



# HELP TO KEEP GOING AS LONG AS THEY NEED ME:

## A REPORT ON SENIORS RAISING CHILDREN

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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.<sup>1</sup> 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.<sup>2</sup>

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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<sup>1</sup> 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](http://www.gu.org/Files/ChallengesSheetfinal10_02.pdf) on April 7, 2004.

<sup>2</sup> “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](http://research.aarp.org/general/kinship_care_2003_il.pdf) on April 12, 2004.

DCFS to provide foster care services.<sup>3</sup> 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.<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> 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,<sup>7</sup> 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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<sup>3</sup> Ibid.

<sup>4</sup> 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](http://www.futureofchildren.org) on April 7, 2004.

<sup>5</sup> 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.

<sup>6</sup> 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.

<sup>7</sup> 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

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### 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

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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

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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.<sup>8</sup>

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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<sup>8</sup> 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 receives 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.

# CENTER FOR IMPACT RESEARCH

Founded in 1975, the Center for Impact Research (CIR) focuses its work on issues of economic and social justice. CIR uses community-based research to advocate for and achieve changes in public policy and programs. The Center works collaboratively with diverse partners, who are all striving to eliminate the fundamental causes of poverty and injustice. CIR is focusing its current work in four project areas: Working Families; Children and Adolescents; Seniors; and Alternatives to Incarceration.

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