local chapters of the American Association of Retired Persons (AARP) are facilitating or providing networking support to grandparent-support groups. For some grandmothers, such outlets may provide short-term relief and an outlet for processing the changes they are experiencing. However, as Hayslip & Kaminski (2005) caution, support groups without a clear focus may simply become sessions for venting frustrations, and support groups that turn into such unstructured venting sessions may fail to engage grandparents over a significant amount of time and achieve a limited or even detrimental impact on grandparents' well-being. When we attempted to recruit grandparents through support groups listed by the Illinois Department of Aging and AARP, we found that three of the eleven listed for

our target areas were no longer meeting, and the primary contact for one other one could not be reached despite repeated efforts. Further research is needed to understand better how this population engages with support groups and the benefits and limitations of participation over time.

Experiences with Mental Health Services

According to the grandmothers interviewed, twenty-one of the children had received mental health services in the past. For five of these children, CBCL scores indicated no current need for services, and the grandmothers' assessment of the utility of the previous services – delivered through the school for two of the children – was mixed. A couple of grandmothers said it helped, others said it didn't, and one seemed primarily interested in obtaining an external assessment of the child, saying "the school psychologist…said he seemed to be okay to her." The other sixteen grandchildren who had received mental health services in the past – delivered through the school for six children – all had a current borderline or clinical score on one or more of the CBCL syndrome or composite scales. Just over half of those grandmothers had negative assessments of the usefulness of the services to the child:

> He was on meds but he's not on it right now because it wasn't really helping him.
>
> I don't think the counseling helped her. I think the situation and the time passage is what helped her
>
> I don't think it helped her a lot…she got good enough to know how to tell them what they wanted to hear. I think it helped me a little bit in the sense that I just felt better thinking that she was getting counseling.
>
> They keep telling me that this thing takes a long time and I say I haven't seen one ounce of improvement yet.

Only one of the grandmothers provided positive feedback about the earlier services, saying "It helped him because it helped him open and talk."

Some grandmothers suggested that they might have taken a cost-benefit approach to their evaluating the usefulness of the services. One grandmother in particular spoke of the added transportation and scheduling challenges brought on by additional service appointments:

> I had them in [program name] but my schedule at work wouldn't allow me to keep going. They were seeing them twice a week but I couldn't manage to get them from here to the West side and that was a problem. It lasted like 3-4 months…I get off work here then take em back so that was like a whole lot of traveling and I couldn't do that.

Another grandmother reported stopping the current counseling services in hopes that the children could get the counseling at school, which would be more convenient for her. Others spoke of how the services stopped for summer break or due to the closing of that particular provider location. As one grandmother put it "after that I just didn't look into another one."

As for the grandmothers' experiences with services for themselves, relatively few (4) grandmothers were currently receiving mental health services, but seventeen had used counseling services and/or medication in the past. A small majority of those grandmothers said it was helpful, and the rest had mixed reviews or felt the services they received in the past were not helpful. One of the grandmothers disappointed with the services commented that "They just want you to talk, and it's really just a mater of time before you get over it." Another complained about the staff turnover saying she got tired of having to "catch them up on everything."

Accessing Mental Health Service Providers

Analyses presented in the previous section revealed discrepancies between perceived need for services and current participation in services, both for the grandchildren and for the grandmothers. This is consistent with previous research showing underutilization of mental health services by kinship families, despite demonstrated need. Nevertheless, a considerable number of grandmothers and grandchildren not currently using services had previously

participated in services, suggesting access to and utilization of services had been successful at some point in time. These findings highlight the need to raise questions about potential barriers to accessing services. We began our inquiry by asking grandmothers whether they knew how to access services and whether there was anything keeping them from accessing services.

Five grandmothers indicated that they would not know how to access mental health services for their grandchildren, and fifteen said they would not know how to access these services for themselves. Many more said that they would know how to access mental health services – thirteen said *yes* when talking about services for their grandchildren and nineteen said *yes* when discussing services for themselves. Among those who said they would know how to access services, the most common pathway specified was through such primary supports as schools, doctors, or churches. A few said they would look in a phone book or call their health insurance provider, and a couple said they would return to a provider from whom services had been received in the past.

Many of the grandmothers were able to identify something that was keeping them from accessing mental health services. When discussing services for the grandchildren, several grandmothers cited factors ranging from geographic availability ("All the services [the caseworker] give me, they say we're not in your area, we can't help you") to stigma, ("I try not to bother anybody to come in through the state agency…because they try to be demeaning."). In the discussions of barriers to accessing services, the concerns most frequently mentioned generally had to do with payment or finances:

> It's hard to get these kinds of services with medical cards [i.e., public health insurance]…a lot of places don't want to deal with medical cards. You can't find anything in the phone book because there's nothing in the phone book that lets you know they take medical cards.

> If it was a long-term thing, most insurances will only pay for so many times a year.
>
> Finances…I don't have money for [mental health services].

The discussions of what was keeping grandmothers from accessing mental health services for themselves was very similar in nature. One grandmother who said that she does not know how to access mental health services but feels she needs them, said, "The difficulty is sometimes knowing where to start – who to pick, where to go." She added that some of the free services are short-term. Another grandmother said that she has tried to find services but the referrals she has received are for providers not in her area.

Choosing a Mental Health Provider: What Would You Want to Know?

Regardless of whether the grandmothers felt they or their grandchildren needed services or knew how to access services, they were asked to think about what they might like to know about a provider before seeking their services. The most common answer by far had to do with a provider's "qualifications" or "credentials"; however, very few elaborated as to what that meant. Although grandmothers often responded with "that they be qualified," "that they are reputable," "their background," or "make sure they know what they're doing," none of the grandmothers specified how they would assess that information. There was no indication of a particular licensure or education that was held in high regard, nor any specification of how they might go about evaluating a provider's level of experience or reputation. As an exception to this, one grandmother told of how she attended a DCFS foster parent meeting where service providers came and presented information about their agency or services offered. She said, "I kind of liked what they were saying and then there were some other people there that had used them and they gave them a very high recommendation." Thus, the combination of a face-to-face meeting and

endorsements by people she knew provided her with a unique opportunity to make a more informed choice.

Several other grandmothers expressed an interest in knowing something about the outcomes that might be expected, wanting to know "What kind of results I could look forward to," "What's their goal," or "What exactly are you going to do to help me?" A few grandmothers specified gender or religious preferences in a provider, and several expressed a desire to find a provider who "wasn't too quick to medicate."

Survey of Mental Health Providers

Description of Participating Providers

Table 7 provides descriptive information about the providers who participated in the survey. Sixty-one percent of those who responded were in Cook County and 39 percent were in Will County; however, results of the survey are presented in combined form because the numbers were too insufficient to allow meaningful comparisons by region. The descriptive information about providers is reported separately for those in individual practices and those in group or agency settings because there were significant differences in the likelihood that they had worked with grandparent-caregivers or grandchildren in their grandparents' care. Individual providers were significantly less likely to have worked with grandchildren in their grandparents' care (57.1% vs. 82.8%, $p \leq .05$) and grandparents raising their grandchildren (38.1% vs. 72.4%, $p \leq .05$).

In addition to the information displayed in Table 7, providers were asked to examine a list of towns in their geographic area and check all those that they serve. Approximately two-fifths (38%) of the providers indicated that they serve all of the towns listed in their area. Given that both of these target areas included a number of census tracts considered high-poverty, we

were particularly interested in the proportion of providers who accepted Medicaid—about 20 percent among these respondents. In addition, approximately 20 percent of the providers who did accept Medicaid had a waiting list for their services. Although other providers indicated that they offer a sliding-fee scale, one provider who attended the final workshops commented that her agency's sliding-fee scale still would not come near the co-pay amounts of the public insurance programs.

Respondents also provided some brief information about themselves and their background or credentials. On average, respondents had been with their current practice or agency for 11.2 years. Approximately one-third (31%) reported having attained a doctoral degree and an additional 53 percent reported having attained a master's degree. Of the respondents who reported their highest educational attainment to be bachelor's degree or lower, all reported their positions within the agency to be administrative or directorial, rather than clinical. With respect to licensure, 35 percent of respondents reported themselves as being a licensed clinical social worker (LCSW), 24 percent reported themselves as being a licensed clinical psychologist and an additional 20 percent reported themselves as being a licensed clinical professional counselor (LCPC).

Table 7. Description of Participating Providers

	Individual Practice (*N*=21)	**Group or Agency Setting** (*N*=29)	**Total** (*N*=50)
% of total providers	42	58	100
Average number of full time staff	.90	4.30	2.90
Average number of full time staff equivalents	.95	5.80	3.60
Median # clients per month	30	120	40
% who offer services:			
Individual therapy for children and adolescents	76	90	84
Individual therapy for adults	95	97	96
Family therapy	76	93	86
Group therapy	48	76	68
% who accept payment form:			
Private insurance	91	76	82
Medicare	38	52	46
Private pay	95	90	92
Medicaid	10	28	20
Sliding scale	76	76	76
% professional credentials/licensure			
None given	10	7	8
LCSW	38	35	36
LCPC	14	24	20
Licensed Clinical Psychologist	33	17	24
Psychiatrist	0	3	2
Other	5	14	10
% highest education level attained			
None given	14	0	6
High School graduation or GED	0	0	0
1-2 years of college (no degree)	0	7	4
Community college associates degree	0	3	2
3-4 years college no degree	0	0	0
Bachelor's degree	0	3	2
Masters degree	38	66	54
Doctoral degree	48	21	32
% race			
None given	14	0	6
African American (not Hispanic)	5	14	10
Caucasian (not Hispanic)	67	83	76
Hispanic	0	3	2
Amer. Indian, Eskimo, or Aleut.	0	0	0
Asian or Pacific Islander	0	0	0
Other	14	0	6
% sex			
None given	14	10	12
Male	24	28	26
Female	62	62	62

Clinical Experiences Working with Grandparents & Grandchildren in their Care

Presenting problems

Of the thirty-six providers who indicated they have worked with children being raised by their grandparents, 97 percent responded to a checklist of presenting problems. The three most common presenting problems were poor academic performance, aggressive behaviors, and inability to sit still/easily distracted (See Table 8).[6] These types of presenting problems were highly consistent with the syndromes that emerged more frequently on the CBCL measure and the grandmothers' reports of school-related concerns.

Table 8. Presenting Problems Reported By Providers Working with Grandchildren

	Percent of providers who reported a presenting problem (*N*=35)
Poor academic performance	80
Aggressive/Fights a lot	77
Can't sit still/easily distracted	71
Anxious/fearful	69
Temper tantrums	66
Tearful/sad	60
Poor sleep	43
Physical or sexual abuse	40
Nightmares	29
Violence in the home	29
Violence in the neighborhood	29
Hears voices/sounds that aren't there	6

Of the twenty-nine providers who reported providing services to a grandparent raising a grandchild, all of them reported one or more presenting problems among those grandparents. The three most common presenting problems were being overwhelmed or frustrated, parenting

[6] Please note that percentages in tables 8 & 9 reflect the proportion of providers surveyed who indicated they have worked with a grandparent or grandchild who presented with this type of problem. They do not reflect a proportion of children or grandparents who presented with this type of problem as they were not asked the number of grandparents or grandchildren with whom they have worked.

difficulties, and depression or sadness (Table 9). Again, these presenting problems are highly consistent with the issues that emerged from the interviews with grandmothers.

Table 9. Presenting Problems Reported by Providers Working with Grandparent-Caregivers

	Percent of providers who reported a presenting problem (*N*=29)
Overwhelmed or frustrated	93
Parenting difficulties	86
Sad or depressed	66
Marital or family relationship problems	59
Poor physical health	55
Anxious or fearful	52
Poor sleep	41
Violence in the home	10

Challenges Encountered

An overwhelming majority of providers working with grandchildren in the care of their grandparents reported at least one or more challenges when working with these children. The three most frequently reported challenges were the grandparents' reported failure to see the need for services, not showing up for appointments, and lack of or difficulty with transportation to appointments (See Table 10). In addition to other problems with keeping scheduled appointments, almost half of the providers reported concerns about participation due to the grandparent's health, and two-fifths reported client or family frustration with lack of change or progress. This latter concern is consistent with the grandmothers' accounts questioning the effectiveness of services their grandchildren received.

Table 10. Challenges Reported by Providers Working with Grandchildren

	Percent of providers who reported 1 or more challenges (*N*=35)
Child/family members don't see the need for services	57
Not showing up for appointments	57
Lack of or difficulty with transportation to appointments	57
Cancelling appointments	50
Poor health of grandparent prevents participation	47
Showing up late for appointments	47
Child or family members get frustrated with lack of change or progress	43
Lack of active participation in sessions or treatment planning	43
Lack of insurance or ability to pay	37
Poor health of child prevents participation	10

Of the twenty-nine providers working with grandparents raising grandchildren, 86 percent reported encountering one or more of the challenges listed in the survey. The four most frequently reported challenges all had to do with difficulties around keeping appointments – either by cancellation, showing up late, experiencing transportation difficulties, or not showing up at all. Furthermore, two-fifths of providers reported working with grandparents who had difficulties paying for services, and slightly more than a third indicated that grandparents' health problems interfered with participation in services.

Table 11. Challenges Reported by Providers working with Grandparent-Caregivers

	Percent of providers who reported 1 or more challenges (*N*=25)
Cancelling appointments	64
Showing up late for appointments	48
Lack of or difficulty with transportation to appointments	44
Not showing up for appointments	40
Lack of insurance or ability to pay	40
Poor health of grandparent prevents participation	36
Client doesn't see need for services	32
Client gets frustrated with lack of progress or change	32
Lack of active participation in sessions or treatment planning	28
Poor health of child prevents grandparent's participation	8

DISCUSSION

With a particular emphasis on mental health service utilization, this study provided an in-depth look at the experiences of a small group of grandparent-caregiver families in targeted geographic areas. These grandparent-caregivers were recruited from geographic areas in which a) census data indicated a concentration of grandparent families and b) other research has suggested that access to services may be more difficult due to availability and/or proximity. Despite the targeted nature of the sampling approach, the demographics of the grandparent families who participated in this study were in many ways consistent with the typical profile reported in the literature on grandparents raising grandchildren (see Cuddeback, 2004; Thomas, Sperry, & Yarbrough, 2000; and Hayslip & Kaminski, 2005). This study also confirmed many of the clinical issues discussed elsewhere in the literature on grandparents raising grandchildren. The circumstances that led to the caregiving arrangement – often incarceration or substance use – resonated with prior research (Cuddeback, 2004; Goodman et al., 2004; Gleeson & O'Donnell, 1997), as did the grandparent-caregivers' experiences of employment, role, and lifestyle changes (Landry-Meyer & Newman, 2004; Sands & Goldberg-Glen, 1998).

Beyond yielding consistent findings in the areas already mentioned, this study provided some rich information about these caregivers' experiences that draws on a marriage and family perspective. Caregivers in this study spoke of the impact *on* family and *of* family, drawing attention to marital supports and strains, the omnipresence of the biological parents despite their absence from the home, and the strong connections among all family members having an impact on well being. Among the more striking findings were 1) the emotional impact on the children of the biological parents' absence or inconsistent contact and 2) the significant association

between the caregivers' symptoms of depression and the grandchildren's emotional and behavior problems.

The study's most significant contribution – and one of its main goals – is to increase knowledge of the dynamics underlying grandparent-caregiver families' underutilization of mental health services, which has been widely reported in prior research. A priori hypotheses about the lower rates of service utilization included: the caregiver's perception of the child's needs, the caregiver's own physical or mental health, total family burden and caregiving responsibilities, previous experiences with and attitudes toward service providers, household income, insurance coverage, and other barriers such as childcare or transportation. The relevance of many, if not all, of these factors was borne out in the conversations with grandparents about their need for and use of mental health services.

In this sample of grandparent-caregiver families, over a third of the grandmothers currently reported symptoms of depression, and even more reported struggling with feelings of stress, frustration, and loss. Furthermore, over two-thirds of the grandchildren who were assessed exhibited symptoms in the borderline or clinical range on a standardized measure of children's behavior, and many grandparents reported significant struggles – historically or current – by the grandchildren to cope with the absence or inconsistent contact of their parents. The problems that mental health providers said brought grandparent-caregivers and grandchildren in to see them were very consistent with the emotional and behavioral concerns reported by grandmothers, with a strong presence of school-related or attention-related concerns among children and depression, stress, and frustration among grandparents.

Among these grandparents and grandchildren, the prevalence of depression and emotional or behavioral problems that rise to a level warranting clinical intervention is notable,

in part, because of the sampling approach and characteristics of those who participated in the study. Whereas many previously published qualitative studies have recruited caregivers and children from the formal service system (either public child welfare samples or interventions targeting grandparents), many of the families in this study have had no ties to what might be considered a "formal" service system. In this sample, half of the families had no involvement with a child welfare agency, and fewer than a third of the grandchildren and only a handful of the grandmothers were currently receiving mental health services. Yet, the proportion of families who had participated in services in the past was higher. Thus, the level of distress – for either the caregiver or the child – must have risen to a level that caused them to seek out services in the past. The existence of current, unmet needs – among both grandparents and their grandchildren – represents a challenge for practitioners.

For the most part, the lack of service utilization by grandchildren did not appear to stem from misperceptions of need. Most of the grandmothers acknowledged a need for or potential benefits of mental health services for the grandchildren. When it came to services for themselves however, some grandmothers acknowledged benefits of services and others adopted an attitude of acceptance and a desire to just keep moving forward, many preferring to rely on such informal sources of support as religion, friends, or family.

Grandmothers provided valuable insights into the lack of or inconsistent use of mental health services in their accounts of past experiences using or seeking out mental health services. A significant portion of the grandmothers questioned the effectiveness or utility of services provided to their grandchildren, and a significant proportion of mental health providers acknowledged family members' frustration with lack of change or progress. This finding raises questions about the clarity of expectations about mental health services, the effectiveness of the

types of services being accessed by these families, and the "fit" between the needs of these families and the models of intervention being employed by providers to whom they have access.

Both grandmothers and service providers reported additional barriers to mental health service utilization including scheduling difficulties, transportation arrangements, and insurance coverage or forms of payment accepted. These represent barriers that need to be addressed at the system level with a thorough examination of accessibility. An assessment of accessibility must also acknowledge circumstances at the family level – not only the needs of the child, but the needs and full responsibilities of the caregiver and the intersection of various policies and expectations regarding employment and financial supports.

This study has strong implications for interventions with grandparent-caregiver families. For some families, support groups and informational resources will sufficiently meet the families' needs. However, for approximately one-third of the grandparents and two-thirds of the target grandchildren, the objective assessment measures employed in this study suggest that the emotional distress rises to a level that warrants a more targeted clinical intervention. For those families, interventions that are likely to be most beneficial need to be family-focused and accessible.

By definition, grandparent-caregivers function within a complex family dynamic and, most importantly, in relation to the children in their care. Family-focused interventions consider the impact of stressors on the family and the impact of family members on each other. A family focus does not limit the range of interventions to family therapy, but rather considers family relationships, functioning, and demands in the treatment, whether provided to the individual, the family, or in a group.

Accessibility encompasses ability to pay, proximity to home or available transportation, and the accommodation of family-level needs, such as childcare and multiple schedules. Many of the grandmothers in this study connected mental health services with the schools, both with respect to identification of problems and in delivery or receipt of services. School-based services are convenient geographically and children are easily engaged. However, school-based services are often focused on functioning in the educational environment, and caregiver participation or the ability to use a family focus in such interventions has proven to be challenging. Schools or other community-based agencies could play a key role in provision of mental health services to these families by providing a familiar and convenient space for programs and, when relevant and financially possible, personnel. The accessibility of these organizations can also facilitate resource linkage and coordination among providers to the benefit of grandparent-caregiver families.

Psychoeducational group models represent one particular intervention that is likely to be a good fit for grandparents raising a child with emotional or behavioral problems. This approach incorporates the provision of information with the development of coping skills, emphasizing personal empowerment and collaboration with service providers and often peers. Furthermore, these programs are often designed for specific populations or to target specific problems, offering the advantages of clear expectations and goals and thus addressing grandparent-caregiver concerns about the focus and effectiveness of services. Information provided in psychoeducational approaches includes knowledge of relevant resources. The information provided combined with the development of a collaborative relationship with a service provider can facilitate assessment of additional individual mental health needs and resource linkage. There is a growing body of evidence supporting the use and effectiveness of family-focused

psychoeducational models, such as Mutliple Family Therapy Groups (Meezan & O'Keefe, 1998; McKay, Gonzales, Stone, Ryland, & Kohner, 1995; Stone, McKay, & Stoops, 1996; McKay, Harrison, Gonzales, Kim, & Quintana, 2002).

In conclusion, incorporating perspectives of grandparent-caregivers and service providers who have worked with these families, we obtained two fairly consonant perspectives on the caregivers' and grandchildren's mental health needs and service utilization experiences. The findings in this study are consistent with prior research on caregiving experiences and further underscore a number of service utilization issues. We have reached a point in this area of work that calls for an increased and narrowing focus on the demonstrated effectiveness and accessibility of mental health services available to these families.

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Appendix A
Geographic Boundaries of Cook County South Suburbs Study Target Area

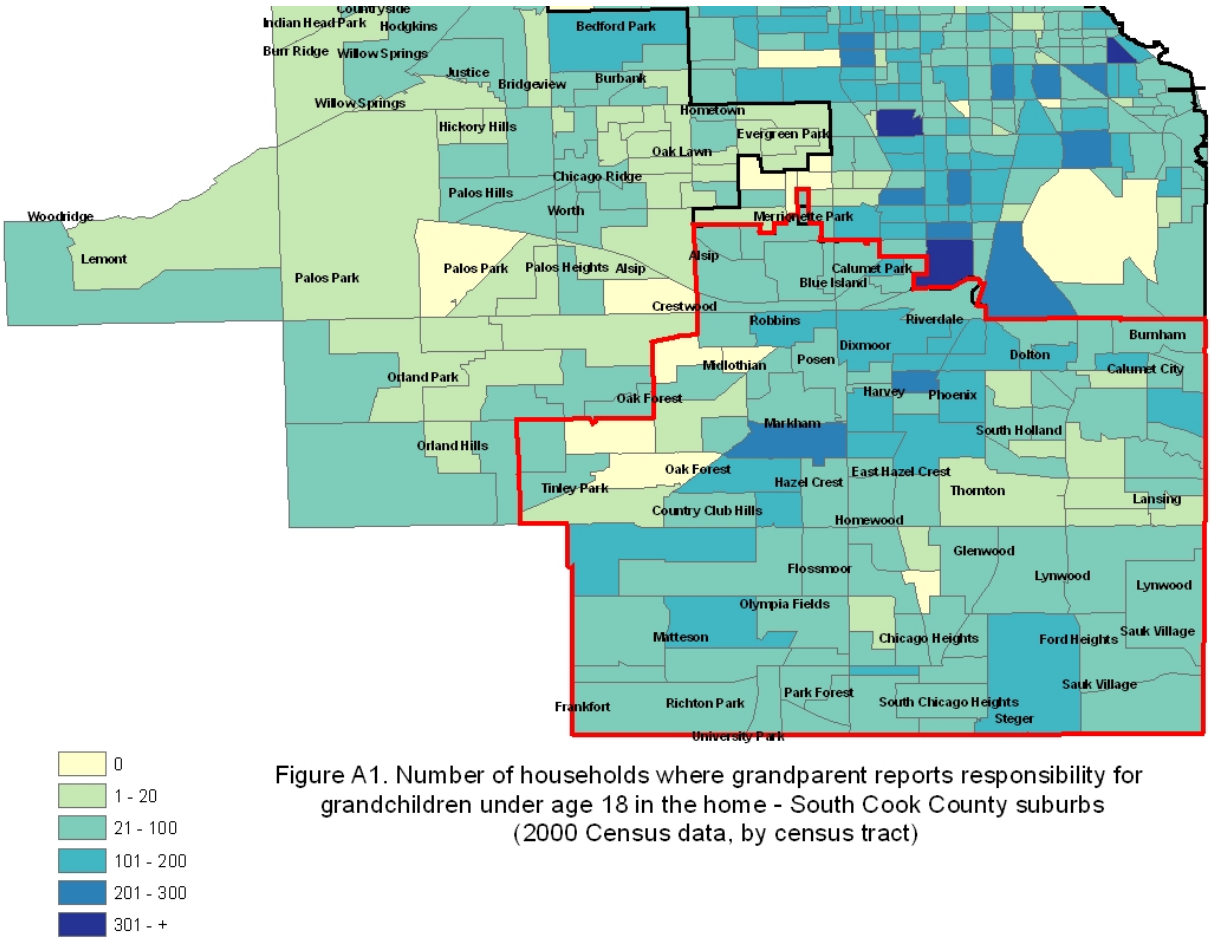

Figure A1. Number of households where grandparent reports responsibility for grandchildren under age 18 in the home - South Cook County suburbs (2000 Census data, by census tract)

Appendix B
Data Collection Instruments

Grandparent Interview Screening Form

SCREENER: Thank you for contacting us regarding our research involving grandparents raising their grandchildren. My name is _____. I am a researcher here at Chapin Hall Center for Children at the University of Chicago; one of my responsibilities is to talk with people who call in about this study. This phone call may take between 5 and 10 minutes. During that time, I'd like to tell you a little bit about the study and then if you are still interested in participating, I will ask you some questions to determine whether it would be appropriate for you to participate in an interview for this study.

Researchers at Chapin Hall are conducting a study that focuses on grandparents who are the primary caregivers for one or more of their grandchildren. We would like to talk with English-speaking grandparent-caregivers about what it is like to care for their grandchildren. By interviewing grandparents, we hope to learn about how they handle the stresses of caring for grandchildren and about the services that the families receive or need to continue to provide care for the children.

If you are interested in participating in the study and if you meet the study criteria determined by the questions I will ask you in this phone call, then we will arrange for you to participate in a one-on-one interview. The interview will take about 1½ hours to complete and you will be asked some questions about your family, your experiences caring for your grandchildren, your health and well-being, the emotional and physical well-being of your grandchildren, and social services that you need or are using. For this interview, one of our staff members will come to your home or meet you at another convenient location. Because we value your time and input, you will receive $20 for participating in the interview. You will also be invited to a workshop later this year - most likely in October or November – where we will present the findings from our study.

Now that I have told you a little bit more about the study, are you still interested in participating?

NO – Thank you for taking the time to call us.

YES – Great! I have about 7 or 8 questions I need to ask you. Your answers will help me determine whether you're eligible to participate in an interview. We will also use this information to provide a count and description of people who responded to the study recruitment materials. May I continue?

1. First, how did you hear about the study?
Saw Flier Heard from someone who participated referred by professional other

2. Is English your native language? IF NO - Do you speak English fluently?

3. Do you live in _____ or _____ *[insert names of target geographic areas; see listing of zip codes included if boundaries are unclear]*
Yes NO **(Exclude)**

4. Are you (the grandparent) currently the primary caretaker for your grandchildren who are residing in your home?
Yes NO **(Exclude)**

5. Where do the parents of the children live?
Exclude if either parent lives in the home

5. How many grandchildren are you caring for and what are their ages?
Exclude if caring for children less than 6 months and/or only child(ren) under age 2

6. Are you currently employed? **[placebo question]**

Grandparent Interview Protocol

FINAL VERSION

ID CODE: _____

Caring for the grandchildren

So let's start with how you came to care for your grandchildren. Tell me a little bit about that.
[How long ago? What was happening in your family at that time? Etc.]

How has caring for your grandchildren affected your relationship with other family members? your spouse/partner? your relationship with your children? Your relationship with other grandchildren?

How has caring for your grandchildren affected you financially?

Employment: Were you working when you started caring for them? Have you had to return to work, change jobs, or change your work schedule?

Expenses: What if any additional costs have you incurred because of your decision to care for the children?

How about physically or emotionally – have there been any changes in how you feel since the time you started caring for your grandchildren?

ID CODE: _____

Household Demographics

Now I'd like to get some more details by gathering some information about your family and any others who either live with you or that you provide care for.

[INTERVIEWER: FILL IN THE HOUSEHOLD INFORMATION CHART FOR EACH OF THE PERSONS IDENTIFIED BY ONE OF THE QUESTIONS BELOW…]

a) According to the information we received from the phone screening, your first name is _(NAME OF GRANDPARENT). Is that correct?

b) Do you currently have a spouse, partner, or significant other? YES NO

   a. If yes, does your spouse reside in this home YES NO

      i. IF YES…What is the first name of your spouse?

c) You also informed us that you are the primary caretaker for your grandchildren. Is that correct?
I'd like to talk with you more about your grandchildren but I want to make sure we keep their identities confidential, so does [the/each] child have a nickname or would you like to use initials for each grandchild currently in your care? [IF first initial is the same for 2 or more members, use first two initials]

COMPLETE THE TABLE ON THE NEXT TWO PAGES FOR THE GRANDPARENT, SPOUSE (if applicable), AND THE GRANDCHILDREN IN HIS/HER CARE.

ID CODE: _____

Household Information – sheet 1

	Nickname or Initials of First Name (or 1st two initials if same as another member of the family)	Relationship to you	Age (years)	Gender (M/F)	Race/ Ethnicity	Enrolled in School (yes/no)	Length of time in your care	Status of DCFS involvement? 0 = never involved 1 = currently open for investigation or services 2 = previously open, not currently	Legal Custody Status 1 = parent has legal custody 2 = DCFS has custody 3 = Guardianship 4 = Adopted 5 = Other _____	Health Insurance Coverage (a) private insur. (b) Medicaid (c) Kidcare/SCHIP (d) Medicare (e) No insurance (f) other (write in)
1		~~N/A – [GRANDPARENT CAREGIVER]~~								
2		Respondent's SPOUSE								
3		GRANDCHILD								
4		GRANDCHILD								
5		GRANDCHILD								
6		GRANDCHILD								
7		GRANDCHILD								

ID CODE: _____

	Nickname /Initials (cont.)	**HEALTH OR OTHER PROBLEMS** IF Emotional or Behavioral Concerns is CHECKED, ASK: Are you /IS child currently receiving services or participating in treatment to address these concerns?			Currently in services to address Emotional/ Behavioral Concerns?
1		__ Arthritis/Joint problems __ Asthma __ Cancer (of _____) __ Diabetes __ Heart Disease	__ High Blood Pressure __ HIV or AIDS __ Learning/ developmental disability __ Memory problems __ Substance Abuse	__ Emotional or Behavioral Concerns if yes, brief description: _____→ __ Other: _____	YES NO
2		__ Arthritis/Joint problems __ Asthma __ Cancer (of _____) __ Diabetes __ Heart Disease	__ High Blood Pressure __ HIV or AIDS __ Learning/ developmental disability __ Memory problems __ Substance Abuse	__ Emotional or Behavioral Concerns if yes, brief description: _____→ __ Other: _____	YES NO
3		__ Arthritis/Joint problems __ Asthma __ Cancer (of _____) __ Diabetes __ Heart Disease	__ High Blood Pressure __ HIV or AIDS __ Learning/ developmental disability __ Memory problems __ Substance Abuse	__ Emotional or Behavioral Concerns if yes, brief description: _____→ __ Other: _____	YES NO
4		__ Arthritis/Joint problems __ Asthma __ Cancer (of _____) __ Diabetes __ Heart Disease	__ High Blood Pressure __ HIV or AIDS __ Learning/ developmental disability __ Memory problems __ Substance Abuse	__ Emotional or Behavioral Concerns if yes, brief description: _____→ __ Other: _____	YES NO
5		__ Arthritis/Joint problems __ Asthma __ Cancer (of _____) __ Diabetes __ Heart Disease	__ High Blood Pressure __ HIV or AIDS __ Learning/ developmental disability __ Memory problems __ Substance Abuse	__ Emotional or Behavioral Concerns if yes, brief description: _____→ __ Other: _____	YES NO
6		__ Arthritis/Joint problems __ Asthma __ Cancer (of _____) __ Diabetes __ Heart Disease	__ High Blood Pressure __ HIV or AIDS __ Learning/ developmental disability __ Memory problems __ Substance Abuse	__ Emotional or Behavioral Concerns if yes, brief description: _____→ __ Other: _____	YES NO

ID CODE: _____

NOW THAT WE'VE talked about your grandchildren, I HAVE A FEW MORE QUESTIONS ABOUT YOUR HOUSEHOLD and YOUR AVAILABLE RESOURCES.

d) Are there other family members living with you?

If YES How many other ADULTS: _____

Their relationship to the grandchildren:

Grandparent	_____
Aunt	_____
Uncle	_____
Siblings (step/half/adopted)	_____
Cousins	_____
Nieces/nephews	_____
OTHER: _____	_____
OTHER: _____	_____

How many other CHILDREN: _____

Their relationship to the grandchildren:

Son/Daughter	_____
Aunt	_____
Uncle	_____
Siblings (step/half/adopted)	_____
Cousins	_____
Nieces/nephews	_____
OTHER: _____	_____
OTHER: _____	_____

e) Are there any siblings of the grandchildren in your care who do not live in this household?

If YES

Where do they live?

Are there scheduled visits between the siblings?

IF YES, what is your role in those visits? (transportation, supervision, none, other?)

f) Are there any other adults or children who are *not* members of your family but who reside in your home?

If YES, how many adults? _____ how many children? _____

ID CODE: _____

INCOME

g) What are the primary sources of income for your household?

h)What would you estimate is your **annual** household income (i.e. income for those who reside with you)? Please include all sources such as Social Security or TANF or payments from DCFS.

0 to 10,000
10,000 to 20,000
20,000 to 30,000
30,000 to 40,000
40,000 to 50,000
over 50,000

i) How adequate is your income at this point in time?

What, if any, expenses are you currently having trouble meeting? (probe: are you be able to handle an emergency expense or an unexpected bill on occasion?)

ID CODE: _____

Caregiver Health and Depression Inventory

I'd like to ask you some more specific questions about your health and well-being. For each of the following statements, please tell me IN THE PAST WEEK how frequently you might agree with the statement (INTERVIEWER – Read response headings after each item)

Center for Epidemiologic Studies Depression Scale (CCES-D)

	Rarely or none of the time (< 1 day)	**Some or a little of the time** (1-2 days)	**Occasionally or a moderate amount of time** (3-4 days)	**All of the time** (5-7 days)
I was bothered by things that usually don't bother me				
I did not feel like eating; my appetite was poor				
I felt that I could not shake off the blues even with help from my family				
I felt that I was just as good as other people				
I had trouble keeping my mind on what I was doing				
I felt depressed				
I felt that everything I did was an effort				
I felt hopeful about the future				
I thought my life had been a failure				
I felt fearful				
My sleep was restless				
I was happy				
I talked less than usual				
I felt lonely				
People were unfriendly				
I enjoyed life				
I had crying spells				
I felt sad				
I felt that people disliked me				
I could not "get going"				

ID CODE: _____

Caregiver Health Distress Assessment
(Source: Standford Patient Education Research Center,
http://patienteducation.stanford.edu/research/healthdistress.html)

Now, I have just four more brief questions about your health, and after each one, I'll ask you to tell me how often you have felt this way in the past month…

How much time during the past month...	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**
Were you discouraged by any health problems?	0	1	2	3	4	5
Were you fearful about your future health?	0	1	2	3	4	5
Was your health a worry in your life?	0	1	2	3	4	5
Were you frustrated by any health problems?	0	1	2	3	4	5

Follow the Caregiver assessment with:

Are you currently participating in counseling, therapy, or other mental health services?
If yes, tell me about those services?

how frequently? How do you get there? How long does it take?
Do you have to pay for this service?
If yes, how? (insurance? Out-of-pocket?)
How useful are you finding your therapy/counseling/mental health treatment? In what way(s) is this useful or not useful?

If no,
How would benefit from using this service now?
How would you access this service?
Is there anything keeping you from accessing this service? If yes, please describe.

Have you participated in counseling, therapy, or other mental health treatment in the past?

If YES, tell me about that experience. [Probes: what was the service, how long did you participate, what impact did participation in this service have or what did it accomplish?]

If NO, if you were referred for mental health services, what would you want to know about a provider before working with them? What concerns do you have about mental health services?

ID CODE: _____

IV. CHILD MENTAL HEALTH ASSESSMENT

Hierarchy of selection criteria for selecting which CHILD to reference for the CBCL instrument:

1) only 1 child

2) of the children in the home, if in the initial table of household information the caregiver reported emotional or behavioral concerns about only one child, select that child.

3) If emotional/behavioral concerns in initial table was not checked for any of the children, OR
   If there is more than one child with emotional/behavioral concerns…

   ask Caregiver, which of the children he/she is most concerned about with respect to the child's emotional well-being?

Administer CBCL here.

ID CODE: _____

Follow the child assessment with:

Is CHILD currently participating in counseling, therapy, or other mental health treatment?
If yes, tell me about those services?

how frequently? How do you get there? How long does it take?
Do you have to pay for this service?
If yes, how? (insurance? Out-of-pocket?)
How useful are you finding CHILD'S therapy/counseling/mental health treatment? In what way(s) is this useful or not useful?

If not currently participating in counseling, therapy, or other mental health treatment,
How would CHILD benefit from using this service now?
How would you access this service for CHILD?
Is there anything keeping you from accessing this service? If yes, please describe.

Has CHILD participated in counseling, therapy, or other mental health treatment in the past?

If YES, tell me about that experience. [Probes: what was the service, how long did CHILD participate, what impact did participation in this service have or what did it accomplish?]

If NO, if CHILD were referred for mental health services, what would you want to know about a provider before working with them? What, if any, concerns do you have about mental health services?

Is there anything else you would like to share with me today about your experiences caring for your grandchildren? IF NOT – Thank you very much for taking the time to talk with me. In about 1-2 months, you will be receiving a letter inviting you to a workshop in which we will present the findings of this study.

ID CODE: _____

Chapin Hall Survey of Mental Health Providers – Grandparents Raising Grandchildren Project

---

Agency/Organization Name: _____

Address where services are provided: _____

I. Services offered & capacity

A. Of the following mental health services listed, which ones does your agency provide:

Individual therapy for children & adolescents
Individual therapy for adults
Family Therapy
Group Therapy
Other – please specify: _____

B. How many staff do you currently have providing clinical mental health services?

full-time staff _____
part-time staff _____

C. On average, to how many clients do you provide mental health services?

Per month_____
Annually _____

D. Do you currently have a waiting list for clients seeking mental health services?

If yes, please specify the services for which there is a waiting list and the estimated time that clients are on the waiting list before receiving services:

Individual therapy for children & adolescents	Estimated Wait: _____
Individual therapy for adults	Estimated Wait: _____
Family Therapy	Estimated Wait: _____
Group Therapy	Estimated Wait: _____
Other – please specify: _____	Estimated Wait: _____
Other – please specify: _____	Estimated Wait: _____
Other – please specify: _____	Estimated Wait: _____

E. What towns or geographic areas do you serve?

(provide selection of surrounding towns/neighborhoods once target areas have been identified)

F. What types of payment arrangements do you offer/accept?

Private insurance
Medicare
Private pay
Medicaid
Sliding fee scale
Other – please specify: _____

ID CODE: _____

II. Your experiences working with grandparents raising grandchildren

A. Have you in the least year or are you currently providing direct clinical services to children who were being cared for primarily by their grandparents?

YES NO

If YES…

A1) Please check the presenting problems that you are aware of for children receiving services at your agency who are being raised by their grandparents. Check all that apply:

___Tearful or sad
___Anxious or fearful
___Aggressive, fights alot
___Poor sleep
___Can't sit still or easily distracted
___Nightmares
___Poor academic performance
___Temper tantrums
___Hears voices or sounds that aren't there
___Impact of physical or sexual abuse
___Violence in the home
___Violence in the neighborhood
___ Other (please write in any other problems not listed above): _____

A2) Which, if any, of the following challenges have you experienced when working with children being raised by their grandparents? Check all that apply.

___Not showing for appointments
___Canceling appointments
___Showing up late for appointments
___Children or family members don't see the need for services
___Lack of active participation in sessions or treatment planning
___Lack of insurance or ability to pay
___Lack of or difficulty with transportation to appointments
___Poor health of child or family member prevent participation
___Child or family members get frustrated with lack of change or progress
___Other _____
___I have not experienced any challenges

ID CODE: _____

B. Have you in the last year or are you currently providing direct clinical services to adults who were grandparents with primary responsibility for raising their grandchildren? These services might be specifically geared to grandparents or might be traditional services for adults and some of those adults receiving services are raising their grandchildren?

YES NO

B1) If YES, Please briefly describe the concerns that were addressed in your work with these adults/grandparent caregivers.

___Sad or depressed
___Parenting difficulties
___Anxious, fearful
___Violence in the home
___Poor sleep
___Marital or family relationship problems
___Overwhelmed or frustrated
___Poor physical health
___Other (please write in any other problems not listed above): _____

B2) Which, if any, of the following challenges have you experienced when working with adults who are grandparent caregivers? Check all that apply.

___Not showing for appointments
___Canceling appointments
___Showing up late for appointments
___Client doesn't see the need for services
___Lack of active participation in sessions or treatment planning
___Lack of insurance or ability to pay
___Lack of or difficulty with transportation to appointments
___Poor physical health prevents participation
___Client gets frustrated with lack of progress or change
___Other _____
___I have not experienced any challenges

ID CODE: _____

III. About Yourself

Your position/title within the agency: _____

Length of time you have been with the agency: _____

Your professional credentials/licensure:

___ LSW
___ LCSW
___ LCPC
___ Licensed clinical psychologist
___ Psychiatrist
Other – please specify: _____

What is the highest education level you have attained?
(PLACE X IN APPROPRIATE BOX)

a.. High School graduation (or GED) ..... ☐
b. 1-2 years college (no degree) ..... ☐
c. Community college associate degree ..... ☐
d. 3-4 years college (no degree) ..... ☐
e. Bachelor's degree ..... ☐
f. Graduate study (no degree) ..... ☐
g. Master's degree ..... ☐
h. Doctoral degree ..... ☐

Do you consider yourself . . .
(PLACE X IN APPROPRIATE BOX)

a. Black (not Hispanic)..... ☐
b. White (not Hispanic) ..... ☐
c. Hispanic ..... ☐
d. Amer. Ind., Eskimo, or Aleut. ..... ☐
e. Asian or Pacific Isl. ..... ☐
f. Other (SPECIFY) _____ ☐

Sex: Male Female

Thank you for participating in this study! If you would like to receive an invitation to the fall workshop where we will disseminate findings and other information on this topic, please click on this email link and provide your contact information. Providing your contact information via the link will ensure that your personal information is not connected to your survey responses.

ID CODE: _____

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