HELP TO KEEP GOING AS LONG AS THEY NEED ME:

A REPORT ON SENIORS RAISING CHILDREN

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CENTER FOR IMPACT RESEARCH
APRIL 2006

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EXECUTIVE SUMMARY

Today in the United States there are 2.1 million children being raised solely by their grandparents or other relatives with no parents present.[1] This situation is associated with a range of circumstances, such as parents struggling with substance abuse, physical and mental illness, incarceration, economic hardship, divorce, domestic violence, unemployment, and HIV/AIDS. Family members who assume the responsibility for children are known by the U.S. government as "kinship caregivers" and care for children both inside and outside the foster care system.[2]

Through the Department of Children and Family Services (DCFS), senior caregivers can become adoptive parents or subsidized guardians, foster parents or "home of relative" placements. Each of these relationships entitles caregivers to a variety of state services and resources. However, many senior caregivers become unofficial guardians and caretakers and are ineligible for state services or resources through DCFS.

State child welfare agencies across the nation have placed children requiring foster care with grandparents or other relatives. In Illinois, state policy dictates that kin be considered first when out-of-home placement is sought, even if the relatives and their homes are not licensed by

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[1] Generations United, "Grandparents and Other Relatives Raising Children: Challenges of Caring for the Second Family," August 2000. Accessed at http://www.gu.org/Files/ChallengesSheetfinal10_02.pdf on April 7, 2004.

[2] "Illinois: A State Fact Sheet for Grandparents and Other Relatives Raising Children," October 2003. Accessed at http://research.aarp.org/general/kinship_care_2003_il.pdf on April 12, 2004.

DCFS to provide foster care services.[3] Placement with kin is the preferred option for children because it provides continuity and connectedness for children who cannot remain with their parents, enhancing the children's well-being.[4] However, many kinship caregivers are older, with lower incomes, poorer health, and less education than non-kin foster parents. These differences can lead to greater challenges for kinship caregivers than for non-kinship caregivers.[5] Although state policies promote kinship placement, DCFS does not provide kin caregivers who are unlicensed with the same level of payments, supervision, and services as kin and non-kin caregivers who are licensed.

DCFS has almost 5,000 caregivers over the age of 60 caring for over 10,000 children.[6] Some of these foster parents are elder relatives, but others are non-related older individuals who have become caretakers of children. Kin caregivers who are 60 years of age or older are overwhelmingly female,[7] with 90% of these homes being headed by women. When these older individuals assume the responsibility of caring for children, often their lives become unpredictable and their households unstable. Financial shortfalls, space constraints, legal authority, and family dynamics can all coalesce to make caring for these children a complicated and potentially problematic responsibility.

The number of seniors (60 years of age and older) who are parenting their grandchildren, nieces, nephews, and other relatives has been growing and is expected to continue to increase until 2030. In collaboration with the Department of Children and Family Services (DCFS) and its Office of Inspector General, the Center for Impact Research (CIR) conducted a study of elder caregivers of DCFS wards, examining the challenges confronting these grandparents and other senior adults as they are increasingly called upon to raise their kin. Many of these seniors not only struggle to provide for their and their family's daily needs but also face difficulties as the emotional, physical, and financial demands of parenting stretch their capacity, and in some cases undermine their own health and well-being.

It is our hope that those public and private agencies working to support these senior caregivers and their children will find the data in this report helpful to their efforts to provide better services, better advocate for their needs, and create better policies and legislation.

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[3] Ibid.

[4] Rob Geen. "The Evolution of Kinship Care Policy and Practice," in *Children, Families, and Foster Care*, 14: 1, 131-149 (Winter 2004). Accessed at www.futureofchildren.org on April 7, 2004.

[5] U.S. Department of Health and Human Services, "Report to the Congress on Kinship Foster Care," June 2000. Accessed at http://aspe.hhs.gov/hsp/kinr2c00/ on April 12, 2004.

[6] These data are as of January 23, 2004 and include foster parents, relatives who have not taken on the legal status of "foster parent," subsidized guardians and adoptive parents. Personal communication, A. Ingram, DCFS, April 14, 2004.

[7] E. Fuller-Thomson, M. Minkler, and D. Driver, 1997. "A Profile of Grandparents Raising Grandchildren in the United States." *Gerontologist*, 37(3), 406-11.

KEY FINDINGS

DEMOGRAPHIC HIGHLIGHTS

- Nearly three-fifths (59%) of respondents hold less than a high school diploma.

- Most respondents report their current health as fairly good, with two-thirds describing themselves as somewhat to very healthy. However, slightly over one-quarter of the caregivers have a physical disability, and one-half of these respondents report that their disability has either just arisen or worsened in the past year.

- Almost one-quarter of respondents experience problems related to memory loss.

- Two-thirds of the respondents are able to carry out common daily life tasks including using the telephone, traveling by car or public transportation, shopping for food or clothes, preparing meals, doing housework, using medication, and managing their money without any assistance, while the remaining one-third need help with one or more of the tasks, requiring some assistance or needing someone else to do them entirely.

- Most caregivers in this study have adults (primarily family members) who help them, while 16% are caring for themselves and their children completely on their own.

- Respondents are caring for an average of 2.1 children.

- The children ranged from 1 month to 18 years of age, with a mean of 13 years.

CHILDREN'S INVOLVEMENT WITH CAREGIVER

- Almost three-quarters of the children are not living with their parents due to problems related to alcohol and drug abuse, and over one-third due to neglect.

- The senior caregivers in this study are adoptive parents or subsidized guardians for almost three-quarters of the children, and foster parents for almost one-fifth of the children.

CHILDREN'S HEALTH

- Almost three-quarters of the children of these providers are reported to be very healthy, and only 4% of the children are reported to be somewhat sick or very sick. However, 9% of the children have not attended school regularly due to health problems.

- Most of the children's healthcare is provided by Medicaid.

- 8% of the caregivers are unable to access medical care for their children, citing medical providers' unwillingness to consult with or serve them because they are not their children's biological parents, or they do not have legal authority to obtain medical services for the child.

- Despite reportedly high levels of overall health status, 41% of the children have one or more disabilities. The needs related to their disabilities are being met for two-thirds of these children, while the remaining one-third of the children have disability-related needs that remain unmet.

- Over one-half of the children in the study were exposed to drugs or alcohol in utero, and just over one-half of the children who were exposed have resulting health problems.

- Almost one-quarter of the youth were sexually, physically, or emotionally abused in their past.

CHILDREN'S EDUCATION

- Of the 102 caregivers with children who have disabilities, over one-half report that their children's disabilities interfere with their education, and over two-thirds of these children have Individualized Educational Plans.

- Caregivers report that over one-third of their children need tutoring, with children between the ages of 11 and 14 having the greatest need.

CHILDREN'S FINANCIAL SITUATION

- Slightly under one-half of the caregivers report that some or all of their children receive government aid, other than Medicaid. Given the high rates of poverty among the caregivers and their children, the receipt of government support is either highly underreported or many children who are eligible for public benefits are not receiving them.

CAREGIVER'S FINANCIAL SITUATION

- Over one-half of the caregivers report that their monthly funds are inadequate to support themselves and their children, and over one-third of the respondents report that they have difficulty providing food, clothing, or other necessities for their dependents.

- Much higher rates of respondents in the south suburbs and on Chicago's north side report monthly funds being inadequate to meet their and their family's needs than respondents living in the other areas encompassed by the study.

- Almost 40% of respondents have gone without food, clothing, or other necessities in order to provide for their dependents, with clothing and food being the needs most often unmet.

- 14% of respondents have not taken medication, skipped a dose, or not had a prescription filled, and 16% have had their gas or electricity disconnected due to lack of funds.

CURRENT LIVING SITUATION

- Almost three-quarters of respondents are living with their children in their own houses, with most of the remaining caregivers living in their own apartments.
- Almost one-half of the respondents live alone with the children for whom they are caring on behalf of DCFS. The other one-half of the caregivers live with relatives, including other children, grandchildren, spouses, and other adult relatives.

CHILDREN'S BEHAVIOR

- Almost one-third of the senior caregivers in this study report that their children have behavior problems. Almost one-quarter of the caregivers are unable to successfully discipline some or all of their children.

- Older children (11-18 years old) are over 60% more likely to have behavior problems than younger children (1 month-10 years old).

- With the exception of the oldest caregivers who report the lowest level of problems disciplining their children, age of caregivers had no significant effect on their ability to successfully discipline their children.

CHILDREN'S KIN

- Although the children in this study are not living with their parents, over two-thirds of them have contact with at least one of their parents.

- Four-fifths of the caregivers' children have siblings not currently residing with them.

CASE STATUS AND PLACEMENT

- Slightly more than one-half of respondents had time to prepare for caregiving before their children arrived. The remaining respondents had no time to prepare, primarily due to their children coming to them as emergency placements.

- Most senior caregivers report having a back-up plan, in the event that they are unable to care for their children. With few exceptions, caregivers expect that their relatives will take over responsibility for caring for the children if they are unable to do so for any reason.

- Caregivers between the ages of 65 and 69 were almost twice as likely as other senior caregivers not to have a back-up plan.

NEEDS OF SENIOR CAREGIVERS AND THEIR CHILDREN

- Almost one-fifth of the senior caregivers said that they have no current unmet needs.

- When asked whether they or their children needed any of 35 specified services or resources, senior caregivers averaged needing three resources or services for themselves and three for their children.

- Financial resources for caregivers (61%) and their children (56%) was the most frequently reported unmet need.

- A significant number of caregivers identified housing repairs (35%), respite care services (32%), clothing (22%), food (19%), dental services (19%), optometry services (17.0%), and transportation (16%) as resources that they need for themselves.

- Caregivers said that other than financial resources, their children's primary unmet needs are clothing (34%), food (22%), respite care services (21%), and educational support (19%).

ACCESSING RESOURCES

- The majority (58.9%) of respondents said that they know where to find the resources they need; 40.6% of report that they do not know how to access services and resources if they are needed.

- Over two-thirds of respondents tend to go to one or more places for resources and services, with community agencies (26%), church (24%), friends (19%), family (14%), DCFS (13%), and IDHS (12%) as the most frequently contacted places.

- Over 80% of respondents have used some type of resource to address their multiple needs. In some cases, friends, relatives, or neighbors provided the assistance. However, in most cases, a public agency or private organization was the resource provider.

- Many caregivers made use of more than one resource or service, with 23% reporting using three to five resources, and 38% reporting using six or more resources.

SOURCES OF STRENGTH AND SUPPORT

- By far the most frequently cited sources of strength for the senior caregivers in this survey are God, faith, and religion.

- Over one-fourth of the caregivers cite family and friends as a primary source of strength and support.

- For some of the respondents, their love for their children energizes them and the children provide welcome companionship.

- Most of the caregivers have raised their own children and many have had extensive experience caring for other children, either through work or in their personal lives.

SENIOR CAREGIVERS SPEAK OUT

- By far the most common concern, expressed in over one-third of the comments, was the need for greater financial support. Over two-thirds of these were general comments, focused on the need for improved overall financial support and the senior caregivers' inability to provide for their children's needs with the funds that they currently receive. 12% of the caregivers spoke about the need for Food Stamps, and often about the difficulty or inability that they have experienced in trying to access them. Respondents are critical of the insensitivity of the system to increases in the cost-of-living when determining the level of financial support for families. Other caregivers focused on the specific financial demands placed on them due to school expenses, and requested that government officials help them cover these costs.

- The need for more respite care services is another issue that respondents want highlighted for public officials.

- Some of the caregivers addressed frustrations that they experience as parents who have adopted their children, and what feels to them as an abandonment by the government as a result of their making this commitment to their children.

- A significant number of senior caregivers believe that improved and increased contact with DCFS is an issue that requires greater attention by public officials.

- Quite a few of the respondents are dissatisfied with the quality of schooling and educational support that their children receive.

- Caregivers reiterated their need to find more and higher quality afterschool and summer programs and activities for their children.

- Caregivers addressed the need for improved and increased availability of counseling and support groups for their children as well as themselves.

- A number of respondents feel that as seniors, their needs are different than those of younger caregivers. They would like service providers to be more sensitive to their circumstances.

RECOMMENDATIONS

The focus of this study is senior caregivers of children who are involved with the state child welfare system. However, many of the findings and subsequent recommendations apply to senior caregivers of children outside of the state system as well. Those recommendations that specify involvement with DCFS pertain specifically to families that are involved in the child welfare system. Given the current funding and structure of the state agencies, DCFS cannot support senior caregiver families who are not involved in the child welfare system. Support for these families must be established or enhanced through other agencies.

- Identify case managers within DCFS to work with senior caregivers who are trained in issues specific to older caregivers and are familiar with the resources available to help them.

- Ensure that case managers are knowledgeable about the rights of caregivers regarding the healthcare of their children and can intervene for caregivers unable to access medical care for their children.

- Provide information to caregivers about the effects of in utero drug exposure, measures that they should take to assess any impact this may have had on their children, and guidance on symptoms and treatment.

- Provide information to caregivers about the effects of abuse and neglect on children, potential ways to identify children who have been abused and neglected, and recommendations for appropriate services. Provide a contact person who is trained to identify and address child abuse and neglect as a resource available for ongoing counseling and support to these children and their families.

- Provide ongoing screening of every family involved with DCFS to ensure that the caregivers and children are receiving all of the benefits to which they are entitled through local, state, and federal programs. Provide support to the caregivers throughout the process of applying for benefits, following up as needed to ensure that they receive them.

- Coordinate DCFS's outreach to senior caregiver families with the Illinois Department of Human Services, the Illinois Department of Healthcare and Family Services and the Illinois Department on Aging to ensure that all caregivers have access to information and benefits.

- Increase the use of community-based organizations, including religious-based institutions, to provide outreach and information regarding programs and resources available to assist senior caregivers.

- Provide an increased level of financial support for caretakers who are unable to meet their and their children's basic needs due to insufficient funds.

- Provide parenting training and support for caregivers around issues of child behavior.

- Provide a supplement for respite care services for senior caregivers.

- Work with all caregivers to ensure that they have a back-up plan for caring for their children, in the event that they are unable to do so.

- Provide information and referrals to tutoring services, as well as financial resources to enable caregivers to access these services.

CONCLUSION

The needs and resources of senior caregivers and their children as documented in this research do not come as a surprise to service providers, advocates, or policymakers involved with this population. A large percentage of the respondents in this study are poor and living on fixed incomes. Over one-half of the caregivers are unable to support themselves and their children on their monthly income; 40% are unable to provide for their basic food, clothing, and medication needs. The need for financial resources was identified by over 60% of the respondents for themselves and by 56% for their children, far greater than for any other need identified in the study. And when given the opportunity to tell city or state officials anything that they felt might be useful to government workers who want to help them, they wanted their financial needs to be understood and taken seriously.

Thirty-five percent of the caregivers rate their own health status as so-so, somewhat sick or very sick, and one-third of the respondents report needing assistance to carry out basic tasks of daily life. These physical problems and limitations negatively impact their ability to care for their children and are problems that are likely to worsen as they age. These findings parallel the experiences of senior caregivers nationally.[8]

The resiliency and commitment of these older caregivers is as striking as their vulnerability and frustration. Most of these caregivers have resumed child-rearing responsibilities after having raised their own children. Most often, their grandchildren and other young kin have come under their care due to drug and alcohol abuse and neglect by the children's parents. While

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[8] Burnette, D. *Grandparents as Family Caregivers.* New York State Office of Aging. Accessed at http://aging.state.ny.us/explore/project2015/artGran.pdf on April 11, 2006.

most of the seniors have adults who help them, just under one-fifth are caring for themselves and their children completely on their own. Yet few expressed any bitterness or anger. Far more of the respondents spoke about the joy that the children bring into their lives and are grateful that they are able to take care of the children and keep them out of the foster care system.

Yet despite their desire to keep their children out of state care, many respondents spoke about their sense of being abandoned or left with insufficient support in caring for their children. Whether it is respite care, support and guidance in addressing behavioral problems, an advocate to insure that they are able to meet the medical needs of their children, or someone to check in on their own needs, senior caregivers need more intense and proactive support for themselves and their children. As one caregiver commented, "I tell you I'm blessed with these children. I don't want anyone taking them away from me. But it would sure be good if someone would give me just a little help along the way so I can keep goin' as long as they need me."

These senior caregivers are providing an invaluable service to these children and our communities. Some of the recommendations require little or no additional expenditure and should be considered for immediate implementation. The additional public expenditure would be more substantial for providing these families with more intensive case management and additional financial resources for basic expenses of food, clothing, health care, and housing as well as respite care services. However, the benefits that the public recieves from the willingness, hard work, and loving care of seniors in caring for children—many of whom have been abandoned and neglected—greatly exceeds the cost of expanding efforts to meet these basic needs. Despite the state's budgetary constraints that are forcing departments to cut expenses, this additional expense on the basic needs of senior caregivers of our children is not only fiscally prudent, but also prudent and ethical social policy as we continue to rely on grandparents and other seniors to care for some of our most vulnerable children.

INTRODUCTION

Today in the United States there are 2.1 million children being raised solely by their grandparents or other relatives with no parents present.[9] This situation is associated with a range of circumstances, such as parents struggling with substance abuse, physical and mental illness, incarceration, economic hardship, divorce, domestic violence, unemployment, and HIV/AIDS. Family members who assume the responsibility for children are known by the U.S. government as "kinship caregivers" and care for children both inside and outside the foster care system.[10]

According to the 2000 Census, 6.6% of Illinois children or 213,465 children live in grandparent-headed households.[11] In Illinois 103,717 grandparents reported that they are responsible for their grandchildren who live with them; 28% of these grandparents live in households where the children's parents are not present.[12] The number of seniors who are parenting their grandchildren, nieces, nephews, and other relatives has been growing and is expected to continue to increase until 2030. Of grandparents responsible for their grandchildren in Illinois, 41% are African American, 39% are White, 16% are Hispanic/Latino, and 2% are Asian.[13]

Through the Department of Children and Family Services (DCFS), senior caregivers can become adoptive parents or subsidized guardians, foster parents or "home of relative" placements. Each of these relationships entitles caregivers to a variety of state services and resources. However, many senior caregivers become unofficial guardians and caretakers and are ineligible for state services or resources through DCFS.

State child welfare agencies across the nation have placed children requiring foster care with grandparents or other relatives. In Illinois, state policy dictates that kin be considered first when out-of-home placement is sought, even if the relatives and their homes are not licensed by the DCFS to provide foster care services.[14] Placement with kin is the preferred option for children because it provides continuity and connectedness for children who cannot remain with their parents, enhancing the children's well-being.[15] However, many kinship caregivers are older, with lower incomes, poorer health, and less education than non-kin foster parents. These differences can lead to greater challenges for kinship caregivers than for non-kinship

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[9] Generations United, "Grandparents and Other Relatives Raising Children: Challenges of Caring for the Second Family," August 2000. Accessed at http://www.gu.org/Files/ChallengesSheetfinal10_02.pdf on April 7, 2004.

[10] "Illinois: A State Fact Sheet for Grandparents and Other Relatives Raising Children," October 2003. Accessed at http://research.aarp.org/general/kinship_care_2003_il.pdf on April 12, 2004.

[11] Ibid.

[12] Ibid.

[13] Ibid.

[14] Ibid.

[15] Rob Geen. "The Evolution of Kinship Care Policy and Practice," in *Children, Families, and Foster Care,* 14: 1, 131-149 (Winter 2004). Accessed at www.futureofchildren.org on April 7, 2004.

caregivers.[16] Although state policies promote kinship placement, DCFS does not provide kin caregivers who are unlicensed with the same level of payments, supervision, and services as kin and non-kin caregivers who are licensed.

DCFS has almost 5,000 caregivers over the age of 60 caring for over 10,000 children.[17] Some of these foster parents are elder relatives, but others are non-related older individuals who have become caretakers of children. Kin caregivers who are 60 years of age or older are overwhelmingly female,[18] with 90% of these homes being headed by women. When these older individuals assume the responsibility of caring for children, often their lives become unpredictable and their households unstable. Financial shortfalls, space constraints, legal authority, and family dynamics can all coalesce to make caring for these children a complicated and potentially problematic responsibility.

In 2005, in collaboration with the Department of Children and Family Services (DCFS) and its Office of Inspector General, the Center for Impact Research (CIR) conducted a study of 182 elder caregivers of children aged 18 and younger who are or were involved with the DCFS system, examining the challenges confronting these grandparents and other senior adults as they are increasingly called upon to raise their kin. Many of these seniors not only struggle to provide for their and their family's daily needs, but also face difficulties as the emotional, physical, and financial demands of parenting stretch their capacity, and in some cases undermine their own health and well-being. In addition to conducting the survey, CIR interviewed senior caregiver service providers, advocates, and public policy personnel working at public and private agencies. These interviews provided further information about the needs of senior caregivers and the resources currently available to them, as well as ways that the various systems serving this population might be improved.

It is our hope that those public and private agencies working to support these senior caregivers and their children will find the data in this report helpful to their efforts to provide better services, better advocate for their needs, and create better policies and legislation.

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[16] U.S. Department of Health and Human Services, "Report to the Congress on Kinship Foster Care," June 2000. Accessed at http://aspe.hhs.gov/hsp/kinr2c00/ on April 12, 2004.

[17] These data are as of January 23, 2004 and include foster parents, relatives who have not taken on the legal status of "foster parent," subsidized guardians and adoptive parents. Personal communication, A. Ingram, DCFS, April 14, 2004.

[18] E. Fuller-Thomson, M. Minkler, and D. Driver, 1997. "A Profile of Grandparents Raising Grandchildren in the United States." *Gerontologist*, 37(3), 406-11.

METHODOLOGY

STUDY DESIGN

At the outset of the project, the Center for Impact Research (CIR) met with senior policy makers in the Department of Children and Family Services (DCFS) and its Office of Inspector General to determine the initial scope and focus of the project. Following these meetings, CIR created a working group consisting of representatives of DCFS, the Illinois Department on Aging, the Chicago Department on Aging, advocacy organizations, and service providers for senior caregivers in the Chicago metropolitan area.[19] Working group members conferred on research design and survey development. After the data were collected, working group members discussed the research findings with CIR staff, and helped craft the policy recommendations.

THE SURVEY

The initial design was to choose three or four communities in the Chicago metropolitan area in which the surveys would be conducted, primarily to facilitate their administration. However, given the considerable differences in needs and resources that might be found among neighborhoods within Chicago, and the potential differences in the suburban and outlying areas, we decided to broaden the area from which respondents would be chosen to include a group of communities on the north, west, and south sides of Chicago, and in the north, northwest, and south suburbs.[20] A list of 1,768 potential respondents aged 60 and older who are caring for children aged 18 and younger who are or were involved with the DCFS system was provided by DCFS. The sample was stratified along caregivers' ethnicity and age as well as geographic location.[21]

The project had a total of 182 valid surveys completed. Four hundred survey respondents were initially selected. Of those respondents, 210 were unable to be interviewed. Over two-thirds

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[19] The Senior Caregivers' Working Group includes Barb Schwartz, Illinois Department of Aging, Grandparents Raising Grandchildren Program; Barbara Bouie Scott, Chicago Department of Aging; Linette Kinchen, GRANDFamilies Program of Chicago; Jean Xoubi, Metropolitan Family Services; and June Dohrn, DCFS.

[20] **North side** communities include Jefferson Park, Forest Glen, North Park, Albany Park, Portage Park, Irving Park, and Avondale; **West side** communities include Humboldt Park, Austin, West Garfield, East Garfield, North Lawndale, and South Lawndale; **South side** communities include Chatham, Avalon Park, South Chicago, Chicago Lawn, West Englewood, Englewood, Greater Grand Crossing, and Auburn Gresham; **North suburban** area included McHenry County; **West suburban** communities include Oak Park, Forest Park, and Maywood; **South suburban** communities include Blue Island, Riverdale, Dolton, Harvey, and South Holland.

[21] Some of the communities on the initial list from which we wished to sample respondents were not included in the final list because there were no caregivers aged 60 and older caring for children aged 18 and younger living in these neighborhoods.

(68.6%) of these non-surveyed individuals were unable to be contacted due to their not answering their telephones, or their telephone numbers being disconnected or incorrect with no new telephone number available. Only 29 (7.3%) of the potential respondents refused to participate. Of the 190 completed interviews, eight were discarded due to problems with appropriateness or validity.

Table 1: Reasons for Non-completion of Survey

	Survey Frequency
No answer	62
Disconnected	47
Wrong number	35
Refused	29
No show at scheduled interview	5
Cancelled and not rescheduled	4
No phone	4
Deceased	3
Out of town	3
Spanish only	3
Too sick, in hospital	3
No such person	1
Does not have grandchild - lives in senior housing	1
Unknown	10
Total	210

When collecting data from marginalized and at-risk populations, the use of peer surveyors increases the likelihood that potential respondents will choose to participate in the research. Furthermore, respondents often feel more comfortable being interviewed by a peer than by a professional researcher, who may seem unfamiliar and whose intentions may seem unclear or threatening. Fifteen adult women, six of whom are senior caregivers, were recruited and trained to interview respondents for the project. Each of the women lives in the community area where she administered the surveys. The surveyors have a wide range of volunteer and life experiences, and have worked in the following capacities: elementary school teacher (3), community educator (2), community organizer, esthetician, librarian, non-profit agency director, social worker, nurse's aid (2), minister, research data collector, and homemaker.

The surveyors attended training sessions that were 2.5 hours in length on three consecutive days, during which they learned about survey research methods and the goals of the project. They also practiced administering the survey and made suggestions for its revision. The survey included primarily closed-ended and multiple response questions, with a variety of open-ended questions for obtaining greater detail to enrich the data. The sessions provided in-depth training on appropriate ways to ask questions and query respondents, addressing issues related to ensuring confidentiality and the safety of both surveyors and respondents.

During July and August 2005, surveyors interviewed senior caregivers, primarily in the respondents' homes; some interviews were conducted in local libraries and community agencies. Surveys with senior caregivers were completed in approximately 30 to 45 minutes and respondents received a $10 store gift card as an incentive to participate and in appreciation for their time. Surveyors were paid $20 for each completed interview.

In addition to conducting the survey, CIR interviewed senior caregiver service providers, advocates, and public policy personnel working at public and private agencies. These interviews provided further information about the needs of senior caregivers and the resources currently available to them, as well as ways that the various systems serving this population might be improved.

The youth surveyors and the project advisory groups reviewed the draft report and provided suggestions for changes and additions to the data analysis and final recommendations.

THE DATA

The 182 surveys were administered by the fifteen surveyors to senior caregivers throughout the Chicago metropolitan area. We have presented the data as available from other sources to provide a larger context for the survey data.

Subgroup differences are presented when they are statistically significant ($p < .05$), and when the strength of the relationships is sufficiently strong to merit attention.

DEMOGRAPHICS

DEMOGRAPHIC HIGHLIGHTS

- Nearly three-fifths (59%) of respondents hold less than a high school diploma.

- Most respondents report their current health as fairly good, with two-thirds describing themselves as somewhat to very healthy. However, slightly over one-quarter of the caregivers have a physical disability, and one-half of these respondents report that their disability has either just arisen or worsened in the past year.

- Almost one-quarter of respondents experience problems related to memory loss.

- Two-thirds of the respondents are able to carry out common daily life tasks including using the telephone, traveling by car or public transportation, shopping for food or clothes, preparing meals, doing housework, using medication, and managing their money without any assistance, while the remaining one-third need help with one or more of the tasks, requiring some assistance or needing someone else to do them entirely.

- Most caregivers in this study have adults (primarily family members) who help them, while 16% are caring for themselves and their children completely on their own.

- Respondents are caring for an average of 2.1 children.

- The children ranged from 1 month to 18 years of age, with a mean of 13 years.

CAREGIVER'S AGE AND GENDER

The senior caregivers are between the ages of 60 and 89 years, with just over one-half of the respondents age 71 or older. The age distribution reflects the intentional over-sampling of the oldest caregivers in order to ensure that we would gather a sufficient amount of data to be able to draw valid conclusions about their experiences, as contrasted with those of younger seniors.

Table 2: Age of Caregiver

Age	Survey Frequency	Survey Percent	DCFS Sr. Caregivers Percent
60-64	44	24.4%	39.4%
65-69	43	23.9%	29.9%
70-74	31	17.2%	18.1%
75-79	43	23.9%	9.6%
80-89	19	10.6%	3.0%
Total	180	100.0%	100.0%

Table 3: Gender of Caregiver

Gender	Survey Frequency	Survey Percent
Female	170	94.4%
Male	10	5.6%
Total	180	100.0%

The gender divide among caregivers in this study reflects both the distribution among the DCFS senior caregiver population as well distribution in the larger senior caregiver population, with the vast majority of senior caregivers being women.[22]

ETHNICITY, RESIDENCY STATUS, AND LANGUAGE OF CAREGIVERS

The ethnicity of the caregivers reflects a far larger percentage of non-whites than found in the Chicago or Illinois populations. The large number of African-Americans reflects their large majority within the DCFS senior caregivers population, and would have been even greater, had we not over-sampled among the Hispanic/Latino and White/Caucasian populations. In this study, the ethnic group of both respondents listed as 'Other' is Native American.

Table 4: Ethnic Background of Caregiver[23]

	Survey Frequency	Survey Percent	DCFS Sr. Caregivers Percent	Chicago Percent	Illinois Percent
African American/Black	155	85.2%	95.6%	35.8%	15.1%
Hispanic/Latino	17	9.3%	1.5%	27.9%	12.3%
White/Caucasian	10	5.5%	2.3%	47.1%	67.8%
Other	2	1.1%	0.6%	0.2%	0.2%
n=182					

*Totals exceed 100% due to respondents selecting multiple ethnic backgrounds

Fourteen of the respondents are immigrants, twelve of whom are Latino (Mexican, Puerto Rican, and Honduran). With the exception of two caregivers who are legal, permanent residents, all respondents report their status as U.S. Citizens.

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[22] T. Simmons, J. Lawter Dye. "Grandparents Living with Grandchildren, 2000." U.S. Census Bureau, October 2003. Accessed at http://www.census.gov/prod/2003pubs/c2kbr-31.pdf on April 17, 2006.

[23] DCFS data as of June 22, 2005. Chicago data from American Community Service Profile, U.S. Census Bureau, 2002 and Illinois data derived from U.S. Census, 2000 figures for Illinois, available at www.census.gov.

Given that most of the respondents were born in the U.S., it is not surprising that 91.2% of them report English as their primary language, with the remaining 8.8% reporting Spanish as their primary language. In their self-assessments of their language skills, most respondents describe themselves as having strong English speaking, reading, and writing skills. Caregivers whose primary language is Spanish assessed their English skills significantly weaker than those for whom English is their native tongue.

Table 5: Caregiver's English Proficiency

	No Skill (1)	Weak Skills (2)	Strong Skills (3)	
Speaking	1.1%	7.1%	91.8%	Mean=2.9 (n=182)
Reading	2.2%	16.6%	81.2%	Mean =2.8 (n=181)
Writing	1.7%	16.6%	81.8%	Mean=2.8 (n=181)

CAREGIVER'S EDUCATION

The caregivers' educational level is low, with 59.2% of respondents holding less than a high school diploma, with a mean of 11.4 years of school.

Table 6: Highest Grade Completed by Caregiver

	Survey Frequency (n=182)	Survey Percent
1-8	45	24.9%
9-11	62	34.3%
12 (HS/GED)	40	22.1%
13-22	36	18.8%
Total	181	100.0%

Five of the caregivers are currently enrolled in school, taking vocational and GED (high school equivalency) courses.

CAREGIVER'S EMPLOYMENT

Only 12.1% of the senior caregivers are currently employed or in a job-training program, with most of these workers less than 70 years old. Their jobs are primarily in the service sector.

Table 7: Caregiver's Employment

	Survey Frequency	Survey Percent
Factory worker	5	31.3%
Day care worker	3	18.8%
Home care worker	2	12.5%
Cashier	1	6.3%
CPS lunchroom manager	1	6.3%
Hotel/banquet worker	1	6.3%
Juvenile detention center worker	1	6.3%
Letter carrier	1	6.3%
School aide	1	6.3%
Total	16	100.0%

Those senior caregivers who are employed work between five and 60 hours per week, with a mean of 33 hours per week. Their earnings range from $260 per month to $4,057 per month, with a mean of $1,761 per month.

Most of the respondents (76.4%) have retired from employment; 5.5% have had to reenter the workforce after retiring to support the children for whom they are now caring, which represents 15.0% of the respondents who are working. Those respondents with spouses are five times as likely to be working as those who do not have a spouse.

CAREGIVER'S HEALTH

Senior caregivers were asked about their current health status and their health status one year ago. Most respondents report their current health as fairly good, with two-thirds describing themselves as somewhat to very healthy. One-quarter of the caregivers report a change in their health over the past year, with an identical number (12.2%) reporting an improvement as those who report a decline.

Table 8: Caregiver's Current Health

Health Status	Survey Frequency	Survey Percent
Very healthy	57	31.3%
Somewhat healthy	62	34.1%
So-So	55	30.2%
Somewhat sick	6	3.3%
Very Sick	2	1.1%
Total	182	100.0%

When controlling for age, no significant health differences were found. Older senior caregivers did not report better or worse health than younger senior caregivers, nor had their health improved or deteriorated any more or less than younger respondents within the past year.

However, slightly over one-quarter (26.7%) of the caregivers have a physical disability, and one-half of these respondents report that their disability has either just arisen or worsened in the past year. Just over one-half (51.1%) of the senior caregivers report that their families help them with their disability. There is not a significant relationship between respondents' health status and their disability status, although this may be a function of the small number of caregivers who report poor health and those who have any disabilities.

When asked about problems related to memory loss, almost one-quarter (22.7%) report experiencing difficulties, with 7.6% of respondents reporting that their memory problems have worsened within the past year. The incidence of memory loss problems is significantly higher for caregivers 80 years of age and older, 42.1% of whom report memory loss problems as compared to 21.1% of caregivers less than 80 years old.

Caregivers also were asked a series of questions about their ability to carry out common daily life tasks including using the telephone, traveling by car or public transportation, shopping for food or clothes, preparing meals, doing housework, using medication, and managing their money.

Table 9: Caregiver's Ability to Carry Out Activities of Daily Life

	Can Do It Completely On Own	Needs Some Assistance	Needs someone else to do it	Total
Use the telephone	97.8%	1.1%	1.1%	100.0%
Travel by car or public transportation	82.3%	8.8%	8.8%	100.0%
Shop for food or clothes	82.4%	11.5%	6.0%	100.0%
Prepare meals	91.2%	4.9%	3.8%	100.0%
Do housework	77.5%	13.2%	9.3%	100.0%
Use medication	97.2%	2.8%	0.0%	100.0%
Manage money	95.0%	4.4%	0.6%	100.0%

n=182

Two-thirds (67.8%) of respondents are able to carry out all of these tasks without any assistance; one-third (32.2%) need help with one or more of the tasks, requiring some assistance or needing someone else to do them entirely. The only activities with which respondents report increasing difficulty as their age increases are housework and preparing meals.

When asked whether they find helping their children physically demanding and tiring, over one-third (35.4%) of the respondents replied that they did. Interestingly, when controlling for age of caregiver, respondents 70 years of age and older report feeling far less physical demand than respondents between the ages of 60 and 69.

Table 10: Caregiver's Age by Caregiver Finds Helping Children Physically Demanding/Tiring

Caregiver Finds Helping Children Physically Demanding/Tiring	Caregiver's Age				
	60-64	65-69	70-74	75-79	80+
No	47.7%	60.5%	77.4%	74.4%	77.8%
Yes	52.3%	39.5%	22.6%	25.6%	22.2%
Total n=179	100.0%	100.0%	100.0%	100.0%	100.0%

CAREGIVER'S KIN

One out of five respondents (21.3%) have a spouse, with almost twice as many male respondents in a marital partnership as compared to the female respondents (40.0% versus 20.5%). The respondents have between zero and twelve of their own children, with a mean of 3.9 children who range in age from 18 to 73 years, with a mean of 43.5 years.

Most caregivers in this study (83.5%) have adults that help them, while 16.2% report that they are caring for themselves and their children completely on their own.

Table 11: Adults Who Help Caregiver

	Survey Frequency	Survey Percent*
Daughter	78	42.9%
Son	38	20.9%
Sister	25	13.7%
Friend/neighbor	20	11.0%
Granddaughter	12	6.6%
Husband	8	4.4%
Other^	39	21.4%

n=182

^Includes adult helpers receiving less than 4% response, including aunt, brother, child, church member, cousin, family, father, grandson, great grandchild, homemaker service, mother, nephew, niece, other grandma, and wife.

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one category of helper.

These responses, when examined in terms of kin and non-kin, show that a large majority (87.8%) of the adult helpers identified were family members, while 12.3% were non-related.

Caregivers received a variety of types of assistance from family and friends, with most respondents receiving more than one type of help.

Table 12: Types of Support Received by Caregiver

	Survey Frequency	Survey Percent*
Transportation	82	45.1%
Shopping	76	41.8%
Respite care	61	33.5%
Financial, paying bills	52	28.6%
Meal Preparation	37	20.3%
Home repairs	34	18.7%
Cleaning	14	7.7%
Emotional/social	2	1.1%
Other	3	1.6%

n=182

*Total percentage for survey responses exceeds 100% due to respondents reporting receipt of more than one form of support.

Assistance with transportation (45.1%), shopping (41.8%), and respite care (33.5%) were the types of help most often received by caregivers, followed by help with managing household finances (28.6%), meal preparation (20.3%), and home repairs (18.7%).

CHILDREN'S AGE AND GENDER

The 182 senior caregivers in this study are caring for a total of 383 children,[24] with an average of 2.1 children per caregiver. Exactly one-half of the children are female and one-half are male.

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[24] For the purposes of this report, caregiver's "children" unless otherwise stated refers to the minor children for whom they are caring, other than their own children, including grandchildren, nieces, nephews, other kin, and unrelated children.

Table 13: Number of Children in Caregiver's Care

Number of Children	Survey Frequency	Survey Percent
1	72	39.6%
2	55	30.2%
3	31	17.0%
4	16	8.8%
5	6	3.3%
6	1	0.5%
8	1	0.5%
Total	182	100.0%

Table 14: Child's Gender

Gender	Survey Frequency	Survey Percent
Female	190	50.0%
Male	190	50.0%
Total	380	100.0%

The children ranged from 1 month to 18 years of age, with a mean of 12.6 years.

Table 15: Child's Age

Age	Survey Frequency	Survey Percent
0 thru 1	2	0.5%
2 thru 5	21	5.5%
6 thru 10	74	19.4%
11 thru 14	156	40.8%
15 thru 17	124	32.5%
18	5	1.3%
Total	382	100.0%

Table 16: Child's Age by Caregiver's Age

	Caregiver's Age				
Child's Age	60-64	65-69	70-74	75-79	80+
0 thru 5	6.7%	10.2%	6.9%	5.6%	
6 thru 10	18.1%	23.5%	22.2%	36.1%	15.6%
11 thru 14	41.9%	35.7%	38.9%	48.6%	37.5%
15 thru 18	33.4%	30.6%	32.0%	9.7%	46.9%
Total	100.0%	100.0%	100.0%	100.0%	100.0%
n=379					

Among the respondents, there was not a consistent relationship between the caregiver's and children's ages. The children in this study are slightly older on average than DCFS's children for all caregivers over age 62, with 56.0% of this study's youth age 13 or older, as compared to 45.6% of the youth in DCFS's care.[25]

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[25] From data as of October 17, 2003, supplied by DCFS.

CHILDREN'S INVOLVEMENT WITH CAREGIVER

KEY FINDINGS

- Almost three-quarters of the children are not living with their parents due to problems related to alcohol and drug abuse, and over one-third due to neglect.

- The senior caregivers in this study are adoptive parents or subsidized guardians for almost three-quarters of the children, and foster parents for almost one-fifth of the children.

When asked why their children are not living with their birth parents, senior caregivers gave an array of reasons, ranging from insufficient resources to death of one or both parents. However, the reason that was offered for almost three-quarters (72.4%) of the children was drug and alcohol abuse by the parents. Parental neglect (38.9%), parents not wanting the responsibility of child rearing (18.1%), incarceration (13.5%), and child abuse (11.1%) were frequent responses as well.

Table 17: Why Child Does Not Live With Birth Parents

	Survey Frequency	Survey Percent
Drugs/Alcohol	268	72.4%
Neglect	144	38.9%
Parents don't want responsibility	67	18.1%
Parents incarcerated	50	13.5%
Abuse	41	11.1%
Mental illness	25	6.8%
Death	24	6.5%
Domestic violence	24	6.5%
Bad relationship	13	3.5%
Lost housing	9	2.4%
Parent is working	9	2.4%
No/insufficient money	6	1.6%
Parent is young teen	5	1.4%
Physical illness	4	1.1%
Parent disability	2	0.5%
Parent in military	1	0.3%
Don't know	9	2.4%

n=370

*Total Survey percentage exceeds 100% due to some respondents reporting more than one reason for child not living with birth parents

When asked why they are caring for their children, most respondents (68.1%) report that they received a call from DCFS (or another state's protective services agency) asking them to take the children. Just over one-fifth (21.4%) had children who were going to be sent into non-relative foster care, and they did not want this to happen, while 17.0% received a call from another relative, asking them to take the children.

Table 18: Why Respondent is Caring for Children

	Survey Frequency	Survey Percent
I received a call from DCFS/Protective Services	124	68.1%
Children were going to be sent into non-relative foster care	39	21.4%
I received a call from another relative	31	17.0%
I received a call from the police/courts	8	4.4%

n=182

The senior caregivers in this study are adoptive parents or subsidized guardians for almost three-quarters (74.4%) of the children, and foster parents for almost one-fifth (18.8%) of the children. In two families, some of the respondents' minor children are a result of formal caregiving placements through DCFS, while the other minor children for whom they are caring are through informal, non-DCFS placements.

Table 19: Caregiver's Guardian Status

	Survey Frequency	Survey Percent
Adoptive parent/subsidized guardian	285	74.4%
Foster parent	72	18.8%
Informal caregiver	7	1.8%
Missing data	19	5.0%

n=383

Table 20: Caregiver's Guardian Status by Relative Status

	Relative Status		
Guardian Status	Relative	Non-Relative	Total
Adoptive parent/subsidized guardian	70.5%	29.5%	100.0%
Foster parent	36.5%	63.5%	100.0%
Informal caregiver	100.0%	0.0%	100.0%

n=341

Over two-thirds of the adoptive parents or subsidized guardians are relatives; less than one-third are non-relatives. In the case of foster parents, the relationship is reversed, with just over one-third of foster parents relatives of the children for whom they are caring, as compared to almost two-thirds of the foster parents who are not related to the children.

For most of the children in this study (86.1%), the senior caregivers have been appointed legal guardians. Caregivers who are not the legal guardian for one or more of their children offered a few explanations for this situation.

Table 21: Why Caregiver Was Not Appointed Legal Guardian

	Survey Frequency	Survey Percent
Child will/may be returned to parent	5	22.7%
Guardianship is in process - we have a future court date	4	18.2%
Foster care placement only	4	18.2%
Child has only been with me a short time	2	9.1%
I didn't want to involve the state	1	4.5%
Child ran away when process began	1	4.5%

n=22

In almost one-half of the cases (45.4%) in which the caregiver has not been appointed legal guardian, there is no plan to do so, the caregiver expecting that their children may return to their parent's custody, the placement only intended as a foster care living arrangement, or the caregiver not wanting to involve the state in changing their children's legal status.

ETHNICITY, IMMIGRATION STATUS AND PRIMARY LANGUAGE OF THE CHILDREN

The ethnicity of the children in this study closely parallels the ethnicity of the senior caregivers.

Table 22: Child's Ethnic Background

	Survey Frequency	Survey Percent	Caregivers' Ethnicity
African American/Black	333	85.4%	85.2%
Hispanic/Latino	29	7.4%	9.3%
White/Caucasian	26	6.7%	5.5%
Other	6	1.5%	1.1%

N=390

Over four-fifths of the youth (85.4%) are African American; 7.4% are Hispanic; and 6.7% are Caucasian.

Although 7.7% of the senior caregivers are immigrants, only three (0.8%) of the children are immigrants, and all are U.S. citizens.

Other than two children for whom Spanish is their primary language, and three for whom Arabic is their primary language, English is the primary language for all of the children. Most caregivers report that their children have strong speaking, reading, and writing skills.

Table 23: Children's English Proficiency

	No Skill (1)	Weak Skills (2)	Strong Skills (3)	
Speaking	3.7%	10.8%	85.5%	Mean=2.8 (n=352)
Reading	5.7%	17.5%	76.7%	Mean =2.7 (n=331)
Writing	5.8%	14.2%	80.0%	Mean=2.7 (n=330)

CHILDREN'S HEALTH

KEY FINDINGS

- Almost three-quarters of the children of these providers are reported to be very healthy, and only 4% of the children are reported to be somewhat sick or very sick. However, 9% of the children have not attended school regularly due to health problems.
- Most of the children's healthcare is provided by Medicaid.
- 8% of the caregivers are unable to access medical care for their children, citing medical providers' unwillingness to consult with or serve them because they are not their children's biological parents, or they do not have legal authority to obtain medical services for the child.
- Despite reportedly high levels of overall health status, 41% of the children have one or more disabilities. The needs related to their disabilities are being met for two-thirds of these children, while the remaining one-third of the children have disability-related needs that remain unmet.
- Over one-half of the children in the study were exposed to drugs or alcohol in utero, and just over one-half of the children who were exposed have resulting health problems.
- Almost one-quarter of the youth were sexually, physically, or emotionally abused in their past.

Caregiver's reports of the health status of their children vary considerably, depending on the specific question that was asked. In response to the question, "How physically healthy are your children," caregivers report quite a high level of health.

Table 24: Child's Physical Health

	Survey Frequency	Survey Percent
Very sick	2	0.5%
Somewhat sick	12	3.2%
So-so	33	8.8%
Somewhat healthy	52	13.9%
Very healthy	276	73.6%
	375	100.0%

Table 25: Child's Health Insurance Provider

	Survey Frequency	Survey Percent
Medicaid	371	97.4%
Private Insurer	5	1.3%
Medicaid + Private	5	1.3%
	381	100.0%

Almost three-quarters (73.6%) of the children of these providers are reported to be very healthy; and only 3.7% of the children are reported to be somewhat sick or very sick. Yet when asked whether their children's health has prevented them from attending school regularly, caregivers report that 9.4% of their children have not attended school regularly due to health problems. While in the senior caregiver's care, 19.3% of the children have been hospitalized, either for a physical or mental problem or both.

Table 26: Child's Hospitalizations When Living with Caregiver

	Survey Frequency	Survey Percent
Never	169	44.1%
Yes, for a physical problem	56	14.6%
Yes, for a mental problem	13	3.4%
Yes, for both a physical and a mental problem	5	1.3%

n=383

Children's poor health has had a detrimental effect on less than 5% of the caregivers' ability to work consistently. There is no significant difference in this for respondents who are working and those who are not employed.

Most of the children are coverered by Medicaid; 2.6% of children are covered partially or entirely by private insurance. While most of the caregivers (92.3%) are able to access medical care for their children, 7.7% are unable to do so, citing medical providers' unwillingness to consult with or serve them because they are not their children's biological parents, or that they do not have legal authority to obtain medical services for the child.

Despite reported high levels of overall health status, 158 (41.4%) of the children are reported by their caregivers to have one or more disabilities, ranging from bedwetting (2.6%) and obesity (2.9%) to asthma (12%) and learning disabilities (17%). Almost one-quarter (23.1%) of the respondents have more than one child with learning disabilities.

Table 27: Child's Disabilities

	Survey Frequency	Survey Percent
Learning disability	65	17.0%
Hyperactivity	64	16.8%
Asthma	46	12.0%
Social skills delay	28	7.3%
Developmentally delays	21	5.5%
Language delay	17	4.5%
Gross motor delay	14	3.7%
Obesity	11	2.9%
Bed wetting	10	2.6%
Fine motor delay	8	2.1%
Attention-deficit/hyperactivity disorder (ADHD)	8	2.1%
Sleep problem	7	1.8%
Mental illness (depression, psychosis, bipolar)	5	1.3%
Cerebral palsy	4	1.0%
Life threatening illness (sickle cell, leukemia, brain tumor)	3	0.8%
Behavioral problem	2	0.5%
Autism	1	0.3%
Other physical disabilities (deaf, blind, hearing problems, ulcers, high blood pressure, heart murmur, diabetes, brain injury)	11	2.9%
n=382		

*Number of survey responses exceeds 158 (number of children with disabilities) due to some respondents reporting receipt of more than one type of disability.

Caregivers report that the needs related to their disabilities are being met for two-thirds (66.7%) of these children, while the remaining one-third of the children have disability-related needs that remain unmet.

Caregivers were also asked whether their children were exposed to drugs or alcohol while their mothers were pregnant. Over one-half (56.6%) of the children in their care were exposed to drugs or alcohol in utero, and just over one-half of the children who were exposed have resulting health problems.

Table 28: Mother Used Drugs/Alcohol When Pregnant

	Survey Frequency	Survey Percent
No	135	36.4%
Yes	210	56.6%
Don't know	26	7.0%
n=371		

Table 29: Child Has Any Resulting Health Problems From Mother's Drug/Alcohol Use

	Survey Frequency	Survey Percent
No	90	48.9%
Yes	93	50.5%
Don't know	1	0.5%
n=184		

When asked to specify what specific health problems occurred as a result of their children's exposure to drugs or alcohol while in utero, caregivers listed both emotional and behavioral problems as well as physical problems ranging from asthma to brain damage.

Table 30: Problems Caused in Child from Mother's Drugs/Alcohol Use

	Survey Frequency	Survey Percent
Attention deficit hyperactivity disorder	11	11.8%
Hyperactivity	9	9.7%
Emotional problems	8	8.6%
Asthma	6	6.5%
Attention Deficit Disorder	6	6.5%
Learning disability	5	5.4%
Behavior disorder	5	5.4%
Bipolar disorder	4	4.3%
Delay in social skills	3	3.2%
Brain damage	3	3.2%
Developmentally disability	2	2.2%
Obsessive compulsive disorder	2	2.2%
Mental health problems	2	2.2%
Autism	1	1.1%
Cerebral palsy	1	1.1%
Psychosis	1	1.1%
HIV	1	1.1%

N=93

When asked whether any of their children suffer from severe emotional disturbances or mental health issues, 29 (7.6%) of the youth are reported to have these problems. However, caregivers report that almost one-quarter (22.4%) of the youth had been sexually, physically, or emotionally abused in their past while 28% had been neglected.

Table 31: Has Child Experienced Abuse

	Survey Frequency	Survey Percent
No	287	75.7%
Yes	85	22.4%
Don't Know	7	1.8%
	379	100.0%

CHILDREN'S EDUCATION

KEY FINDINGS

- Of the 102 caregivers with children who have disabilities, over one-half report that their children's disabilities interfere with their education, and over two-thirds of these children have Individualized Educational Plans.

- Caregivers report that over one-third of their children need tutoring, with children between the ages of 11 and 14 having the greatest need.

Most (95.0%) of the children being cared for by the seniors in this study are enrolled in school.

Table 32: Child's Grade in School

Grade	Survey Frequency	Survey Percent
Pre-K - Kdgn	17	4.5%
1st - 5th	91	24.0%
6th - 8th	98	25.9%
9th - 10th	107	28.2%
11th - 13th*	48	12.7%
Not enrolled	19	5.0%
Total	379	100.0%

*Includes 2 persons who are taking college courses

Table 33: Type of School Attended by Child

	Survey Frequency	Survey Percent
Public school	280	90.6%
Private school	10	3.2%
Private parochial school	14	4.5%
Home school	1	0.3%
Alternative school	4	1.3%
Total	309	100.0%

Slightly over one-half (54.4%) of the students are in preschool or primary school, while another 40.9% are in high school. Only 5.0% of the children are not enrolled in any school.[26] Most of the students (90.6%) attend public school, while 9.1% attend a private or alternative school.

Of the 102 caregivers with children who have disabilities, over one-half (52.0%) report that their children's disabilities interfere with their education, and over two-thirds (69.8%) of these children (a total of 37 children) have Individualized Educational Plans (IEPs).

Caregivers were also asked about their ability to help their children with homework. Over three-quarters (77.3%) of the respondents said that they are able to help their children with homework, while just under one-fifth (19.3%) said that they are unable to do so. Most of the caregivers who are unable to help their children with homework report that it is too difficult for them.

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[26] Of the children not enrolled in school, five are two years old or younger, two are three to four years old, one is 16 years old, eight are 17 years old, and two are 18 years old.

Table 34: Can Caregiver Help With Schoolwork

	Survey Frequency	Survey Percent
No	35	19.3%
Yes	140	77.3%
Sometimes	6	3.3%

n=181

Table 35: Why Caregiver Cannot Help With Schoolwork

	Survey Frequency	Survey Percent
Work is too difficult overall	9	5.0%
Math is too difficult	6	3.3%
Child doesn't need help	4	2.2%
Health / Age	4	2.2%
Other family members are helping	3	1.7%
Using outside help	3	1.7%
Sometimes I can help	3	1.7%

n=181

Caregivers report that over one-third (34.2%) of their children need tutoring, with those children between the ages of 11 and 14 having the greatest need.

Table 36: Child's Age by Need for Tutoring

Age	Survey Frequency	Survey Percent Who Need Tutoring	Survey Percent Who Don't Need Tutoring	Total
0 thru 5	2	8.7%	91.3%	100.0%
6 thru 10	19	25.7%	74.3%	100.0%
11 thru 14	67	42.9%	57.1%	100.0%
15 thru 18	36	27.9%	72.1%	100.0%

n=379

A small number (4.7%) of the respondents' children are having problems with truancy, primarily with students who are enrolled in high school.

Table 37: Children With Truancy Problems

Age	Survey Frequency	Number of Children in Survey of this Age	Survey Percent of Children Within This Age With Truancy Problems
11-12	1	71	1.4%
13-14	1	85	1.2%
15-16	9	89	10.1%
17-18	7	40	17.5%

n=379

Over one-half (52.2%) of the children have changed school districts since coming to live with the senior caregiver. Less than one-tenth (8.6%) of the caretakers experienced any difficulty registering any of their children for school for any reason, and four-fifths (80.9%) of the caregivers participate in their children's parent-teacher conferences. When asked whether they have had any difficulties communicating with their children's schools, 8.3% of the respondents said that they have had some problems with at least some of their children's schools. Respondents report both individual and structural reasons for the problems.

Table 38: What Makes It Difficult to Communicate With School

Response	Survey Frequency
School matters are confusing or complicated	6
They wouldn't give them the services they needed - racism; the school is racist	2
Teacher is uncooperative; principal is not helpful	2
They don't welcome you in the school	1
School doesn't listen to what child has to say regarding suspension	1
Unfairness	1
Teacher was telling me ways she acted different than at home and I didn't agree	1

Most of the children walk to and from school. However, over one-quarter (27.8%) of the senior caregivers transport at least one of their children to and from their school.

Table 39: How Children Get To and From School

	Survey Frequency	Survey Percent
By foot	102	56.7%
Caregiver transports them	50	27.8%
Public transportation	38	21.1%
School bus	27	15.0%
Carpool	6	3.3%
n=180		

*Number of survey responses exceeds 180 (number of caregivers who responded to this question) due to some respondents reporting multiple means of transportation.

CHILDREN'S FINANCIAL SITUATION

KEY FINDING

- Slightly under one-half of the caregivers report that some or all of their children receive government aid, other than Medicaid. Given the high rates of poverty among the caregivers and their children, the receipt of government support is either highly underreported or many children who are eligible for public benefits are not receiving them.

With only 21.5% of the children in the study aged 16 or older, it is not surprising that only 14 (3.7%) have a job of any type, working a mean of 19.2 hours per week and earning an average of $533 monthly. All of those who are working are also enrolled in school and are employed in a variety of jobs, primarily in the service sector.

Table 40: Child's Job

	Survey Frequency
Computer	2
Teen literacy coach	2
Art work	1
Cashier	1
Food service	1
Janitor	1
Pizza delivery	1
Rehab center	1
Stuffing coupons	1
Summer job	1
Surveying	1
Warehouse	1
Total	14

In terms of government assistance, slightly under one-half (46.7%) of the caregivers report that some or all of their children receive government aid other than Medicaid. Given the high rates of poverty among the caregivers and their children, the receipt of government support appears to be highly underreported. At a minimum, a majority of the children would have been eligible for subsidized school breakfasts and lunches, yet less than one-fifth of the respondents report their children receiving this benefit.

Table 41: Public Benefits Received by Child

	Survey Frequency	Survey Percent
TANF	44	24.2%
School Breakfast/Lunch	33	18.1%
Social Security	19	10.4%
Food Stamps	5	2.7%
Social Security – survivor's	2	1.1%
WIC	2	1.1%

n=182

If indeed such low percentages of children who are eligible for public benefits are receiving them, this may indicate the need for more targeted outreach or streamlining of application procedures.

When asked whether or not their children receive any non-governmental financial support, only four of the respondents responded affirmatively, with each of the four receiving money from other family members, ranging from $15 to $75 per month. Only three of the children in this study have parents who still receive benefits on their children's behalf, though none of the caregivers know what the parents are receiving, nor the dollar value of the benefit.

CAREGIVER'S FINANCIAL SITUATION

KEY FINDINGS

- Over one-half of the caregivers report that their monthly funds are inadequate to support themselves and their children, and over one-third of the respondents report that they have difficulty providing food, clothing, or other necessities for their dependents.

- Much higher rates of respondents in the south suburbs and on Chicago's north side report monthly funds being inadequate to meet their and their family's needs than respondents living in the other areas encompassed by the study.

- Almost 40% of respondents have gone without food, clothing, or other necessities in order to provide for their dependents, with clothing and food being the needs most often unmet.

- 14% of respondents have not taken medication, skipped a dose, or not had a prescription filled, and 16% have had their gas or electricity disconnected due to lack of funds.

While 11.1% of the caregivers earn employment income, almost all of the respondents (98.3%) receive financial support either from the government or other sources. Almost three-quarters (70.8%) of the caregivers report receiving some type of government assistance, primarily from the DCFS adoption/guardian subsidy (44.0%), SSI payments for low income disabled persons (24.2%), and foster care board payments (15.9%). The adoption/guardian subsidy and the foster care board payment are the sources that provide the highest levels of government assistance, averaging $800 and $913 monthly per household respectively. Together, the government assistance payments amount to a monthly mean of $766 and median of $500.

Table 42: Governmental Assistance Received by Caregiver

	Survey Percent	Median Value
Adoption/Guardian Subsidy	44.0%	$800
SSI (Supplemental Security Income for low-income aged, blind and disabled persons)	24.2%	$579
Foster Care Board Payment	15.9%	$913
TANF Child-only Grant	4.4%	$384
Food stamps	4.4%	$95
Medicaid	3.3%	*
TANF (Temporary Aid for Needy Families)	1.6%	**

n=182

* Not applicable; ** Unavailable

Table 43: Caregiver's Total Monthly Government Assistance Levels

	Survey Frequency	Survey Percent
$0	52	32.7%
$110 - $450	26	16.4%
$476 - $900	29	18.2%
$903 - $1,350	24	15.1%
$1,378 - $4,369	28	17.6%
Total	159	100.0%

mean = $766; median = $500

Over three-quarters (77.0%) of the respondents report other sources of income, including Social Security (49.5%), family support (27.0%), and retirement (21.4%). Caregivers with rental property and investment income had the highest levels of monthly income from other sources, with Social Security and retirement also providing some caregivers with substantial monthly income. Together, the non-government assistance payments amount to a monthly mean of $742 and a median of $673.

Table 44: Caregiver's Other Monthly Income Sources (Non-Governmental Assistance)

	Survey Percent	Median Value
Social Security	49.5%	$778
Family Support	27.0%	$413
Retirement	21.4%	$700
Other (Veteran's Benefits, Spousal Benefits, Investments)*	2.7%	$1,400
Rental property	2.2%	$825

N=182

*The value of these monthly benefits varied dramatically, from a low of $127 for Veteran's Benefits, to a high of $6,700 for husband's income.

Table 45: Caregiver's Other Monthly Income Levels (Non-Governmental Assistance)

	Survey Frequency	Survey Percent
$0	40	27.4%
$55 - $579	26	17.8%
$590 - $853	27	18.5%
$875 - $1,200	27	18.5%
$1,245 - $6,700	26	17.8%
Total	146	100.0%

mean = $742; median = $673

When combined, the financial support from employment, government assistance, and other sources provides the senior caregivers in this survey with an average (mean) monthly income of $1,756, and a median of $1,427.

Table 46: Caregiver's Total Monthly Income

	Survey Frequency	Survey Percent
$0 - $499	9	6.7%
$500 - $999	33	24.4%
$1,000 - $1,999	48	35.6%
$2,000 - $2,999	24	17.8%
$3,000 - $7,400	21	15.6%
Total	135	100.0%

mean = $1,756; median = $1,427

Over one-half (50.8%) of the caregivers report that their monthly funds are inadequate to support themselves and their children, and over one-third (37.6%) of the respondents report that they have difficulty providing food, clothing, or other necessities for their dependents.

Table 47: Monthly Funds Adequate to Support Caregiver and Children

	Survey Frequency	Survey Percent
No	92	50.8%
Yes	89	49.2%
Total	181	100.0%

Table 48: Difficulty Providing Food, Clothing, Other Necessities for Children

	Survey Frequency	Survey Percent
No	113	62.4%
Yes	68	37.6%
Total	181	100.0%

The adequacy of monthly funds was examined according to the location of respondents' residence. Much higher rates of respondents in the south suburbs and on Chicago's north side report monthly funds being inadequate to meet their and their family's needs than respondents living in the other areas encompassed by the study. The relationship between income and neighborhood was similar, though not as strong.

Table 49: Adequacy of Monthly Funds by Community

	North Suburban	West Suburban	South Suburban	Chicago - North Side	Chicago - West Side	Chicago - South Side
Monthly Funds Inadequate	12.5%	42.9%	75.0%	77.8%	59.6%	44.6%
Monthly Funds Adequate	87.5%	57.1%	25.0%	22.2%	40.4%	55.4%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

n=180

Caregivers were asked about the degree to which their own basic needs were unmet as a result of caring for their children. Nearly two-fifths (39.8%) of respondents have gone without food, clothing or other necessities in order to provide for their dependents, with clothing and food being the needs most often unmet.

Table 50: Caregiver Deprived of Own Basic Needs to Provide for Children

	Survey Frequency	Survey Percent
No	109	60.2%
Yes	72	39.8%
Total	181	100.0%

Table 51: What Basic Needs Caregiver is Unable to Fulfill

	Survey Frequency	Survey Percent
Clothing	53	29.1%
Utilities	1	16.2%
Medications	4	14.1%
Food	16	8.8%
Vacation, entertainment	9	4.9%
Personal (beauty, toiletries)	6	3.3%
Household items and repairs	5	2.7%
Personal time	2	1.1%
Car	1	0.5%
Mortgage	1	0.5%

n=182

14.1% of the respondents have not taken medication, skipped a dose or not had a prescription filled, and 16.2% have had their gas or electricity disconnected due to lack of funds.

Twenty (11%) of the caregivers across the income spectrum of the respondents also provide financial assistance to other family members (children or grandchildren) at an average of $199 per month.

CURRENT LIVING SITUATION

KEY FINDINGS

- Almost three-quarters of respondents are living with their children in their own houses, with most of the remaining caregivers living in their own apartments.
- Almost one-half of the respondents live alone with the children for whom they are caring on behalf of DCFS. The other one-half of the caregivers live with relatives, including other children, grandchildren, spouses, and other adult relatives.

Almost three-quarters (73.6%) of the respondents are living with their children in their own houses, with most of the remaining caregivers living in their own apartments.

Table 52: Housing type

	Survey Frequency	Survey Percent
Own house	134	73.6%
Own apartment	41	22.5%
Relative/friend's home	5	2.7%
Relative/friend's apartment	1	0.5%
Public housing	1	0.5%
	182	100.0%

Eight (4.4%) of the caregivers are in jeopardy of losing their homes (seven of whom live in their own houses and one who lives in her own apartment); seven of the situations are due to respondents having insufficient funds, and in one case, the building is being torn down. Only one of the respondents is living in a senior housing facility. Most caregivers report that their homes are both accessible and safe for themselves and their children.

Almost two-thirds (62.6%) of the caregivers live in the same school district as their children's previous school, and most (91.1%) live in their children's current school district.

Table 53: Is Housing in Children's Previous School District

	Survey Frequency	Survey Percent
Yes	112	62.6%
No	63	35.2%
Some yes, some no	3	1.7%
Don't know	1	0.6%
Total	179	100.0%

Table 54: Is Housing in Children's Current School District

	Survey Frequency	Survey Percent
Yes	164	91.1%
No	14	7.8%
Some yes, some no	2	1.1%
Total	180	100.0%

Almost one-half (49.5%) of the respondents live alone with the children for whom they are caring on behalf of DCFS. The other one-half of the caregivers are living with relatives, including other children, grandchildren, spouses, and other adult relatives. Four caregivers have a parent of the children for whom they are caring living with them as well.

Table 55: With Whom Caregiver Lives (Other than Survey Children)

	Survey Frequency	Survey Percent
One of his/her adult children	48	26.4%
Spouse/Partner	33	18.1%
Grandchild/ren	20	11.0%
Other children	16	8.8%
Other adult relative	8	4.4%
Friend	1	0.5%
Own mother/father	1	0.5%

n=182

Eleven (6.0%) of the survey respondents are the primary caregivers for people other than the children for whom they are caring on behalf of DCFS, including their own adult children as well as other people's children.

CHILDREN'S BEHAVIOR

KEY FINDINGS

- Almost one-third of the senior caregivers in this study report that their children have behavioral problems. Almost one-quarter of the caregivers are unable to successfully discipline some or all of their children.

- Older children (11-18 years old) are over 60% more likely to have behavioral problems than younger children (1 month-10 years old).

- With the exception of the oldest caregivers who report the lowest level of problems disciplining their children, age of caregivers had no significant effect on their ability to successfully discipline their children.

Almost one-third (31.8%) of the senior caregivers in this study report that their children have behavioral problems, accounting for 23.2% of the total number of children. Almost one-quarter (22.5%) of the caregivers are unable to successfully discipline some or all of their children.

Table 56: Child’s Behavioral Problems

	Survey Frequency	Survey Percent	Percent of Caregivers Whose Children Have These Problems (n=182)
Children with any behavioral problems	89	23.2%	31.8%
Children who caregiver cannot successfully discipline	73	19.1%	22.5%
Children who have stolen money or property	44	11.5%	19.7%
Children who have destroyed personal/household property	38	9.9%	15.4%
Children with arrest record	27	7.0%	11.5%
Children whose behavior causes caregiver to feel threatened	16	4.2%	4.4%
Children who have been incarcerated	10	2.6%	5.4%
Children who have been involved with gangs	8	2.1%	3.2%
Children who have injured caregiver	3	0.8%	1.1%

n=383

Although there is no significant relationship between the age of the caregiver and children’s behavioral problems, a significant relationship exists between the age of the child and reported behavioral problems, with older children (11-18 years old) over 60% more likely to have behavioral problems than younger children (1 month-10 years old).

Table 57: Problems with Child's Behavior By Child's Age

Child Has Behavior Problems

	Survey Frequency			Percentage of “Yes"
Child's Age	No	Yes	Total	Responses
0 - 5	19	3	22	13.6%
6 - 10	63	11	74	14.9%
11 - 15	77	19	96	19.8%
16 - 18	59	23	82	28.0%

n=381

Table 58: Can Successfully Discipline Child By Child's Age

Caregiver Can Successfully Discipline Child

	Survey Frequency			Percentage of “No”
Child's Age	No	Yes	Total	Responses
0 – 5	3	19	22	13.6%
6 – 10	11	60	71	15.5%
11 – 15	13	81	94	13.8%
16 – 18	19	63	82	23.2%

n=377

With the exception of the oldest caregivers who report the lowest level of problems disciplining their children, the age of caregivers had no significant effect on their ability to successfully discipline their children.

Table 59: Can Successfully Discipline Child By Caregiver's Age

Caregiver Can Successfully Discipline Child

	Survey Frequency			Percentage of “No”
Caregiver's Age	No	Yes	Total	Responses
60-64	21	82	103	20.4%
65-69	20	78	98	20.4%
70-74	15	57	72	20.8%
75-79	14	58	72	19.4%
80+	4	28	32	12.5%

n=377

CHILDREN'S KIN

KEY FINDINGS

- Although the children in this study are not living with their parents, over two-thirds of them have contact with at least one of their parents.
- Four-fifths of the caregivers' children have siblings not currently residing with them.

Although the children in this study are not living with their parents, over two-thirds of them have contact with at least one of their parents.

Table 60: Parental Contact with Child

	Survey Frequency	Survey Percent
No contact	115	30.3%
Periodic contact	166	43.7%
Regular contact	99	26.1%
Total	380	100.0%

Caregivers report that there is a greater frequency and quality of contact with the children by their mothers than their fathers. Over one-half (51.0%) of the children have a good or fair relationship with their mothers, as contrasted with less than one-third (32.4%) of the fathers.

Table 61: Child's Relationship with Mother

	Survey Frequency	Survey Percent
Good	97	25.9%
Fair	94	25.1%
Poor	33	8.8%
Non-existent	151	40.3%
Total	375	100.0%

Table 62: Child's Relationship with Father

	Survey Frequency	Survey Percent
Good	67	17.8%
Fair	55	14.6%
Poor	19	5.0%
Non-existent	236	62.6%
Total	377	100.0%

Four-fifths (80.0%) of the caregivers' children have siblings not currently residing with them. Just over one-fifth (20.6%) of the siblings are living with a parent, while 31.8% are living with another relative. An additional 33.6% are either a ward of DCFS or have been adopted, while 14.0% of the siblings are living on their own. The whereabouts of 17.8% of the siblings is unknown.

Table 63: Where Siblings Reside

	Survey Frequency	Survey Percent	
Mother	13	12.1%	20.6%
Father	5	4.7%	
Parent	4	3.7%	
Grandparent	9	8.4%	31.8%
Relative	25	23.4%	
Friends	1	0.9%	
DCFS	26	24.3%	
Adopted	10	9.3%	
On their own	15	14.0%	
Don't Know	19	17.8%	

N=107

One of the children in this survey, a fourteen-year-old female, has a child of her own.

CHILDREN'S PAST LIVING SITUATION

One-fifth (20.1%) of the children in this study have lived with the senior caregiver for their entire lives. Before coming to live with their senior caregiver, 44.9% of the children lived with their parents; 21.9% lived with foster parents; and 11.2% lived with other relatives. Most of the children had lived in Chicago (87.6%) or the suburbs (7.4%).

Table 64: Who Previously Raised Child

	Survey Frequency	Survey Percent
Parents	172	44.9%
Foster Parents	84	21.9%
No one - Caregiver had them since birth	77	20.1%
Grandparents	26	6.8%
Other Relatives	17	4.4%
Group Home	5	1.3%
Other	4	1.0%

n=383

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one previous caregiver.

Table 65: Child's Hometown Prior to Current Location

	Survey Frequency	Survey Percent
Chicago	318	87.6%
Chicago suburb	27	7.4%
Collar counties	10	2.8%
Out-of-state	8	2.2%
Total	363	100.0%

Almost one-half (46.2%) of the children had been involved in some way with DCFS apart from and prior to their coming to live with the senior caregiver, either through foster care or a group home, or by living with someone who was their subsidized guardian/adoptive parent.[27] Neglect, drug abuse, and child abuse were the reasons most often cited for children's prior involvement with DCFS, while almost one-half (49.2%) left that placement due to adoption or because they were taken in by the senior caregiver.

Table 66: Why Child Was Involved with DCFS

	Survey Frequency	Survey Percent
Neglect	23	28.0%
Parent on drugs	22	26.8%
Abuse	11	13.4%
Abandonment	7	8.5%
Drug baby	5	6.1%
Parental problems	3	3.7%
Parental violence	3	3.7%
Parent mental illness	2	2.4%
Grandmother died	2	2.4%
Parent not want child	2	2.4%
Parent unable to handle child	1	1.2%
Parent died	1	1.2%
Total	82	100.0%

Table 67: Why Child Left Previous DCFS Placement

	Survey Frequency	Survey Percent
Adopted	19	27.5%
To come live with me	15	21.7%
Better accommodations	5	7.2%
Abused	4	5.8%
Caregiver died	4	5.8%
Relative wanted child	4	5.8%
I was concerned about child	3	4.3%
Caregiver unable to care	3	4.3%
To come live with relatives	3	4.3%
Neglect	2	2.9%
To keep siblings together	2	2.9%
Placed in foster home	2	2.9%
Wanted Hispanic caregiver	1	1.4%
Didn't get along	1	1.4%
Unfit foster home	1	1.4%
Total	69	100.0%

CASE STATUS AND PLACEMENT

KEY FINDINGS

- Slightly more than one-half of respondents had time to prepare for caregiving before their children arrived. The remaining respondents had no time to prepare, primarily due to their children coming to them as emergency placements.

- Most senior caregivers report having a back-up plan, in the event that they are unable to care for their children. With few exceptions, caregivers expect that their relatives will take over responsibility for caring for the children if they are unable to do so for any reason.

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[27] The data from the survey, documenting the breakdown between the three categories of their prior DCFS placement (foster care, group home, subsidized guardianship/adoption) are not reliable and therefore not included. However, there are clearly a larger number of children who were in foster care than a group home, and even fewer in subsidized guardianships/adoptions.

- Caregivers between the ages of 65 and 69 were almost twice as likely as other senior caregivers not to have a back-up plan.

Slightly more than one-half (55.2%) of respondents had time to prepare for caregiving before their children arrived. The remaining 44.7% had no time to prepare, primarily due to their children coming to them as emergency placements.

Most senior caregivers (82.9%) report having a back-up plan, in the event that they are unable to care for their children. With few exceptions, caregivers expect that their relatives will take over responsibility for caring for the children if they are unable to do so for any reason.

Table 68: Back-up Care Provider for Children

	Survey Frequency	Survey Percent
Daughter	67	44.7%
Other relatives (niece, family members, aunt, uncle, cousin)	19	12.7%
Son	17	11.3%
Sister	14	9.3%
Granddaughter (great-granddaughter, great great-granddaughter)	10	6.7%
Children	5	3.3%
Children's Grandmother	5	3.3%
Child's Parents (mother, father)	5	3.3%
Friend	3	2.0%
Spouse	3	2.0%
Agency	3	2.0%
Brother	2	1.3%
Pastor and wife	1	0.7%
Group home	1	0.7%
Nurses	1	0.7%

n=150

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one back-up care provider.

** Back-up caregivers listed in table are in terms of their relationship to the caregiver, unless otherwise noted.

Caregivers between the ages of 65 and 69 were almost twice as likely as other senior caregivers not to have a back-up plan, with 25.6% of them reporting no alternative care arrangements available for their children, as compared to 14.0% of the other senior caregivers.

Most of the survey respondents (89.0%) expect and want their children to remain permanently under their care, while the remaining 11.0% hope or expect that at least one of the children's parents will resume his/her parenting role in the future. Ten of the caregivers (5.6%) anticipate problems that could arise, which they might not be able to resolve if their children were to remain under their care permanently. The majority of the problems are behavioral.

> My grandson doesn’t want to remain under my care because he is in the Audy home for selling drugs and I wouldn’t lie for him. I can’t allow him to take over my house.

> I’m having behavior problems with her involving the birth parents, and I may have to let my daughter take over her care.

> He wants to stay out all the time now.

A smaller number of the problems relate to the caregiver’s health and physical frailty.

> My old age or sickness might stop me.

> I may get too old to care for the children.

A few responses related to concerns about children’s emotional and educational needs.

> I need appropriate help for my children’s learning disabilities and counseling.

NEEDS OF SENIOR CAREGIVERS AND THEIR CHILDREN

KEY FINDINGS

- Almost one-fifth of the senior caregivers said that they have no current unmet needs.

- When asked whether they or their children needed any of 35 specified services or resources, senior caregivers averaged needing three resources or services for themselves and three for their children.

- Financial resources for caregivers (61%) and their children (56%) was the most frequently reported unmet need.

- A significant number of caregivers identified housing repairs (35%), respite care services (32%), clothing (22%), food (19%), dental services (19%), optometry services (17.0%), and transportation (16%) as resources that they need for themselves.

- Caregivers said that other than financial resources, their children's primary unmet needs are clothing (34%), food (22%), respite care services (21%), and educational support (19%).

An important focus of this research was to learn from senior caregivers their own perspective on their needs. Respondents were asked about their needs in general, and then were queried about 35 specific potential needs. When the surveyors asked the respondents the open-ended question, "What are your needs right now?" 18.5% replied that they had no needs.

> I don't have any. No gal. I'm just an old woman. I don't need much. My sister says I need new living room furniture, but I think I'm fine.
>
> My needs? Just the blessing from the Lord to help me from day to day to do.

The remaining 81.5% of respondents identified one or more (mean = 2.1) unmet needs for themselves and their children, with money (38.2%), clothing (11%), home repairs (10.4%), school fees, supplies or uniforms (10.4%), food (9.8%), and medical care or medicines (9.2%) being the most frequently mentioned.

Table 69: Caregiver's Needs – Initial Open Ended Question

	Survey Frequency	Survey Percent		Survey Frequency	Survey Percent
Money	66	38.2%	After school programs	3	1.7%
Clothes	19	11.0%	College assistance	3	1.7%
Home repairs	18	10.4%	Computer	3	1.7%
School fees, supplies, uniforms	18	10.4%	Household chore help	3	1.7%
Food	17	9.8%	Job	3	1.7%
Medical care, meds	16	9.2%	Counseling for myself	2	1.2%
Transportation	13	7.5%	Dental care	2	1.2%
Furniture	12	6.9%	Legal help	2	1.2%
Counseling, support group for kids	11	6.4%	DCFS help	1	0.6%
Respite care	9	5.2%	Help dealing with child's parent	1	0.6%
Housing	8	4.6%	Help with caring for elder family member	1	0.6%
Child care	7	4.0%	Piano lessons for child	1	0.6%
Utilities	7	4.0%	Support with child's behavioral problems	1	0.6%
Education	6	3.5%	Translation help	1	0.6%
Tutoring	4	2.3%	Everything	1	0.6%
Vacation	4	2.3%	Help child get around- I have trouble walking	1	0.6%

n=173

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one need.

When asked whether they or their children needed any of a specified list of 35 services or resources, senior caregivers report slightly higher levels of service needs, averaging 3.06 needs for themselves as well as their children. Money was identified as the greatest need for both caregivers (61.0%) and their children (56.0%). A significant number of caregivers also identified housing repairs (35.1%), respite care services (32.9%), clothing (22.5%), food (19.2%), dental services (18.6%), optometry services (17.0%), and transportation (16.4%) as resources that they need for themselves.

Surveyors also asked the caregivers about their children's needs. Other than money, caregivers identified clothing (34.1%), food (22.0%), respite care services (21.4%), and educational support (19.2%) as their children's primary needs.

Table 70: Caregiver's Needs - Specified

	Percent of Caregivers Needing Resource
Money	61.0%
Housing repairs	35.1%
Respite care services	32.9%
Clothing	22.5%
Food	19.2%
Dental services	18.6%
Optometry services	17.0%
Transportation	16.4%
Support group	12.1%
Advocacy services	9.9%
Parenting support	9.0%
Medical services	8.2%
Legal services	6.5%
Relocation assistance	5.4%
Housing	4.9%
Education Support – Elementary/High School	3.8%
Education – GED	3.3%
Getting legal documentation (birth certificate, driver's license)	3.3%
Disability services	2.7%
Mental health services/ counseling	2.7%
Job training/readiness services	2.7%
Job placement	2.7%
Medication management	1.1%
Substance abuse services	0.5%
Education – ESL	0.5%
Education – Vocational	0.5%
Child care	0.5%
Money management skills	0.5%
HIV services	0.0%
Domestic/intimate partner violence services	0.0%
LGBTQ resources	0.0%
Head Start/Early Head Start	0.0%
WIC (Food support for mothers and young children)	0.0%
Protection from gangs	0.0%
Pregnancy services	0.0%

n=182

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one need.

Table 71: Children's Needs – Specified

	Percent of Children Needing Resource
Money	56.0%
Clothing	34.1%
Food	22.0%
Respite care services	21.4%
Education Support – Elementary/High School	19.2%
Mental health services/ counseling	13.7%
Transportation	13.1%
Job training/readiness services	13.1%
Job placement	12.1%
Support group	11.0%
Optometry services	10.9%
Dental services	9.3%
Advocacy services	7.7%
Protection from gangs	5.5%
Relocation assistance	4.9%
Education – GED	4.9%
Child Care	4.4%
Education – Vocational	4.3%
Medical services	3.8%
Housing	3.8%
Disability services	3.8%
Education – ESL	2.7%
Getting legal documentation (birth certificate, driver's license)	2.2%
Head Start/Early Head Start	2.2%
Pregnancy services	2.2%
Substance abuse services	2.1%
Legal services	1.6%
Medication management	1.6%
Money management skills	1.1%
HIV services	1.1%
WIC (Food support for mothers and young kids)	1.1%
Domestic/intimate partner violence services	0.5%
LGBTQ resources	0.5%
Parenting support	0.0%

n=182

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one need.

One of the concerns that prompted the initiation of this study was that particular subgroups of senior caregivers may be experiencing situations and conditions that make them more vulnerable and place them and their children at greater risk, relative to the larger senior caregiver population. It is the hope that by identifying subpopulations that are at greater risk, services and resources can be targeted to meet their needs.

Although many of the needs are reported consistently across the various subgroups of respondents, other needs showed significant differences, depending on the age, community location, and income of the respondents. The following section identifies the needs that differed significantly from the overall levels of need.

MONEY

Money is the need that the senior caregivers most frequently report. Respondents who live in the south suburbs and on Chicago's north, south, and west sides more frequently report a need for money than respondents in other communities.

Table 72: Need Additional Money by Location of Home

	North Suburban	West Suburban	South Suburban	Chicago - North Side	Chicago - West Side	Chicago - South Side
Don't need at all	62.5%	57.1%	0.0%	22.2%	34.0%	31.5%
Need for Caregiver	25.0%	14.3%	0.0%	0.0%	28.3%	4.3%
Need for Children	12.5%	14.3%	8.3%	0.0%	7.5%	6.5%
Need for Both	0.0%	14.3%	91.7%	77.8%	30.2%	57.6%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

N=181

Although the relationship between need for money and caregiver's income is not statistically significant, respondents who report having inadequate funds to support themselves and their children report much higher need for money than those who report having sufficient funds to meet their monthly needs.

HOUSING REPAIRS

Over one-third of the respondents need housing repairs. However, the need for housing repairs is greatest in the south suburban and Chicago's south side communities, where between 43% and 59% of the senior caregivers need these services.

Table 73: Need Housing Repairs By Location of Home

	North Suburban	West Suburban	South Suburban	Chicago - North Side	Chicago - West Side	Chicago - South Side
Don't need	100.0%	85.7%	41.7%	100.0%	69.8%	56.5%
Need	0.0%	14.3%	58.3%	0.0%	30.2%	43.5%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

n=181

RESPITE CARE

Slightly less than one-half (47.8%) of the senior caregivers had ever heard of respite services, and less than one-tenth (9.3%) of all caregivers have ever used them.[28] However, when asked if they need or would benefit from respite care services, almost two-thirds (60.8%) said that they would like to have them for themselves, and over one-fifth (21.4%) thought that their children need them. When examining this need by geographic community, respondents from the Chicago's north side report the highest levels of need for themselves; respondents from the northern suburbs report the highest needs for their children; and respondents from the south suburban areas report the highest level of need for both themselves and their children.

Table 74: Need Respite Care Services by Location of Home

	North Suburban	West Suburban	South Suburban	Chicago - North Side	Chicago - West Side	Chicago - South Side
Don't need at all	62.5%	57.1%	50.0%	33.3%	49.1%	77.2%
Need for Caregiver	25.0%	28.6%	8.3%	44.4%	18.9%	8.7%
Need for Children	12.5%	0.0%	0.0%	0.0%	5.7%	2.2%
Need for Both	0.0%	14.3%	41.7%	22.2%	26.4%	12.0%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

N=181

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[28] These are services in which people come to the caregiver's home periodically to give the caregiver a chance to rest and take some time off from caregiving.

When examining need for respite services in terms of respondent's financial situation, an interesting relationship can be seen. Caregivers with inadequate funds to meet their monthly needs report a lower need for respite services (37.5%) than those who have adequate funds (42.9%). Yet when examined by income, respondents in the highest monthly income bracket ($2,195 - $7,400) report the highest level of need for respite care.

Table 75: Need Respite Care Services by Adequacy of Monthly Income

	Inadequate Funds	Adequate Funds
Don't need at all	62.5%	57.1%
Need for Caregiver and/or children	37.5%	42.9%
Total	100.0%	100.0%

n=181

Table 76: Need Respite Care Services by Monthly Income

	$0 - $920	$921 - $1,438	$1,439 - $2,194	$2,195 - $7,400
Don't need at all	62.5%	57.1%	50.0%	33.3%
Need for Caregiver and/or children	37.5%	42.9%	50.0%	66.7%
Total	100.0%	100.0%	100.0%	100.0%

n=135

CLOTHING AND FOOD

Almost one-quarter of the respondents (22.5%) need clothes for themselves and over one-third (34.1%) report that their children need clothes, while 19.2% of the caregivers and 22.0% of their children have insufficient food. Although the relationship between need for clothing or food and caregiver's income is not statistically significant, respondents who report having inadequate funds to support themselves and their children report much higher need for clothing and food than those who have sufficient funds to meet their monthly needs.

Table 77: Need Clothing by Adequacy of Monthly Income

	Inadequate Funds	Adequate Funds
Don't need at all	45.7%	77.5%
Need for caregiver	6.5%	3.4%
Need for children	22.8%	10.1%
Need for both	25.0%	9.0%
Total	100.0%	100.0%

n=181

Table 78: Need Food by Adequacy of Monthly Income

	Inadequate Funds	Adequate Funds
Don't need at all	58.7%	92.1%
Need for caregiver	3.3%	2.2%
Need for children	9.8%	1.1%
Need for both	28.3%	4.5%
Total	100.0%	100.0%

n=181

SUPPORT GROUP

Similar to the need for food and clothing, respondents whose monthly funds are inadequate report significantly higher needs for support groups for themselves and/or their children, relative to the needs of those caregivers whose monthly incomes are sufficient.

Table 79: Need Support Group by Adequcy of Monthly Income

	Inadequate Funds	Adequate Funds
Don't need at all	75.0%	92.1%
Need for caregiver	7.6%	3.4%
Need for children	7.6%	1.1%
Need for both	9.8%	3.4%
Total	100.0%	100.0%

N=181

One-quarter of the respondents who have insufficient monthly income report needing the help of a support group for themselves and/or their children, as compared to less then 10% of those who have sufficient funds to cover their monthly expenses.

MEDICAL SERVICES

Finally, the need for medical services varied significantly by only one factor – geographic location. Respondents who live in the south suburbs report a far higher level of need for medical services than any of the other respondents, with 41.7% of them needing medical services for themselves and/or their children. None of the respondents who live in the north or west suburbs report any unmet needs for medical services. The needs for medical services of approximately 90% of respondents living in Chicago are being met, with the remaining 10% reporting receiving insufficient medical services for themselves and/or their children.

Table 80: Need Medical Services By Location of Home

	North Suburban	West Suburban	South Suburban	Chicago - North Side	Chicago - West Side	Chicago - South Side
Don't need	100.0%	100.0%	58.3%	88.9%	90.6%	91.3%
Need for caregiver	0.0%	0.0%	16.7%	0.0%	9.4%	5.4%
Need for children	0.0%	0.0%	16.7%	11.1%	0.0%	1.1%
Need for both	0.0%	0.0%	8.3%	0.0%	0.0%	2.2%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

N=181

ACCESSING RESOURCES

KEY FINDINGS

- The majority (59%) of respondents said that they know where to find the resources they need; 41% report that they do not know how to access services and resources if they are needed.

- Over two-thirds of respondents tend to go to one or more places for resources and services, with community agencies (26%), church (24%), friends (19%), family (14%), DCFS (13%), and IDHS (12%) as the most frequently contacted places.

- Over 80% of respondents have used some type of resource to address their multiple needs. In some cases, friends, relatives, or neighbors provided the assistance. However, in most cases, a public agency or private organization was the resource provider.

- Many caregivers made use of more than one resource or service, with 23% reporting using three to five resources, and 38% reporting using six or more resources.

The majority (58.9%) of respondents said that they know where to find the resources they need; 40.6% of report that they do not know how to access services and resources if they are needed. Over two-thirds (68.7%) of respondents tend to go to one or more places for resources and services, with community agencies (25.6%), church (24.0%), friends (19.2%), family (14.4%), DCFS (12.8%), and IDHS (12.0%) as the most frequently contacted places. When asked how they found the services that they use, caregivers most often cited agencies (61.4%), family members (33.1%), or friends (25.5%).

Table 81: Where Caregiver Goes for Services

	Survey Frequency	Survey Percent
Community agency	32	25.6%
Church	30	24.0%
Friends	24	19.2%
Family	18	14.4%
DCFS (Dept. Children and Family Services)	16	12.8%
IDHS (IL Dept. of Human Services)	15	12.0%
School (child's)	11	8.8%
Social/case worker	10	8.0%
CEDA (Community and Economic Development Association of Cook County)	9	7.2%
Phone book/ Operator/ 311	7	5.6%
Chicago Dept. on Aging	7	5.6%
Police	4	3.2%
Alderman/Township Supervisor	3	2.4%
Doctor/clinic	3	2.4%
Food pantry	3	2.4%
Mental Health Board	3	2.4%
Hospital	1	0.8%
Landlord	1	0.8%
Legal Aid	1	0.8%
Online	1	0.8%
Resource guide	1	0.8%
Social Security office	1	0.8%
Transportation company	1	0.8%

N=125

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one place contacted for services.

Table 82: How Caregiver Found Services

	Survey Frequency	Survey Percent
Agency	89	61.4%
Family ember	48	33.1%
Friend	37	25.5%
Newspaper/magazine article	11	7.6%
Support group	10	6.9%
Church	9	6.2%
Conference	5	3.4%
Children's school	4	2.8%
Counselor	3	2.1%
On my own	3	2.1%
Foster parenting classes	2	1.4%
Other** (IDHS, TV, On-line, Neighbor, DCFS, Court services, 311, Yellow pages, Someone came to my door)	9	6.2%

n=145

*Total percentage for survey responses exceeds 100% due to respondents reporting more than one place through which they found their current services.

**Each of these sources was indicated by only one respondent.

Over four-fifths of the senior caregivers have used some type of resource to address their multiple needs. In some cases, friends, relatives, or neighbors provided the assistance. However, in most cases, a public agency or private organization was the resource provider. Many caregivers made use of more than one resource or service, with 23.1% reporting using three to five resources, and 38.5% reporting using six or more resources.

Table 83: Number of Resources Used

	Survey Frequency	Survey Percent
0 Resources	29	15.9%
1-2 Resources	41	22.5%
3-5 Resources	42	23.1%
6-8 Resources	38	20.9%
9-15 Resources	32	17.6%
Total	182	100.0%

Respondents were asked about 26 areas of need to determine whether or not they had accessed resources to address these needs. The caregivers were then asked to rate the services, on a scale from terrible (1) to excellent (5), and to provide comments as to what they liked and disliked about the services.

Table 84 summarizes the respondents' assessment of the resources that they have accessed. Resources are presented according to the frequency that caregivers report using them, and the mean score refers to the assessment scores that the seniors assigned to the service providers.

Table 84: Resources Used by Caregiver

Resource Used	Percent Reporting Use of Resource*	Mean Score Across Providers**	Resource Used	Percent Reporting Use of Resource*	Mean Score Across Providers**
Health Services for Child	56.6%	3.8	Disability services	10.4%	3.7
Health Services for caregiver	50.5%	3.7	Clothing	10.4%	3.9
Dental Services for Child	50.5%	3.8	Transportation	7.7%	3.8
Optometry	42.9%	3.6	Child care	6.6%	3.2
Education - Elementary	34.6%	3.9	Permanent housing	4.9%	4.4
Dental Services for caregiver	29.1%	3.9	Job training / readiness services	2.2%	3.3
Food (pantry, etc.)	28.6%	3.6	Temporary housing	1.6%	3.3
Mental Health Services /counseling	22.5%	3.6	Substance abuse services	1.6%	4.0
Education - High School	20.9%	3.7	Education - Vocational	1.6%	4.0
Legal Services	18.7%	3.7	HIV services	1.1%	2.5
WIC	16.5%	3.8	Education - GED	1.1%	4.0
			Education - ESL	1.1%	3.0
Help getting legal documents (license, birth certificate)	15.9%	3.9	Job placement	0.0%	NA
Head Start / Early Head Start	15.4%	4.0	n=182		

*The total percentage exceeds 100% due to respondents listing multiple expectations.

**	1	2	3	4	5
	Terrible	Bad	Okay	Good	Excellent

The next section presents a summary of positive and negative comments by the senior caregivers regarding service provision for each of the resource areas that they accessed.

HEALTH SERVICES

HEALTH SERVICES FOR CHILD

Senior caregivers more frequently accessed health services for their children than any other resource. The 56.6% of the respondents who used health services for their children give providers a mean score of 3.8 (4.0 is good; 3.0 is okay).

Positive comments relate to respondents' sense of comfort with their service providers and satisfaction with the quality of services that they have received.

> The doctor sits down and talks to me and explains things.
>
> The doctors and nurse are so patient with the children.
>
> They take care of all his different needs.
>
> A good pediatrician and good bedside manners.
>
> I have a good relationship with the doctor.
>
> Medicaid makes everything okay for my child.
>
> I can take him anytime.
>
> I am able to go anywhere.
>
> My child has asthma and the health services have kept the attack under control.
>
> Services are fast and in Spanish.

Negative comments make reference to the quality of care as well as the difficulty of receiving prompt and timely service.

> DCFS is slow on getting approvals to see specialists.
>
> Doctors stop taking Medicaid. I had to find other doctors. The quality of service was bad.
>
> Slow service. Doctors didn't explain well when asked questions.
>
> Service is good, but we wait too long.
>
> Too many medications that don't help any.
>
> Too many patients.

HEALTH SERVICES FOR CAREGIVER

One-half (50.5%) of the senior caregivers report accessing health services for themselves and give providers a mean score of 3.7 (4.0 is good; 3.0 is okay).

Positive comments address respondents' satisfaction with the quality of care that they receive. A few noted that payment was not an issue, given that most of their medical care and medicines are covered by Medicaid or Medicare.

> Same steady doctor.
>
> Sufficient, caring services.
>
> The doctors and nurses are so patient with you.
>
> The doctors are professionals and give me what I need.
>
> They gave me a medical card for medication.
>
> They always did good work for me.
>
> They accept me wherever I go.
>
> They've been taking care of me pretty good.

Negative comments made reference to the quality of care as well as the difficulty of getting prompt and timely service. Although a few caregivers were critical of the quality of care that they have received, more than one-half of the respondents commented that the wait for medical care or prescriptions is too long.

> They did not follow up with [my] medical concerns.
>
> I do not get enough info from doctors.
>
> My health care is not sufficient.
>
> Too expensive.
>
> There are such delays in getting prescriptions.
>
> I go to the county hospital and I need to wait so long. Being 82 years old that is hard.

DENTAL SERVICES FOR CHILD

Dental services for their children were accessed by one-half (50.5%) of the caregivers. Service providers were given a mean rating of 3.8 (4.0 is good; 3.0 is okay).

Positive comments referred to caregivers' satisfaction with the concern, quality of care, and ease of getting services.

> They care about child's fear.
>
> Good doctors that show they care.
>
> I talked with the doctor. He listened and answered my questions.

> The truck comes to my block.
>
> They really work hard to complete the work they do or refer you elsewhere.
>
> Very good services. They take good care of [child's] dental needs.
>
> Takes care of kids teeth with what state will pay.

Negative comments referred both to the poor quality of service and long waits for service, as well as the difficulty of finding a dentist who would accept Medicaid/KidCare.

> Slow response with registration.
>
> The wait was too long.
>
> The services are insufficient.
>
> It was difficult finding a dentist that accepts KidCare.
>
> The office was dingy, not clean. The special cleaning is not covered by Medicaid and I had to pay for it out of my pocket.

DENTAL SERVICES FOR CAREGIVER

Less than one-third (29.1%) of caregivers used dental services for themselves. Service providers were given a mean score of 3.9 (4.0 is good; 3.0 is okay).

Positive comments related to respondents' satisfaction with the dental care that they receive and their ability to afford the services.

> Same doctor – wonderful.
>
> [My dentist] pulls teeth and cleans. No problems.
>
> I have a good, nice looking set of teeth.
>
> They pull my teeth and give me good care.
>
> Very nice people and I pay later.
>
> I went for an emergency dental need. The service was acceptable.
>
> The rates are reasonable and they do a good job.
>
> Health insurance does cover all cost.

Negative comments related to respondents' dissatisfaction with the quality, cost, and timeliness of their dental services.

> My teeth didn't fit.
>
> The dentists hurt.
>
> It is very expensive.

> I don't think insurance will cover.
>
> I have to wait too long.
>
> There was a delay in getting an appointment.

OPTOMETRY SERVICES FOR CAREGIVER

Over two-fifths (42.9%) of caregivers have used optometry services for themselves. Service providers were given a mean score of 3.6 (4.0 is good; 3.0 is okay).

Positive comments related to respondents' satisfaction with the optical care that they receive, the ease of getting an appointment, and their ability to afford the services.

> The exams were so thorough.
>
> Sufficient, caring services.
>
> My glasses were fixed to stop falling off my face.
>
> If it weren't for them, I wouldn't see now.
>
> Service was good - no complaints.
>
> It was fast getting an appointment.
>
> I didn't have to pay out-of-pocket.

Negative comments focused primarily on the cost of services, with a few respondents also dissatisfied with the quality of the services received. One-half of respondents who accessed these services commented that the glasses or optometry services were too expensive.

> Too expensive.
>
> Public aid doesn't pay for glasses.
>
> Doctor didn't speak Spanish.
>
> My glasses didn't fit properly.
>
> My glasses are too loose. They said they fixed them, but the problem is still there.

SUBSTANCE ABUSE SERVICES

Three respondents report using substance abuse services either for themselves or their children, with a mean rating of 4.0 (4.0 is good). Only positive comments were offered by caregivers.

Positive comments related to respondents' satisfaction with the quality of care.

> He's being kept clean.
>
> The treatment was excellent.

HIV SERVICES

Two respondents report using HIV services, with a mean rating of 2.5 (2.0 is bad; 3.0 is okay).

Negative comments were made by one caregiver.

> The worker's reaction was unprofessional.

EDUCATION

ELEMENTARY EDUCATION

More than one-third (34.6%) of the caregivers have received help with their children's elementary school with a mean score of 3.9 (3.0 is okay; 4.0 is good).

Positive comments reflected the respondents' satisfaction with schools' efforts to provide their children with an education appropriate to their needs, and appreciation for helpful and concerned teaching staff. One respondent received training from the school for her own needs as well.

> My children get very good special education.
>
> The alternative school was excellent with anger management and guidance.
>
> I got computer training through my child's school.
>
> The school is bringing them up to their right grade level.
>
> The teacher takes time with the students if they are having trouble.
>
> They call me and talk to me about what's going on.
>
> The staff was very attentive.

Negative comments described problems with the quality of teaching, gangs, and lack of discipline. A number of respondents were critical about the number of days that schools are closed.

> [Child] is not getting help with his/her learning disability.
>
> The teachers couldn't control kids. Kids bullied him.
>
> Some teachers are not helpful or patient.
>
> [Child's] emotional state made it difficult. Teachers didn't understand.
>
> They do not provide a good education. So many days out of school.

HIGH SCHOOL EDUCATION

Just over one-fifth (20.9%) of the caregivers have received help with their children's high school with a mean score of 3.7 (3.0 is okay; 4.0 is good).

Positive comments reflected the respondents' satisfaction with the teaching quality, the care shown for their children, the communication between the school and themselves, and their children's academic progress.

> The education service is good. All of my kids are doing pretty good in school.
>
> The teacher takes time with students if they are having trouble.
>
> Staff is caring.
>
> They informed me of everything that happened.
>
> My daughter is in a college prep school and is doing real good.

Negative comments described problems with insufficiently rigorous coursework, violence, and a lack of discipline.

> Courses weren't challenging to him; he was bored.
>
> I'm afraid of something happening to my daughter because the kids are rough.
>
> There isn't adequate discipline.

HEAD START/EARLY HEAD START EDUCATION

Head Start/Early Head Start programs were used by 15.4% of all senior caregivers for their preschool children, with a mean score of 4.0 (4.0 is good).

Positive comments referred to caregiver's appreciation of the service both due to the positive developmental impact that it has had on their children, as well as the break in caregiving that it has provided.

> It helped children. Every child should be in Head Start.
>
> She is able to play with other kids.
>
> She learned a lot in there. They met all of her needs.
>
> The children liked it.
>
> It gave me some rest.
>
> It's a life saver.

Negative comments referred to poor program quality and unsatisfactory supervision of children.

> Child didn't get benefits.

It could be better—kids are not supervised well.

VOCATIONAL, ESL, AND GED EDUCATION[29]

Few (3.8%) respondents report having used any resources or services to help themselves or their children with vocational, ESL, or GED educational programs. Those who have used these services only provided surveyors with general responses (e.g., "They were good," "Poor job") and did not provide more information when asked what they liked or disliked about the programs.

FOOD AND CLOTHING

FOOD PANTRIES AND SOUP KITCHENS

Over one-quarter of respondents (28.6.0%) have accessed food resources, including soup kitchens and food pantries, which received a mean score of 3.6 (3.0 is okay; 4.0 is good).

Positive comments referred to the good quality and variety of food, and the care with which they are treated when they come for groceries or a meal.

> I get good quality food from them.
>
> They have a variety and allow me to come two times per week.
>
> It helps when I'm short on canned goods.
>
> They would call back on holidays and leave a food basket.
>
> It was organized.
>
> They're friendly.

Negative comments referred to the quantity and quality of the food, with several respondents noting that the food is old or that they receive an inadequate supply.

> The food is not good quality.
>
> They didn't give enough food.
>
> The food is usually things I can't use or want.
>
> Some food was too old or even expired.
>
> Not a good diet—too many starches.

---

[29] English as a Second Language (ESL); High School Equivalency Diploma (GED).

WIC[30]

WIC use is reported by 16.6% of the senior caregivers, with a mean score of 3.8 (3.0 is okay; 4.0 is good).

Positive comments primarily noted the financial benefits of the program.

> Because milk is so high to buy.
>
> The food was okay and I could use it.
>
> It really helps me out financially.
>
> It was helpful with the milk and food.
>
> When I go for milk, I never had any trouble.

Negative comments referred to the problems that caregivers had when trying to get WIC food supplements, either in getting approved for the benefit, or in the way they were treated once they were approved to receive it.

> We had to wait a lot for the appointments.
>
> There was too much bureaucracy.
>
> I was treated unfair and there was long waiting.
>
> I'm still waiting.

CLOTHING

A total of 10.4% of respondents have accessed clothing resources, primarily for their children, giving them a mean score of 3.9 (3.0 is okay; 4.0 is good).

Positive comments referred to the quality and ease of obtaining the clothing.

> It is clean and wearable.
>
> Good condition. They're able to use it.
>
> I got uniform shirts from a church and they were like new.
>
> You were free to take what you needed.

Negative comments were offered by one respondent, critical of the quality of the clothing.

> The clothing wasn't too good.

---

[30] Special Supplemental Nutrition Program for Women, Infants, and Children.

COUNSELING AND DISABILITY SERVICES

MENTAL HEALTH AND COUNSELING SERVICES

Mental health or counseling services were used by slightly less than one-quarter (22. 5%) of the senior caregivers' or their children, with a mean score of 3.6 (3.0 is okay; 4.0 is good).

Positive comments largely pertained to the helpfulness of counseling.

> The counseling is helping a lot.
>
> It brought the family together.
>
> We had family counseling for my child. Service was good and it helped me understand his problem.
>
> There is a great mentor program.
>
> It helps me to deal with stress.
>
> I get a chance to vent.
>
> Services are very consistent.
>
> They come to the house
>
> Staff are on top of problem and are concerned.
>
> People are kind and nice.

Negative comments reflected concerns that the help they had received was ineffective or insufficient, or that there are problems with accessibility, e.g., language and long waits for an appontment.

> The school and clinic have given only limited help with behavioral issues.
>
> [Child] attends faithfully but it does not service [the child's] needs.
>
> The counseling services are not in Spanish.
>
> There is a long wait to get an appointment; it's understaffed.

DISABILITY SERVICES

Disability services were used by 10.4% of all caregivers' families, and 22.9% of families with disabled children or caregivers, with a mean score of 3.7 (3.0 is okay; 4.0 is good).

Positive comments noted that services and resources are made available when needed, that they are easily accessible, and that the quality of service is good.

> I was able to get crutches for my daughter when she had surgery.
>
> They make sure he has everything he needs.

> I am currently on disability leave and the disability service has been very good.
>
> It’s easy to get services, being a senior.
>
> Professional.
>
> They asked questions.

Negative comments concerned the ineffectiveness or insufficiency of services.

> They have not done anything.
>
> They are not meeting his need.
>
> If I were a foster parent instead of adoptive, I could get better services for my child.
>
> They have only given very limited treatment.

LEGAL SERVICES

LEGAL SERVICES

Almost one-fifth (18.7%) of the caregivers report accessing legal services, with a mean score of 3.7 (3.0 is okay; 4.0 is good).

Positive comments focused on the high quality of help that caregivers receive in navigating the adoption and legal guardian process, and addressing other legal needs.

> Legal Aid helped me become legal guardian over my sons.
>
> The attorneys are very organized and they help me get paper work done.
>
> I was able to adopt my daughter with the help of Legal Services and I got all of the papers.
>
> They get things done in a timely manner when they say they will.
>
> The lawyer stopped the company from charging for a roof I didn't get.
>
> They explain services well.
>
> I could get services in Spanish.

Negative comments addressed issues of cost and quality of service.

> It is expensive.
>
> The lawyer didn't follow through.
>
> They send you back and forth to many different offices.

HELP OBTAINING LEGAL DOCUMENTS

15.9% of respondents have received help obtaining legal documents, with a mean score of 3.9 (3.0 is okay; 4.0 is good).

Positive comments noted helpful staff, good service, and success in obtaining needed documentation.

> The case manager was very helpful.
>
> They give good and fast services.
>
> They were interested in helping and gave information on how to get the job done.
>
> They provided me with all the birth certificates.

Negative comments reflected dissatisfaction with delays.

> Getting the document change took too long.
>
> Long waiting.

TRANSPORTATION SERVICES

Transportation services (provision of rides by private companies or public transportation) were accessed by 18.9% of respondents, with a mean score of 4.1 (4.0 is good; 5.0 is excellent).

Positive comments referred to quality and availability of services.

> We are picked up and dropped off on time.
>
> They are on time and wait until all my prescriptions are filled.
>
> It is available when needed.
>
> I and my children ride the CTA and it gets us where we need to go.

Negative comments referred to the inability to access resources and the poor quality of transportation assistance.

> Because he can walk one block, DCFS won't pay for special services and we have to take the CTA.
>
> It was horrible. They would take you and leave you and not be on time.

HOUSING SERVICES

PERMANENT HOUSING

Permanent housing services were used by 4.9% of the caregivers, with a mean score of 4.9 (4.0 is good; 5.0 is excellent).

Positive comments focused on the good quality of housing that they were able to obtain.

> It is quiet, clean, repairs are good.
>
> I benefited from using Section 8 housing.

TEMPORARY HOUSING

Two of the caregivers report using temporary housing services, with a mean score of 3.3 (3.0 is okay; 4.0 is good).

Positive comments noted the increased convenience of temporary housing.

> You get your own laundry, it is clean, close.

Negative comments reflected safety concerns.

> They were rough.

JOB TRAINING AND READINESS SERVICES

Job training and readiness services were used only by 2.2% of the caregivers, with a mean score of 3.3 (3.0 is okay; 4.0 is good).

Positive comments focused on the quality and accessibility of the training.

> They provided good skills to get a job.
>
> Services were in Spanish.

Negative comments reflected the training’s ineffectiveness in helping achieve employment.

> Didn't get a job afterwards.

SOURCES OF STRENGTH AND SUPPORT

KEY FINDINGS

- By far the most frequently cited sources of strength for the senior caregivers in this survey are God, faith, and religion.
- Over one-fourth of the caregivers cite family and friends as a primary source of strength and support.
- For some of the respondents, their love for their children energizes them and the children provide welcome companionship.
- Most of the caregivers have raised their own children and many have had extensive experience caring for other children, either through work or in their personal lives.

Senior caregivers were asked about the experiences, skills, beliefs, and resources that give them the ability to address all of the challenges in their lives. Their responses were coded into 11 subject categories, with some responses falling into multiple categories.

Table 85: Caregiver's Sources of Strength and Support

Subject Category	Survey Total	Survey Percentage
God/faith/religion	102	56.0%
Family and friends	48	26.3%
Experience	34	18.6%
Kids themselves	19	10.4%
Rely on self	13	7.1%
Concern for child's upbringing	6	3.2%
Church support	6	3.2%
Doing what's needed	6	3.2%
Outside support	4	2.1%
Other	13	7.1%

n = 182

Total percentage exceeds 100% due to comments that spanned multiple subjects.

GOD, FAITH, AND RELIGION

By far the most frequently cited sources of strength for the senior caregivers in this survey are God, faith, and religion.

> Faith in God! God is over my family!
>
> God gave me this child, yes, ma'am. My strength come from God. I didn't think I could do it, but God spoke to me. It's the good Lord helping me all the way. Now He's big enough to help me.
>
> My resources and strength came from Lord and prayer.
>
> The strength of the good Master to guide me that's all I need.
>
> The good Lord, number one. The way I was brought up. I leave it up to the good Lord.
>
> You can't do it on your own. God has to be put first, then you will succeed.
>
> Spiritual base is very strong.
>
> The good Master upstairs. Prayer. Faith the size of a mustard seed—I believe it can move mountains. This is what gives me the courage and strength to carry on.

For some of the respondents, the act of praying itself gives them strength to care for their children.

> Prayer - help you get through anything. I do a lot of praying for these kids and myself.
>
> Prayer. Believing that He will do what He said He will do in His word.
>
> Prayer is the major support.
>
> I just pray about it and take it to the Lord.
>
> God, prayer, and patience.
>
> I pray a lot and ask God for strength and just keep going.

FAMILY AND FRIENDS

Over one-fourth of the caregivers cite family and friends as a primary source of strength and support.

> [Spouse] is there to bounce things off. Friends are there for me and listen.
>
> Each other—we [husband and wife] get our strength from each other.
>
> I have strong family support and interaction. Great communication with daughters.
>
> If it weren't for daughter, I wouldn't know what to do.

> Prayer and my excellent daughter. Extended family helps as well.
>
> Family very supportive, especially with medical care.

EXPERIENCE

Most of the caregivers have raised their own children and many have had extensive experience caring for other children, either through work or in their personal lives. This experience underlies their current strength.

> Experiences. I had to do for my children and other foster kids—I have had over 19 besides my own children.
>
> Wisdom from years of experience and patience and caring.
>
> I worked 40 years at County Hospital, 20 years was in "peds." So all my life I've been dealing with kids. I did a good job with my own kids as a single parent and it all depends on the condition you're in for your age. I'm in good health and have good nerves. I take my kids places so they get a lot of things some kids don't get. So age has nothing to do with it. I don't feel it should matter.
>
> Experience with talking with the children and watching them closely.
>
> Belief in God and the experience of raising 12 children.

KIDS THEMSELVES

Senior caregivers spoke about their love for their children and the way that this energizes them. A fair number also spoke about the welcome companionship that their children provide.

> I guess because I love kids and I love to cook. You can look at me and tell that.
>
> I love kids and I need somebody in the house with me. I fell in love with the kids.
>
> I don't need nobody else but God and the kids. They make me want to do more.
>
> Well at first you know I didn't want to be bothered with him, but somebody had to do it and I fell in love with him and I had a lot of support from my family and friends.
>
> I enjoy having the child for companionship.
>
> Old fashion love. Knowing that if I am available for her, she will trust me and come to me for anything.
>
> Giving hugs just because.
>
> Loving them.

> Well really he is company and he keeps me on the go. I haven't got arthritis or anything because he keeps me busy.

RELY ON SELF

Caregivers spoke about their own resiliency and inner strength and conviction that keeps them going, regardless of the challenges posed by parenting.

> I keep a positive attitude.
>
> Just deal with my problems myself.
>
> My willpower.
>
> I just do it. It comes natural to me.
>
> Just relaxing and attacking it head on.
>
> My beliefs. I believe that if you strive for anything in life and keep working at it, you'll get it.

CONCERN FOR CHILD'S UPBRINGING

Caregivers' are strengthened by the belief that through their intervention in their children's early lives, they can help put the youth on a path to success.

> My strong desire for my daughters to become independent and self-supportive keeps me going.
>
> I have great satisfaction in knowing that I have provided a safe, clean place for them.
>
> Giving them strength. Keep them alive, out of trouble. Give them a place to stay.
>
> I want them to have a good education.
>
> Set a good example for my sons, wisdom, and being able to see pitfalls from experience. Warning the kids about it, all the why and why nots that I am able to tell them about life.

CHURCH SUPPORT

Apart from their religious convictions, some caregivers find significant support and resources from the leaders and fellow members of their church communities.

> The church helps support—they call them their children.
>
> I have a strong church family.
>
> Church pastor has helped tremendously with raising the boys like taking them to the movies.
>
> My pastor is always there for me.

DOING WHAT IS NEEDED

Both a sense of obligation to care for their children and a belief that this is their purpose in life gives some respondents the strength to take on the role of caregivers.

> This is my lot in life. I helped raise my sisters' children.
>
> I'm now raising them. On this planet I'm here to raise children.
>
> I just know I have to do it. I have a strong sense of responsibility. I feel obligated to do it.
>
> Just knowing I have to do it.
>
> Doing the right thing. Do unto others that you have others do unto you.
>
> I'm tired of the aggravation. No one else to care for them.

OUTSIDE SUPPORT

A few respondents spoke about the help that they have received from community and social service organizations.

> The social service agency helps me.
>
> Programs that give me information and resources.

OTHER RESOURCES AND SOURCES OF SUPPORT

Senior caregivers offered a few other resources and sources of support that they have found particularly helpful for raising children. A number concerned activities that they find pleasurable or relaxing.

> Reading.

> Doing crossword puzzles.
>
> Being a smoker, and having a buzz (drink) every now and then.

Some focus on creating a sense of open communication with their children.

> We work together with the children and we talk and see what their needs are and they tell me what their needs are… and we meet that.
>
> Let them feel free that they can talk to you about anything.

Other respondents spoke about the importance of taking care of themselves if they are to have the wherewithal to take care of their children.

> I stay alert by exercising mentally and physically, staying active.

A few caregivers have found ways to have some time away from their children to re-energize.

> At times in the summer, I do get some respite when she goes to camp.
>
> I need to get [the child] out of the house for a while.

And for one caregiver, the fact that the end of her current role in sight is of great help, while another simply takes one day at a time.

> Knowing it will end soon is good. [Child] will soon be 18.
>
> I get up each morning and just deal with what comes.

SENIOR CAREGIVERS SPEAK OUT

KEY FINDINGS

- By far the most common concern, expressed in over one-third of the comments, was the need for greater financial support. Over two-thirds of these were general comments, focused on the need for improved overall financial support and the senior caregivers' inability to provide for their children's needs with the funds that they currently receive. 12% of the caregivers spoke about the need for Food Stamps, and often about the difficulty or inability that they have experienced in trying to access them. Respondents are critical of the insensitivity of the system to increases in the cost-of-living when determining the level of financial support for families. Other caregivers focused on the specific financial demands placed on them due to school expenses, and requested that government officials help them cover these costs.

- The need for more respite care services is another issue that respondents want highlighted for public officials.

- Some of the caregivers addressed frustrations that they experience as parents who have adopted their children, and what feels to them as an abandonment by the government as a result of their making this commitment to their children.

- A significant number of senior caregivers believe that improved and increased contact with DCFS is an issue that requires greater attention by public officials.

- Quite a few of the respondents are dissatisfied with the quality of schooling and educational support that their children receive.

- Caregivers reiterated their need to find more and higher quality afterschool and summer programs and activities for their children.

- Caregivers addressed the need for improved and increased availability of counseling and support groups for their children as well as themselves.

- A number of respondents feel that as seniors, their needs are different than those of younger caregivers. They would like service providers to be more sensitive to their circumstances.

At the conclusion of each interview, senior caregivers were asked what they would like to tell city or state officials who want to help them and other seniors who provide homes for minor children. Their answers were coded into 17 subject categories, with some responses falling into multiple categories.

Table 86: What Caregiver Wants to Tell City and State Officials

Subject Category	Survey Frequency	Survey Percentage
Need more financial help	66	**37.9%**
Need respite care for the caregiver	18	**10.3%**
Need more involvement from DCFS caseworker	17	**9.8%**
School and after school programs	16	**9.2%**
Counseling services	15	**8.6%**
Senior-friendly services	11	**6.3%**
Need more recognition and compassion for caregiver	8	**4.6%**
Housing and environment	8	**4.6%**
Need transportation	7	**4.0%**
Help birth parents	7	**4.0%**
Child rearing	7	**4.0%**
Mentoring and transitional support	6	**3.4%**
Foster parent screening and child placement	6	**3.4%**
Resource information and accessibility	5	**2.9%**
Need more/better health services	3	**1.7%**
Need services in Spanish	3	**1.7%**
Other (miscellaneous needs, race/class, life's wisdom)	39	**22.4%**

n=174

*The total percentage exceeds 100% due to respondents offering multiple comments.

NEED FOR FINANCIAL SUPPORT

By far the most common concern, expressed in over one-third (37.9%) of the comments, was the need for more financial support. Over two-thirds (68.1%) of these were general comments, focused on the need for improved overall financial support and the senior caregivers' inability to provide for their children's needs with the funds that they currently receive.

> We need better financial support; the funding is absolutely unrealistic. For example, $765 for three children.
>
> It is not enough money to meet all of the needs of the kids. That should be overhauled.
>
> More money to assist with kids needs will prevent them from doing things wrong to obtain those things. I am afraid they will be come involved in drug or gang activities because I can't provide their needs.
>
> Please give more support and more money. Being on fixed income—we need more help.
>
> It is very hard for seniors to raise children. They can't get out to a job. We need more funding to raise children.

Food Stamps

12.1% of the caregivers spoke about the need for Food Stamps, and often about the difficulty or inability that they have experienced in trying to access them.

> I don't want to complain because I do what I can to help, but they should give us some Food Stamps or something
>
> Food Stamps are a great help—I need them.
>
> You should provide the means for caregivers to get Food Stamps.
>
> Our families can't get Link/Food Stamps due to formulas and restrictions.

Cost of Living Adjustments

Respondents are critical of the insensitivity of the system to increases in the cost-of-living when determining the level of financial support for families.

> We need a cost-of-living increase just as everyone else. Take into consideration a child's needs and expenses as they grow.
>
> We need better financial support. A cost-of-living increase would help!
>
> To help them out, since the standards of living has gone up, they need to give more money.
>
> We need additional funds each year for kids. The cost of living increases.
>
> Consider the costs as the child grows, taking into consideration cost-of-living increases. Kids age - expenses increase not decrease. Cost-of-living should be calculated each year.

School Expenses

Other caregivers (7.5%) focused on the specific financial demands placed on them due to school expenses, and requested that government officials come up with a way to help them cover these costs.

> You need to provide more money for school supplies.
>
> Make allowances for back to school, separate and additional to the child subsidy, for example an additional $50 in September.
>
> Foster parents should get more money for the child because everything costs so much--school clothes and supplies.

College Expenses

Some respondents (6.0%) addressed concerns that they would not be able to support their children who want to go to college due to insufficient funding.

> It would be helpful if they could find funding for children who want to attend college.
>
> How am I supposed to get money for college for these children?

After School and Summer Programs

A number of the senior caregivers (4.5%) spoke about their concerns regarding the insufficiency or inaccessibility of after school and summer programs.

> I need to get day camp and outside activities for him; paying for the children to go to outside activities is so hard. Sometimes I have to stop the children from continuing outside activities once they began because I can't pay for it.
>
> My kids need more financial aid. They need assistance for such things as recreation. My kids would love to go to Great America now and then.
>
> This is a challenge and we need support from more programs and more money because I use all my money to take care of him. There should be more opportunity to take kids to things around the city by giving passes to seniors and kids; it costs so much for these things.

Utilities, Home Repairs, and Property Taxes

Finally, respondents spoke about their concerns with taxes, utilities, and home repairs and the negative impact of these expenses on their ability to meet their family's needs.

> It would be nice to get help with utility bills.
>
> I pretty much can feed them, but clothing, heat, electric are a bit much.
>
> I could use relief from property taxes and water charges.
>
> Maybe they could provide an incentive, such as a rebate on mortgage or tax or rent, for housing.
>
> They don't give seniors enough money! We need home repairs and cannot afford them.

RESPITE CARE

The need for more respite care services is another issue that respondents want highlighted with public officials.

> I need respite care for me, now that I'm alone.
>
> Respite care is needed by both me and the children.
>
> If I could have someone to take care of them every two weeks or once a month, it would help to have time to myself.

> Could you find more respite care for us? We need more support for grandparents with kids such as agencies for respite.
>
> I was not being aware of respite care and I'm needing it.
>
> I need respite more than anything else and activities for the kids.
>
> Seniors need someone to come and help take the children out.
>
> They need serious respite care so that the adult may do something to enjoy themselves or just sit if they want. They also need to make sure the kids can have some enjoyment.

DCFS INVOLVEMENT

A significant number of senior caregivers believe that improved and increased contact with DCFS is an issue that requires greater attention by public officials.

> There needs to be more social workers to do more one-on-one with the families. Caseworkers don't have time. We need more people involved, a support group. People don't trust DCFS and that needs to change if we are going to help the children.
>
> Try to give more support of the children throughout their stay. Just don't leave me after the case is closed.
>
> I would benefit from having a specific caseworker. The DCFS hotline does not respond with any regularity.
>
> The workers always say "I'll get back to you." When a person needs help, they need help right away, not two-three weeks later. They should not be handing out cards about what you cannot do to the kids. DCFS doesn't make visitation to see how the kids are doing or take the children for physical exams.
>
> I would like them to know that they need to be more present in the kid's life throughout their life span. Don't just drop them off and leave them without any support. Kids already feel abandoned by their parents and now for the caseworker to make no more contact once they are placed in the home permanently is wrong.
>
> Check in to see how the foster parent is doing, or do they need some help.
>
> DCFS needs to continue to stay in contact and provide more services and even better services.
>
> They should come and check on children; if they are a problem they should take them somewhere else.

Some of the caregivers addressed frustrations that they experience as parents who have adopted their children, and what feels to them as an abandonment by the state as a result of their making this commitment to their children.

> They lied. No caseworker to check on kids nor phone call. It was promised that this would happen after adoption, but there's been no post-adoption services. Stop pushing adoption if taking care of relative kin.
>
> When we adopt the children, whatever benefits we had before we adopted them should continue. It would be nice if DCFS continued to check on kids after adoption just so the kids have someone to talk to.
>
> Once we adopted the kids, the services should not be cut. They should continue things, camp, visits, state fair—all the activities to help you to give the kids things to do.

SCHOOLS AND AFTERSCHOOL PROGRAMS

Quite a few of the respondents are dissatisfied with the quality of schooling and educational support that their children receive.

> Our public schools need to be better and friendlier.
>
> We need to find better schools for these kids.
>
> Paying for outside tutoring isn't possible. They need to give it at the school.

Caregivers reiterated their need to find more and higher quality programs and activities for their children.

> I don't like parochial school and after school child care. It's too expensive. Offer more free after school programs.
>
> We need to try to keep them busy with extra programs like swimming and after school programs. Finding positive programs to do is difficult.
>
> Programs and resources for kids especially Saturday and after school that are accessible–we need more of them.

COUNSELING SERVICES

Caregivers addressed the need for improved and increased availability of counseling and support groups for their children as well as themselves.

> The counseling services for children need to be more consistent.

> They need to have counseling services available on the south side.
>
> Have more counseling services available in Spanish for foster parents with children with behavior problems.
>
> We need to be able to get counseling services for the children—they lost their mother.
>
> I need help with communication and building a relationship with my children.
>
> More social workers to do more one-on-one with family. Caseworkers don't have time; need more people involved, support group. People don't trust DCFS and that needs to change if we are going to help children.
>
> Can't someone have support groups for seniors caring for minors?
>
> It would be so good if they would provide senior parents support groups.

SENIOR-FRIENDLY SERVICES

A number of respondents feel that as seniors, their needs are different than those of younger caregivers. They would like service providers to be more sensitive to their circumstances.

> Provide services for seniors that are meant for seniors. You can't expect seniors to wait in line for Food Stamps, etc.
>
> Sometimes there are too many meetings, especially for grandparents. Some meetings are necessary, but be aware of so many meetings. We are older people.
>
> Don't put seniors through all these hoops.
>
> Make sure the paper work is in large print and not a lot of big words.

RECOGNITION AND COMPASSION FOR CAREGIVERS

Some of the respondents are frustrated by what feels like a lack of understanding and appreciation of the efforts that they are making on behalf of their children and would like people who work or come in contact with them to be more sensitive to their needs and feelings.

> Look beyond the seniors' faults and see some of their needs. The senior should be given the highest praise for taking their grandchildren after they raised their own children to have to start all over again raising children.
>
> I would recommend that the city and state officials be more compassion[ate] toward senior caregivers. We may need more help in understanding the difficult laws and paperwork.

> Don't look down on caregivers.
>
> People need to be appreciated for being a foster grandparent and recognition for the caregivers.
>
> Be concerned about the seniors taking on this job; be there to assist them with the children.

Other caregivers want us to share their overall satisfaction with the way that they and their children have been treated by DCFS and other organizations.

> I did not have a problem dealing with the agency. They contacted me directly and it was a "slam dunk" to get the kids.
>
> I have been treated well and the children have been treated well.
>
> They are doing a beautiful job with doing this to help us to help the kids. A lot of time has been put into this. Hope they keep up the good work. Hope someone can learn from this.
>
> I am happy with the way things are. I'm not having any problems with my child.

HOUSING AND ENVIRONMENT

Senior caregivers would like the government to place more attention on finding or creating housing that is appropriate for their and their children's needs.

> I know there's a lot of seniors who has kids. I don't know any place where a senior like me would rent to me with a 15-year-old young man. People aren't renting to those with teenagers. We need a place where we can be accepted. I've never had Section 8, but it would be a tremendous help for seniors.
>
> Make sure that the senior caregiver have a place to stay to raise their children—foster or adoptee. We need more help from the state such as low- income housing.
>
> It's very unfair to give all the young kids Section 8 and being a senior and caregiver, we can't get anything. I've been trying since '90 and nothing has happened.

Some of the caregivers addressed their concerns that their homes are located in communities where they do not feel safe and where their children are at risk due to the violence and drugs around them.

> It's hard [to] bring up children making sure of their safety and I would like them to step up and help us. Make this system fair for those who are less fortunate. Our neighborhood needs more and better protection, which we are not getting. I know they can come up with a plan to make our neighborhood and school safe.

> We need help with a state of environment that is drug free and safe.
>
> Build a place for seniors to raise kids with places for teenagers to hang out that are safe.

TRANSPORTATION

Transportation needs of caregivers are an issue that some respondents want the government agencies to note.

> We need transportation assistance for kids
>
> They need to find transportation to help with the demands.
>
> Help with transportation. What we have is not enough.

HELP BIRTH PARENTS

A number of the respondents, while emphasizing their love of their children, feel strongly that greater effort should be made to help birth parents take better care of their own children.

> Seniors are not really able to provide care the way younger adults should. It’s too easy for parents to walk away from family responsibilities.
>
> We need programs to educate and support birth parents to take care of their own children.
>
> All children don't need to be grouped together and placed in the same circumstances. DCFS just needs to offer family support and not remove child completely from the home.
>
> Give the birth parents more help in keeping their children
>
> Every child needs to be in a home with a family. I wish they could provide some money to help children stay with their own parents.

Other respondents stated that if children are not going to be living with their birth parents, they should not allow the parents to have contact with the children in their new home.

> Shouldn't allow biological parents to visit. They cause a lot of problems/conflicts. It disturbs the children emotionally and causes them to rebel with the one that is caring for them.

CHILD REARING

A number of caregivers spoke positively about the child development and parenting classes that they have taken, while others expressed a need for more of this training and education.

> Classes for foster parenting are very helpful and shown me a lot of resources that I was unaware of.
>
> There is a need for more support and training for those who sincerely want to care for displaced children.
>
> I could use help in learning when should you start teaching a young girl more about her body and sex.
>
> You should give child development classes.

Other caregivers expressed significant frustration at the interference of government agencies in their child rearing practices, particularly as it pertains to physical punishment.

> Stop telling children someone is going to call the police if you spank them and DCFS is going to put you [the caregiver] in jail.
>
> When they [foster children] go into these homes, they know you can't hit them. They use this against the caregiver. Don't tell the child they are not to be hit.

Finally, one respondent wants policy makers to think about ways to improve the interactions between the police and their children when they are having serious problems with their behavior.

> There has to be a better way the police can help with problem children.

MENTORING AND TRANSITIONAL SUPPORT

Respondents would like to see greater resources focused on providing mentors and other adult role models to help guide their children and prepare them to live on their own as they become adults.

> We need a big brother program
>
> Peer mentors are needed.
>
> There needs to be more Boys and Girls clubs, Big Brothers and Sisters program—someone to come and help take the children out.
>
> A year before they are getting ready to leave the foster home, they should provide transitioning for a home, job, independent living for the child.

> The children need direction and adult awareness programs to become more responsible and able to care for themselves.
>
> I need assistance with transition of my child to independency. There should be some type of training or class for children to bring about more awareness and increase their life coping skills.

FOSTER PARENT SCREENING AND CHILD PLACEMENT

Some respondents expressed concern about the qualifications of other caregivers with whom children have been placed by DCFS, and a desire to see greater care taken in that process.

> Try to place children with people who truly want to help. They have to do better screening of foster parents; more support and training for those who sincerely want to care for displaced children.
>
> Make sure the place where children are placed there is love. Children should be taught values, show love, not just tell them. Make sure the caregiver is not a mean person. Ask people in the neighborhood about them.

Other respondents addressed their concern that DCFS children are moved from one home to another with insufficient effort to keep them in one environment.

> I hate to see kids scattered around. They should try to keep the kids in one place and not moved around. They should help us with enough money to make it.
>
> If the kid is not going back to their mother, leave the kid alone. Don't shift them from foster home to foster home.

A few caregivers were frustrated by the bureaucratic difficulty that they encountered in getting the right to care for their children through DCFS and recommend making the process less cumbersome.

> Make the process less longer and easier.

Finally, one respondent addressed her belief that seniors are not appropriate caregivers for children, given the demands and stress that it places on the caregiver.

> Not a good policy to deal with teens as a senior because of stress. They are better for young people.

RESOURCE INFORMATION AND ACCESSIBILITY

While some respondents are well connected with support services for themselves and their children, others spoke about their lack of information regarding resources and how they can access them.

> Tell them they could do better because we need help to get things the way they supposed to be with wheelchairs and things. Do more visits to senior [to] let them know about programs, activities and locations for handicap kids.
>
> I don't know about any other resources out there. The state should tell us what is available for us once we take the children in.
>
> There is nothing that tells us there are services, dentists, eye doctor, etc. available.

Some of the respondents expressed frustration about the inaccessibility of resources that they need.

> I would like agencies with different services close to my house and clinics around my house.
>
> Make resources more accessible. There simply is inadequate information out there.

HEALTH CARE SERVICES

A few caregivers feel that the government needs to ensure that they have greater access to health care providers who are of high quality and will accept their insurance.

> We need accessibility to better medical doctors, dentist, ophthalmologist that take Medicaid. We should have the same access to Public Aid doctors as other people.
>
> Work harder in enlisting dentists and doctors to accept Public Aid.

SPANISH SERVICES

Having support in learning English and finding services with Spanish speaking staff would help many of the respondents with limited English proficiency.

> I need more help learning English.
>
> It would be helpful if there were personnel who speak Spanish when I need help.

OTHER COMMENTS

A number of caregivers used this question as a way to reiterate a list of service needs that they had discussed previously, including the need for child care, home repairs, and legal services. Two respondents also addressed their concerns about race and class, and the impact that they have on the quality of services that they receive.

> We should have integrated police in the neighborhoods. In this neighborhood, it’s 75% African American and 25% White. Schools should be the same as either neighborhood—good teacher, clean building, caring administrator.
>
> They have to do better than what they are doing. Stop making a difference because of race and class.

Others shared their own favorite words of wisdom and guidance.

> Be brave; just stand up; give love.
>
> I tell them it take patience to raise minors at my age.
>
> I will keep their young.
>
> It’s a blessing to help these children, to give them light and love, to console them. It helps me. It strengthens me.
>
> Tell the truth at all times—don't lie to anyone.
>
> The people that are over the kids have to be loving and be a role model. They have to do the right thing by the kids.
>
> If they're not your own, make them your own and treat them like they supposed to be treated.
>
> Put it in your heart to help no matter what the children has done or is doing. Don't throw them away.
>
> Tell them the history of my life. I'm helping my grandson to survive and help him make it on his own, to go to school and get a job.

RECOMMENDATIONS

The focus of this study is senior caregivers of children who are involved with the state child welfare system. However, many of the findings and subsequent recommendations apply to senior caregivers of children outside of the state system as well. Those recommendations that specify involvement with DCFS pertain specifically to families that are involved in the child welfare system. Given the current funding and structure of the state agencies, DCFS cannot support senior caregiver families who are not involved in the child welfare system. Support for these families must be established or enhanced through other agencies.

- **Identify case managers within DCFS to work with senior caregivers who are trained in issues specific to older caregivers and are familiar with the resources available to help them.**

One-third of the respondents need help with one or more tasks of basic living including using the telephone, traveling by car or public transportation, shopping for food or clothes, preparing meals, doing housework, taking medication, and managing their money. While many caregivers are able to rely on extended family and friends or neighbors to provide this support, 16% of the respondents are completely on their own in caring for themselves and their children.

Specialized case management not only would provide the mechanism for senior caretakers to receive support and services for their children, but also would insure that seniors receive the help that they may need with tasks of basic living. The DCFS case manager could act as a liaison with the Illinois Department on Aging or Area Agencies on Aging, intervening if the caregiver needed medical care and other services or resources for themselves, referring seniors to the proper programs within the aging network that could provide assistance.

- **Ensure that case managers are knowledgeable about the rights of caregivers regarding the healthcare of their children and can intervene for caregivers unable to access medical care for their children.**

While most of the caregivers are able to access medical care for their children, some are unable to do so, citing medical providers' unwillingness to consult with or serve them because they are not their children's parents or legal guardians.

- **Provide information to caregivers about the effects of in utero drug exposure, measures that they should take to assess any impact this may have had on their children, and guidance on symptoms and treatment.**

Over one-half of the children in the care of the respondents to this survey were exposed to drugs or alcohol in utero, and just over one-half of the children who were exposed have resulting health problems. Caregivers cannot do anything about preventing the exposure, but need support with addressing the physical and mental health problems associated with it.

- **Provide information to caregivers about the effects of abuse and neglect on children, potential ways to identify children who have been abused and neglected, and recommendations for appropriate services. Provide a contact person who is trained to identify and address child abuse and neglect as a resource available for ongoing counseling and support to these children and their families.**

Given that almost one-quarter of the youth have been sexually, physically or emotionally abused and over one-third have been neglected, caregivers and their children need to be provided with support and resources to address their emotional and physical needs.

- **Provide ongoing screening of every family involved with DCFS to ensure that the caregivers and children are receiving all of the benefits to which they are entitled through local, state, and federal programs. Provide support to the caregivers throughout the process of applying for benefits, following up as needed to ensure that they receive them.**

Slightly under one-half of the caregivers report that some or all of their children receive government aid, other than Medicaid. Given the high rates of poverty among the caregivers and their children, the receipt of government support appears to be highly underreported. At a minimum, a majority of the youth would have been eligible for subsidized school breakfast and lunches, yet less than one-fifth of the respondents report that their children receive these benefits. If indeed such low percentages of children eligible for public benefits are receiving them, this may indicate the need for more outreach and assistance around accessing benefits as well as streamlining of application procedures.

Given that almost one-half of the caregivers received their children as an emergency placement, having no time to prepare for their new situation or parenting responsibilities, an initial screening should be conducted when children are first placed in the caregiver’s home, including the identification of a viable back-up caregiver. Furthermore, as children and caregivers age, their support systems and needs change, making periodic assessments essential for ensuring that needs are met throughout the duration of the placement and that a viable back-up caregiver remains in place.

- **Coordinate DCFS's outreach to senior caregiver families with the Illinois Department of Human Services, the Illinois Department of Healthcare and Family Services and the Illinois Department on Aging to ensure that all caregivers have access to information and benefits.**

Streamlining the process to access the benefits to which senior caregivers and their dependents are entitled would ease the burden not only on the caregivers, but also on the caseworkers in each of these agencies. DCFS should convene a meeting of these four agencies to determine the best way to provide outreach to these families and ensure that they receive the benefits that they need.

- **Increase the use of community-based organizations, including religious-based institutions, to provide outreach and information regarding programs and resources available to assist senior caregivers.**

One-half of the respondents in this study already go to community agencies and local churches to access services for themselves and their children. These institutions are natural allies of the government agencies and service provider. With adequate support they could provide more outreach and information for their patrons, clients, and church members.

- **Provide an increased level of financial support for caretakers who are unable to meet their and their children's basic needs due to insufficient funds.**

Over one-half of caregivers report that their monthly funds are inadequate to support themselves and their children, and over one-third of respondents report that they have difficulty providing food, clothing or other necessities for their dependents. 16% of these seniors have had their gas or electricity disconnected due to lack of funds, and a small number are in jeopardy of losing their homes. Over one-third of the respondents have gone without food, clothing, medications, or other necessities in order to provide for their dependents.

- **Provide parenting training and support for caregivers around issues of child behavior.**

Almost one-third of the senior caregivers in this study report that their children have behavioral problems and almost one-quarter of the respondents are unable to successfully discipline some or all of their children.

- **Provide a supplement for respite care services for senior caregivers.**

Almost one-third of the senior caregivers identified respite care services as a resource that they need, and over one-half said that they would like to have respite care services available to them. While some of the senior caregivers have other family members who are willing to give them the opportunity to take time away from their caregiving responsibilities, many of the caregivers do not have this option and cannot afford to purchase this service. Caregivers should be provided with the information about how to access these services and the fiscal resources necessary to pay for them.[31]

- **Work with all caregivers to ensure that they have a back-up plan for caring for their children, in the event that they are unable to do so.**

17% of the senior caregivers report not having a back-up plan, in the event that they are unable to care for their children. DCFS recognizes the importance of this for older caregivers and programs are underway to develop this service currently with caregivers 60 years of age or older who plan to adopt a child. Sound casework practices, however, would involve providing assistance with back-up planning for all caregivers, regardless of the caregiver's age or other circumstances.

- **Provide information and referrals to tutoring services, as well as financial resources to enable caregivers to access these services.**

Over one-third of the caregivers say that their children need tutoring. Almost one-fifth of the children have learning disabilities and over one-half of the respondents report that their children's disabilities interfere with their education. If these children are to succeed in school and be able to go on to higher education or find jobs in which they can earn a living wage, they need additional academic support. Tutoring programs that are geographically and financially accessible need to be provided.

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[31] This might be accomplished by a supplemental payment for respite services similar to the Child Care Resource and Referral Contract DHS uses for TANF RPY (Representative Payee) cases (child only cases in which only the children receive a TANF cash assistance grant).

CONCLUSION

The needs and resources of senior caregivers and their children as documented in this research do not come as a surprise to service providers, advocates, or policymakers involved with this population. A large percentage of the respondents in this study are poor and living on fixed incomes. Over one-half of the caregivers are unable to support themselves and their children on their monthly income; 40% are unable to provide for their basic food, clothing, and medication needs. The need for financial resources was identified by over 60% of the respondents for themselves and by 56% for their children, far greater than for any other need identified in the study. And when given the opportunity to tell city or state officials anything that they felt might be useful to government workers who want to help them, they wanted their financial needs to be understood and taken seriously.

Thirty-five percent of the caregivers rate their own health status as so-so, somewhat sick or very sick, and one-third of the respondents report needing assistance to carry out basic tasks of daily life. These physical problems and limitations negatively impact their ability to care for their children and are problems that are likely to worsen as they age. These findings parallel the experiences of senior caregivers nationally.[32]

The resiliency and commitment of these older caregivers is as striking as their vulnerability and frustration. Most of these caregivers have resumed child-rearing responsibilities after having raised their own children. Most often, their grandchildren and other young kin have come under their care due to drug and alcohol abuse and neglect by the children's parents. While most of the seniors have adults who help them, just under one-fifth are caring for themselves and their children completely on their own. Yet few expressed any bitterness or anger. Far more of the respondents spoke about the joy that the children bring into their lives and are grateful that they are able to take care of the children and keep them out of the foster care system.

Yet despite their desire to keep their children out of state care, many respondents spoke about their sense of being abandoned or left with insufficient support in caring for their children. Whether it is respite care, support and guidance in addressing behavioral problems, an advocate to insure that they are able to meet the medical needs of their children, or someone to check in on their own needs, senior caregivers need more intense and proactive support for themselves and their children. As one caregiver commented, "I tell you I'm blessed with these children. I don't want anyone taking them away from me. But it would sure be good if someone would give me just a little help along the way so I can keep goin' as long as they need me."

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[32] Burnette, D. *Grandparents as Family Caregivers.* New York State Office of Aging. Accessed at http://aging.state.ny.us/explore/project2015/artGran.pdf on April 11, 2006.

These senior caregivers are providing an invaluable service to these children and our communities. Some of the recommendations require little or no additional expenditure and should be considered for immediate implementation. The additional public expenditure would be more substantial for providing these families with more intensive case management and additional financial resources for basic expenses of food, clothing, health care, and housing as well as respite care services. However, the benefits that the public recieves from the willingness, hard work, and loving care of seniors in caring for children—many of whom have been abandoned and neglected—greatly exceeds the cost of expanding efforts to meet these basic needs. Despite the state's budgetary constraints that are forcing departments to cut expenses, this additional expense on the basic needs of senior caregivers of our children is not only fiscally prudent, but also prudent and ethical social policy as we continue to rely on grandparents and other seniors to care for some of our most vulnerable children.

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