

Grandparents and Other Relatives Raising Children: *The Second Intergenerational Action Agenda*



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Office Assistant

Douglas Lent

Membership Coordinator

Jaia Peterson Lent

Public Policy Director

Jason Simon

Intergenerational Assistant

Sheri Steinig

Special Projects Director

Generations United

1333 H Street, N.W., Suite 500W
Washington, D.C. 20005
Phone: (202) 289-3979
Fax: (202) 289-3952
Email: gu@gu.org
www.gu.org

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About Generations United

Generations United (GU) is the national membership organization focused solely on improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. GU represents more than 100 national, state, and local organizations and individuals representing more than 70 million Americans. Since 1986, GU has served as a resource for educating policymakers and the public about the economic, social, and personal imperatives of intergenerational cooperation. GU acts as a catalyst for stimulating collaboration between aging, children, and youth organizations providing a forum to explore areas of common ground while celebrating the richness of each generation.

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*This second
intergenerational action
agenda, like the first, is
dedicated to the
grandparents, the
relative caregivers, and
the children in their care
whose commitment to
family serves as an
inspiration to us all.*



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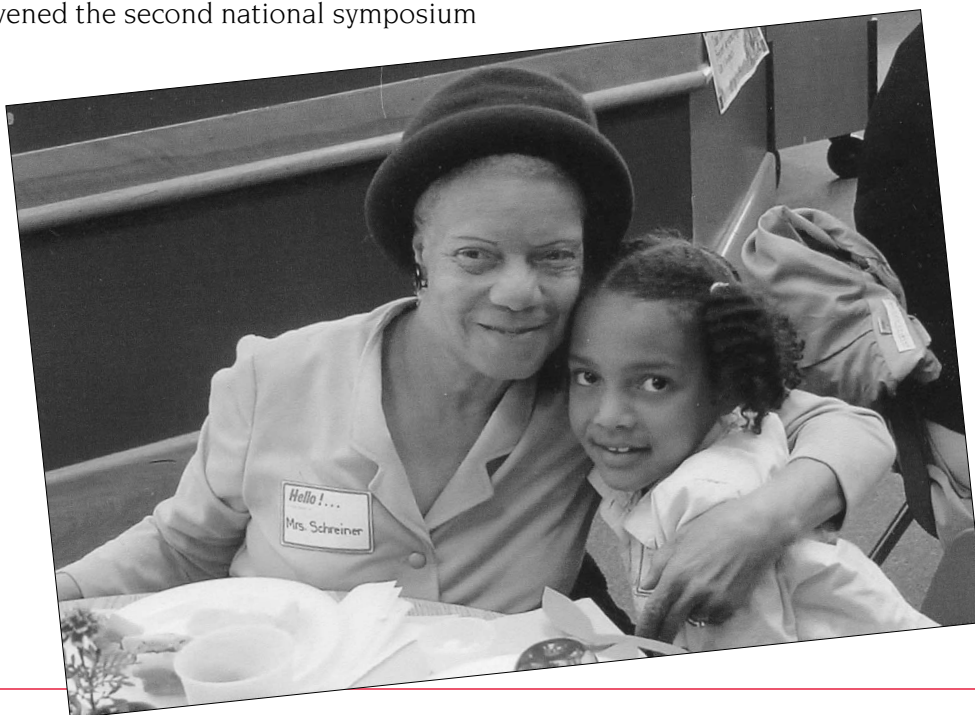
I. Introduction

Since Generations United's first national expert symposium in 1997, great strides have been made to support grandparents and other relatives and the children they raise. Most of the recommendations in the first symposium's resulting action agenda were successfully implemented. There are now increased family supports, a new federal caregiver program, an affordable housing law, targeted publications, positive family portrayals in the media, and new national data collection efforts. The first national GrandRally on Capitol Hill was a tremendous success and rallies at state legislatures around the country have begun. It has been seven positive, exciting years.

To celebrate these achievements and develop next action steps, Generations United and six co-sponsors — AARP, American Academy of Pediatrics, The Brookdale Foundation Group, Casey Family Programs, Child Welfare League of America, and Children's Defense Fund — convened the second national symposium

on grandparents and other relatives raising children on July 7-8, 2004 in Washington, D.C. Experts from around the country were invited to participate in a two-day discussion of what remains to be done to support each generation in these families. Twenty-eight recommended action items resulted, all of which are described in this intergenerational action agenda.

This agenda is intended as a blueprint for a national, collaborative effort to support grandparents and other relatives and the children they raise, and a call to action to anyone interested in joining the effort. The agenda begins with a brief exploration of the accomplishments since 1997 on behalf of relative-headed families. It then sets forth the specific recommendations and concludes with background information in a number of areas impacting the families.



II. Accomplishments

The collective accomplishments since 1997 on behalf of relative-headed families are extraordinary. That year, the symposium recommendations were divided into three general categories: family supports, community education and media advocacy, and data collection. Although not an exhaustive list, below are some highlights of the accomplishments in each of these areas, which give cause for celebration to all those working to support grandparents and other relatives and the children they raise.

Family Supports

SUPPORT GROUPS AND OTHER SUPPORTIVE SERVICES

One of the most notable accomplishments has been the rapid growth of the Brookdale Foundation Group's (Brookdale) Relatives As Parents Program (RAPP). In 1997, there were 20 sites in 8 states. Now, 145 RAPP sites exist in 43 states. (Twenty-seven sites were funded through collaborations with Generations United.) RAPP pioneered support groups for relatives raising children, and its efforts have proven invaluable to the families. RAPP

sites also provide other useful services to the caregivers and the children through community advisory boards and collaborative efforts.

In 1998, Brookdale began working with Generations United (GU) to reach additional caregivers through their innovative behavioral health RAPP program. In that program, which has received four consecutive contracts from the Center for Mental Health Services of the U.S. Department of Health and Human Services (DHHS), GU and Brookdale worked to put RAPPs in mental health centers where the families could access family and individual counseling, respite care, and other types of behavioral health services.

GU and Brookdale next collaborated to create the first national network of support groups for relatives caring for children in the formal foster care system. This partnership, known as KinNET, was funded for three years by the Children's Bureau of DHHS. KinNET has 31 sites throughout the country, which offer support groups and other services tailored to this population.

NEW NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

In late 2000, Congress enacted the innovative National Family Caregiver Support Act (NFCSA). The U.S. Administration on Aging oversees the program, which funds Area Agencies on Aging to provide support groups, respite care, counseling, and other useful assistance to grandparents and other



relative caregivers over age 60 who raise children, in addition to family caregivers of older individuals. Despite the Program's age limitation, the fact that serving relative caregivers of children may be an optional service for the agencies, and the fact that no more than 10 percent of the funds can be used to help these caregivers, it is making a tremendous impact for the families.

LEGACY HOUSING LEGISLATION

A few years after the NFCSA, the first piece of housing legislation to help create affordable housing opportunities for grandparents and other relatives raising children passed the Congress. In 2003, Congress enacted three provisions of LEGACY — Living Equitably: Grandparents Aiding Children and Youth — into federal law as part of the American Dream Downpayment Act. The provisions call for the U.S. Department of Housing and Urban Development (HUD) to (1) develop and distribute grants for demonstration projects to create housing for grandparents and other relatives raising children; (2) provide training to housing officials on issues facing relatives raising children; and (3) work with the U.S. Bureau of the Census to conduct a national study of the housing needs of grandparents and other relatives raising children and make recommendations based on the study. Although this program has yet to be implemented by HUD, its passage is a significant first step to helping grandparents and other relatives and the children they raise with their housing needs.

THREE NATIONAL CENTERS DEVOTED TO THE FAMILIES

Three national centers are now

working to support grandparents and other relatives and the children they raise. GU was awarded two national innovative grants from the DHHS' Administration on Aging (AoA). This funding allowed GU to establish its National Center on Grandparents and Other Relatives Raising Children, which serves as an umbrella for all of GU's long-time work promoting supportive policies and programs on behalf of relatives raising children. In 2001, Georgia State University founded its National Center on Grandparents Raising Grandchildren, building on the success of its Project Healthy Grandparents. AARP's Grandparent Information Center continues its important work as a national center for grandparents seeking assistance in their caregiving roles.

ESSENTIAL STATE-LEVEL AND GRASSROOTS WORK

Much of what can be done to help the families has to be done at the state and grassroots level. Family law is the area of law that most impacts these families, and it is developed by the states. Since 1997, there has been an increase in the number of states that have innovative laws establishing educational and medical consent, open adoptions, de facto custodians, standby guardians, and subsidized guardianships.

The National Committee of Grandparents for Children's Rights (the National Committee) is an effective grassroots coalition of concerned grandparents, citizens, and agencies. Its mission is to advocate and lobby for substantial and urgent legislative changes that allow grandparents to secure their grandchildren's health and well-being.

The National Committee held the first GrandRally in New York. It was part of its tireless effort to enact a New York law that allows grandparents who have had physical custody of grandchildren for a certain period of time to seek legal custody, and provides that grandparents be notified when the state removes a child from a parent's home. The National Committee is working to ensure that GrandRallies are held in other state capitals and that laws similar to the one in New York are enacted in other states.

Kinship navigator programs are another exciting state-level development since 1997. They currently exist on a state-wide basis in New Jersey and Ohio, and are being explored elsewhere. These programs provide information, referral, and follow-up services to relatives raising children to link them to the benefits and services that they or the children need. They also sensitize agencies and providers to the needs of relative-headed families. A new piece of federal legislation was introduced in summer 2004 to promote the development of more of these programs.

Community Education & Media Advocacy

POSITIVE MEDIA PORTRAYAL

The media portrayal of relative-headed families has gone from frequently negative in 1997 to much more positive and strength-based in 2004. Hundreds of positive articles have appeared in national magazines like *Parade* and *Newsweek*, in newspapers such as the *New York Times* and *Wall Street Journal*, and in local papers around the country. There has been coverage on the *Today Show*, *National Public Radio*, and many other TV and radio shows. Award-winning documentaries have also highlighted the strengths and needs of the

families. *Legacy*, a powerful full-length documentary, tells the compelling story of an inner-city grandmother raising her five grandchildren. An outreach campaign around *Legacy*, which was conducted by Outreach Extensions, GU, and others, provided mini-grants to various sites around the country that help the families. The campaign also raised media and public awareness through a toolkit publication, and ultimately resulted in the piece of federal housing legislation known as LEGACY. *Big Mama*, another inspiring documentary, which won the Academy Award in its category, captures the love between an older grandmother and the troubled young grandson she is raising. *Why Can't We Be A Family Again?* chronicles the needs and strengths of a grandmother raising grandchildren, and the challenges of a mother who is addicted to drugs.

OUTREACH AND EDUCATION

In addition to media efforts, outreach and education has occurred through national conferences, Capitol Hill briefings, regional conferences, and satellite videoconferences. The Child Welfare League of America (CWLA) conducted a national kinship care conference in 1998, 2000, and 2002; Brookdale's RAPP continues to hold an annual technical assistance conference; GU has a track devoted to the families at its biennial international conference; and the Children's Defense Fund (CDF) devotes time during its national conferences to relative-headed families and their issues. In 2000-2001, GU and AARP collaborated to hold five regional conferences for caregivers, policymakers, programmers, lawyers, and other professionals. The University of Wisconsin Extension and Purdue University Extension held two national satellite videoconferences on the issues

facing these families. They reached over seven thousand caregivers and practitioners through their efforts. GU also worked to educate federal policymakers through the four briefings it held on Capitol Hill. Together these educational efforts have helped empower relative caregivers, train those working directly with the caregivers and children, and inform policymakers about the needs and strengths of the families.

One of the most exciting gatherings was the 2004 GrandRally to Leave No Child Behind® for grandparents and other relatives and the children they raise. CDF, AARP, CWLA, GU, and the National Committee organized the day. More than 850 caregivers and their supporters from 28 states came to Capitol Hill to tell lawmakers about the challenges they face and how to help them. It was an inspiring day that is being followed by state GrandRallies around the country.

HELPFUL PUBLICATIONS

Many targeted, useful publications have been created at the national, state, local and tribal levels since 1997. Numerous states and localities now have resource guides, which provide relevant, community-based information to the caregivers and children. Efforts to disseminate this information are now more effective than ever due to the growth of the Internet and websites developed for these families.

National nonprofit organizations have created publications for practitioners working with relative-headed families, in addition to the families themselves. The groups have worked collaboratively to create publications and to ensure that their publications are not duplicative of each other. GU and AARP worked together



to create two user-friendly law charts for the families and those working with them. In a unique effort, eight groups — CDF, AARP, Casey National Center for Resource Family Support, Brookdale, CWLA, GU, The Urban Institute, and Johnson & Hedgpeth Consultants — came together to produce State Fact Sheets on Grandparents and Other Relatives Raising Children, one for each state and the District of Columbia. Without designated funding or separate staffing, these various organizations worked collectively to compile state-specific information for the caregivers and those working with them; the eight groups continue to work together to update the information each year. Some of the state fact sheets are also available in Spanish, with more to follow.

Data Collection

NEW U.S. CENSUS BUREAU DATA

The only new question in the 2000 Census was a three-part question concerning grandparents raising grandchildren. For the first time, the Census asked specifically about these families, and as a result, there are useful

national numbers. The additional question and the release of the numbers caused press interest, which in turn increased awareness about the families. It was an exciting step. The three-part question has also been added to the American Community Survey (ACS), a national survey that is conducted annually. For the first time, policymakers, programmers, advocates, and all those interested in these families will have timely numbers available.

Along with its data collection efforts in this area, the Census Bureau also analyzed the data and produced several invaluable issue briefs concerning the families. These briefs have been widely disseminated and used. Other

researchers have used Census data to extrapolate additional numbers concerning the families' needs.

URBAN INSTITUTE WORK

The Urban Institute has collected helpful data about these families through its National Survey of America's Families (NSAF) and produced a number of reports. The Urban Institute also prepared the research review for the 1999 Report to the Congress on Kinship Foster Care. That Report was the culmination of work by DHHS' Children's Bureau and the first nationally appointed Kinship Care Advisory Panel.



III. Recommendations for Action

With these accomplishments in mind, 39 experts from around the country gathered for discussions about how best to continue helping grandparents and other relatives and the children they raise. The experts included grandparent caregivers, a teenager being raised by her grandmother, and professionals from many fields: medicine, psychology, law, social work, public relations, aging, and child welfare. Their work resulted in 28 recommendations for action. The word action is key.

None of these recommendations are purely academic; the participants intend that each recommendation be implemented at some point in the next five years. As of December 2004, work is already underway to implement some of the recommendations, while others are being discussed and funding possibilities explored. All of the recommendations, however, are open for any one or any group interested in helping with the national effort to enact this action agenda and help support grandparents and other relatives and the children they raise. GU is coordinating the national effort, so please consult its website or its staff for the latest information on how you can get involved. GU's contact information is at the beginning and end of this publication.

The symposium participants developed the recommendations for action based on discussions of nine areas critical to relative-headed families: legal relationship options and legal assistance; financial assistance; affordable housing; health and mental health; respite services; education and special education for the children; outreach and information; data collection; and messaging. The participants left the

symposium with refined and clarified collective goals and renewed resolve to continue their important work on behalf of grandparents and other relatives and the children they raise.

Overarching Recommendations

The symposium participants agreed on three recommendations, which they found overlap among all the topic areas and are of critical importance.

1. ARTICULATE A COMMON MISSION

Grandparents and other relatives raising children and those who work on their behalf must articulate a common mission. This mission must reflect an intergenerational approach to the families. It should focus on the strengths and needs of each generation — the children and their caregivers. The mission and resulting work must include use of the same statistics and identically defined terms, such as “kinship care.”¹ With a common mission, it will be easier to engage others in the movement on behalf of relative-headed families.

2. INCORPORATE CULTURAL COMPETENCY THROUGHOUT ALL ACTIVITIES

In light of the fact that grandparents and other relatives and the children come from many racial groups, ethnicities, and tribes, materials and staff must be sensitive to their various needs and strengths. For example, front-line child welfare, aging network, benefits, public housing, and judicial staff need to be trained in cultural sensitivity and inclusiveness for all types of families. Materials for relative caregivers must also be developed in the languages used in the

locality. Caregivers should be asked which format for the materials – e.g., video, audio, written — is most helpful. Warm and hot lines need to be staffed by individuals who know the relevant languages and understand the different groups served.

3. LINK THE FAMILIES TO SERVICES AND EDUCATE PROVIDERS

Relative caregivers and the children they raise must be connected to appropriate services, benefits, and assistance through effective outreach and information. Many relative caregivers lack awareness and knowledge about the array of benefits and services for which they are eligible. Kinship navigator programs, currently operating in New Jersey and Ohio, are a particularly useful outreach and information tool that needs to be implemented in each state. These programs link families to needed services and educate providers about the unique needs of relative-headed families.

Recommendations by Topic

For each of the nine topic areas, participants agreed on several recommendations that need immediate action.

Legal Relationship Options and Legal Assistance

4. SURVEY STATE LAWS, TRACK STATE LEGISLATION, CREATE MODEL LAWS AND PUBLICATION, AND PROVIDE TECHNICAL ASSISTANCE TO THE STATES

National nonprofit organizations should compile and track state laws and legislation designed for grandparents and other relatives raising children and provide technical assistance to those working to enact effective state laws. Knowledge of states' laws is critical to work on behalf of these families, because family law is the area of law that most frequently impacts them and it is primarily developed at the state level.

To this end, the national nonprofits should complete an initial survey of already enacted laws. Periodically throughout each year, they should track active state legislation. Knowing the universe of laws and legislation and how each state's is distinct will allow the national nonprofit organizations to effectively provide technical assistance to those wanting to enact useful laws. State-level advocates and policymakers often ask what other states have done in this area so they have a useful starting point to create legislation addressing their own state-specific needs.

After the initial survey of laws is completed, experts in these families' needs and strengths can work to create model laws in various areas by pulling the best from existing state laws. These models – one for each category of law, such as open adoption – can then be compiled in a publication that will be made available to all people interested in

creating supportive laws for relative-headed families.

With state legislative tracking in place and the model law publication in hand, lawyers who are part of GU's National Network of Expert Trainers and other policy experts can provide individual technical assistance to state- and grassroots-level advocates, policymakers, and professionals interested in enacting laws for relative-headed families. Other types of technical assistance may also be provided in the form of written materials and Internet chats with experts.

5. TRAIN KEY STAKEHOLDERS

Training attorneys, judges, and others working directly with relative-headed families about the families' needs and relevant laws and regulations is critical to ensuring that effective assistance is being provided. Otherwise, laws often go unnoticed by those who are expected to assist the families. National, state, and/or local organizations should partner to reach these professionals through newly designed trainings or through additions to existing trainings.

6. CREATE A CAREGIVER LEGAL GUIDE TEMPLATE

A template should be designed at the national level that states can use to tailor their own legal resource guides. Grandparents and other relatives raising children often acknowledge the value of legal resource guides that explain the specifics of that state's laws and provide resource information on benefits and public assistance and contacts for legal service providers. Some states have very helpful, well-written guides, others have not so useful ones, and some states have no guides whatsoever. The national

template, which will solve these inequities, should contain relevant federal law provisions and other information that is uniform across states. The template will also outline a framework for each state to complete with its own state law provisions and other resource information. Symposium participants particularly stressed the importance of a section on legal service providers. This section will be completed by the states and will list all legal aid clinics, Area Agencies on Aging (AAAs), university law school clinics, and other providers willing to assist these families with their legal issues.

Financial Assistance

7. EXPAND SUBSIDIZED GUARDIANSHIP PROGRAMS

Subsidized guardianship programs should be expanded in two ways: (a) these programs should offer assistance to children being raised by relatives outside the child welfare system; and (b) the federal government should allow states to use the primary source of federal funds for children in the child welfare system — Title IV-E of the Social Security Act — to finance guardianships for children exiting foster care to live with relatives. Currently, Title IV-E only funds subsidized guardianship programs for seven states that have waivers from the federal government. Of the 35 states and the District of Columbia that have subsidized guardianship programs, most use state and local funds. If Title IV-E could be used for all children exiting foster care into subsidized guardianships, the state and local funds could be used to provide subsidized guardianships for those relative-headed families outside the system.



8. PROVIDE TECHNICAL ASSISTANCE TO THE STATES

Technical assistance needs to be provided to states and localities on the federal requirements for public benefits, such as Temporary Assistance for Needy Families, as they impact relative-headed families. Many state and local benefits staff members seem unaware of these requirements as they affect these families. Technical assistance should include both short written materials and videos.

Affordable Housing

9. PROMOTE FUNDING AND IMPLEMENTATION OF LEGACY

The three provisions of LEGACY – Living Equitably: Grandparents Aiding Children and Youth – that were enacted into federal law in 2003 as part of the American Dream Downpayment Act need to be implemented. Affordable housing is a critical issue for relative-headed families, and the LEGACY provisions would greatly assist them. They call for

the U.S. Department of Housing and Urban Development (HUD) to (a) develop and distribute grants for demonstration projects to create housing for grandparents and other relatives raising children; (b) provide training to housing officials on issues facing relatives raising children; and (c) work with the U.S. Census Bureau to conduct a national study of the housing needs of relatives raising children and make recommendations based on the study. As of December 2004, HUD has failed to take significant steps to implement these provisions, primarily because of a controversy over the funding source. National nonprofit organizations and state and grassroots advocates need to educate HUD on the importance of implementing these provisions with existing funds, while working to increase the overall appropriation for elderly and low-income housing.

10. ADAPT THE ECHO HOUSING PROGRAM TO ALLOW ADDITION OF BEDROOMS

Many relative caregivers are homeowners, rather than renters, and their housing needs should also be addressed. Often relatives are living in homes that are too small to take in their grandchildren or other relatives. The problem could be fixed in part by adapting a federal housing program known as ECHO — Elder Cottage Housing Opportunity Program — to allow caregivers to add bedrooms to their homes to accommodate children they did not expect to raise.

11. HOLD A HOUSING SYMPOSIUM WITH KEY STAKEHOLDERS

In January 2005, GU will host a housing symposium with key stakeholders to explore ways to increase affordable, safe housing for relative caregivers and the children they raise. Key stakeholders will include decision-makers from national, state, and local housing developers and funders; public housing authorities, and HUD; the caregivers and children themselves; and others knowledgeable about the needs of these families.

Health and Mental Health

12. INCREASE ACCESS TO HEALTH AND MENTAL HEALTH SERVICES FOR CHILDREN AND CAREGIVERS

The Centers for Medicare and Medicaid Services within DHHS should issue a directive to the states about meeting the health and mental health needs of relative caregivers and the children they raise. It should issue the directive jointly with AoA, which has authority for implementation of the National Family Caregiver Support Program, and with the Administration for Children, Youth and Families. The directive should go to regional Medicare offices, state Medicaid and CHIP agencies, AAAs, and child welfare agencies. It should reaffirm the eligibility of children being raised by relative caregivers for Medicaid and CHIP and reinforce the importance of joint strategies across agencies and with community organizations to train staff about the needs of these families and to engage in outreach efforts on their behalf.

Relative caregivers and the children they raise, and those advocating for them, should join with others who are working in states to expand access to mental health screens, assessments, and necessary follow-up services and supports. They must gather basic data and stories about the need for these screens, assessments, and treatment. Expanding delivery models, promoting the use of screening tools in settings where children and caregivers already receive services — such as Head Start centers, school-based health clinics, and community mental health agencies — and promoting policies to increase access to mental health screens, assessment, and treatment are crucial steps. Special attention also should be given to helping caregivers recognize and seek help for their own and the children's mental health needs and to connect them to supports available through groups like the Federation of Families for Children's Mental Health, the National Alliance for the Mentally Ill Child and Adolescent Networks, and AAAs.

13. CONDUCT A NATIONAL CAMPAIGN FOR HEALTH AND MENTAL HEALTH COVERAGE FOR CHILDREN AND CAREGIVERS

Private foundations, in conjunction with organizations advocating on behalf of relative-headed families, need to support a national campaign to highlight the availability to these families of CHIP, Medicaid, and Medicare.

14. EXPAND AND IMPROVE OUTREACH ABOUT MEDICAL CONSENT LAWS

Health and other advocacy organizations that work to support grandparents and other relatives and the children they raise should work with public and private health and mental health providers to build support for

passage of medical consent and power of attorney laws in every state. These laws can make it easier for relative caregivers to obtain comprehensive health treatment for the children they are raising. The new laws need to include consent for all types of treatment, including dental, mental health, surgery, immunization, and regular check-ups. Unlike the current laws, new laws and amendments to existing laws should also require public health departments to do outreach to relative caregivers to inform them about these consent and power of attorney laws.

Respite Services

15. SUPPORT AND INCREASE RESOURCES FOR THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

National, state, and local groups working on behalf of relative-headed families should advocate to increase funding for the National Family Caregiver Support Program (NFCSP) and eliminate or lower its age restriction. This successful program funds AAAs to provide supportive services, including respite, to the families. The NFCSP, however, has limited funds and is currently restricted to grandparents and other relatives over age 60 who are raising children. Census data show that the vast majority of these caregivers, 71 percent, are under age 60 and therefore cannot be served by the NFCSP.² Lowering or eliminating the age restriction and increasing funding will help the program reach more relative caregivers and their families. If political and practical problems prohibit changing the age limitation in the NFCSP, a parallel program administered by another federal agency should be created for caregivers under age 60.

16. EXPAND COLLABORATIONS TO CREATE OR EXPAND RESPITE SERVICES

New collaborations among local, state, and national programs should be created so that cost-effective respite services for caregivers, youths, and teens can be developed and expanded. Partnerships among school systems, Indian tribes, Cooperative Extension Services, faith-based organizations, Big Brothers/Big Sisters, YM/YWCA's, Boys and Girls Clubs, and other national organizations can result in creative ways to address respite. They may pool funding or in-kind assistance, including staff and facilities. These collaborations can, in turn, be replicated nationwide.

Accessing Education and Special Education for the Children

17. EDUCATE AND TRAIN NATIONAL AND STATE EDUCATION GROUPS, SCHOOLS, AND CAREGIVERS

National nonprofit organizations working to support grandparents and other relatives raising children need to work in conjunction with the U.S. Department of Education to inform education groups, schools, and the caregivers themselves that special education services and parental activities are open to relative-headed families. The campaign will focus on raising awareness of the federal requirements for inclusion of relative caregivers in parental activities and special education services, including the Individualized Education Plan (IEP) process. Many states and localities incorrectly exclude caregivers from parental activities and IEPs by requiring guardianship, legal custody, or the fulfillment of other legal hurdles that are

not in federal law. The goals of this campaign will be to increase access to special education services for the children in these families, and to include caregivers in activities, like parent-teacher conferences, so they can participate in the education of the children they are raising.

18. PROMOTE OUTREACH AND ADVOCATE FOR EARLY INTERVENTION AND PRESCHOOL SERVICES

At the local level, representatives from early childhood programs, schools, and mental health centers should work together with relative caregivers, so they can help caregivers access special education and mental health services for the infants, toddlers, and preschool-aged children they raise. In every state, early intervention services and preschool services are available for qualifying children through the federal Individuals with Disabilities Education Act (IDEA). A grassroots outreach campaign will raise awareness about these services and increase access for children being raised by relatives.

19. EXPAND AND IMPROVE OUTREACH ABOUT EDUCATIONAL CONSENT LAWS

Advocacy organizations working to support grandparents and other relatives and the children they raise should work in conjunction with state departments of education, state and local boards of education, school districts, and individual schools to build support for passage of educational consent and power of attorney laws. These laws can make it easier for relative caregivers to enroll the children tuition-free in public school. Unlike the current laws, new laws and amendments to existing laws should also require school districts to do outreach to

inform relative caregivers about educational consent and power of attorney laws.

Outreach and Information

20. CREATE CONSUMER-ORIENTED INFORMATIONAL TOOLS FOR TARGETED AUDIENCES

Additional accurate, consumer-oriented information tools should be created in print and in electronic/Internet form to inform grandparent and other relative caregivers and refer them to information at the national, state, tribal, and local levels. This information should be tailored to each particular audience, and made available in their language. All materials need to be culturally sensitive and updated regularly. If written language is not effective for a particular audience, alternative approaches, such as videos, should be explored.

21. COORDINATE SHARING OF SUCCESSFUL OUTREACH TOOLS

National nonprofit organizations working to support relative-headed families should organize a method for the families themselves — in addition to national, state, and local organizations whose work impacts them — to share information and network. Efforts should be made to share best practices and avoid “reinventing the wheel” when creating resource guides, warm and hot lines, outreach events, and other outreach tools and mechanisms.

22. CONDUCT A COORDINATED NATIONAL OUTREACH EVENT THAT REACHES THE LOCAL LEVEL

The national nonprofit organizations working to support these families need to organize an integrated collaborative national outreach event that enables caregivers and those supporting them to share information on successful policies, programs, practices, and strategies. This event will be implemented in reciprocity with local efforts utilizing outreach mechanisms.

23. DEVELOP GRASSROOTS OUTREACH CAMPAIGNS

Grassroots-level direct outreach campaigns should be developed to reach relative caregivers in their local communities: their cities, but most importantly their neighborhoods. This recommendation will be best accomplished by increasing the delivery of information through neighborhood and community level organizations, including faith-based organizations (such as churches, synagogues, mosques, and temples), schools, doctors, courts, support groups, and service organizations.

Data Collection

24. EXPAND THE AMERICAN COMMUNITY SURVEY (ACS) TO INCLUDE INDICES FOR GRANDPARENT- AND OTHER RELATIVE-HEADED HOUSEHOLDS

A working group of key researchers should be convened to develop additional questions about grandparent- and other relative-headed families to add to the ACS, a national survey conducted on an annual basis by the U.S. Census Bureau. Currently, the ACS asks a useful, but limited three-part question about

grandparent-headed families only. More data on the grandparent-headed families is needed, as are questions about the other relatives, such as aunts and uncles, who are raising children.

25. CREATE A CLEARINGHOUSE FOR RESEARCH PERTAINING TO GRANDPARENT- AND OTHER RELATIVE-HEADED HOUSEHOLDS

A national nonprofit organization should house a central clearinghouse for research concerning grandparents and other relatives and the children they raise. This clearinghouse would contain national, state, tribal, and local research. A central clearinghouse would assist policymakers, program developers, and state coalitions of grandparents and other relative caregivers to use the latest knowledge to create effective programs and policies for the families.

Messaging

26. HOLD TWO COMMUNICATIONS SYMPOSIA

The national nonprofit organizations working to help grandparents and other relatives and the children they raise should work with professional communications and public opinion experts to conduct two communications symposia. The first symposium will focus on developing a consistent message and effective materials about relative-headed families. The second will broadly engage the media, perhaps by holding it as part of an existing media conference.

27. DEVELOP AND NURTURE CHAMPIONS AND SPOKESPERSONS

At the national, state, tribal, and local levels, champions and spokespersons need to be identified, developed, and nurtured. Relative caregivers and children who are being raised or have been raised by relatives are the most effective messengers about these families' needs and strengths. State, local, and tribal groups can identify their own spokespersons. A central database should be created containing these names so that the media and others building support for the families can be directed to the relevant people in their area. National nonprofit organizations also can work collaboratively to approach a national, high-profile spokesperson to effectively represent relative-headed families.

28. ESTABLISH NETWORKING MECHANISMS FOR NATIONAL ORGANIZATIONS TO SHARE COMMUNICATIONS STRATEGIES

Organizations and individuals working for relative-headed families should monitor and regularly discuss the use of consistent communications strategies. This work can be done through existing forums, like GU's Grandparent Advisory Group meetings and various national, state, and local conferences that focus at least in part on these families' concerns. National organizations engaged in work to help relative-headed families should also conduct quarterly conference calls between their own communications staff, advocates, and caregivers, to encourage joint media efforts and explore creative, new approaches to public messaging.

Areas for Future Work

As the participants reviewed their collective recommendations, they realized that two ways to improve the lives of children and their relative caregivers had not been sufficiently explored. The first is making clear how the needs of children being raised by relatives in the foster care system differ from those outside the system. The second is the need for increased awareness of and support for birth parents. Symposium participants agreed that both of these areas should be considered when implementing each of the above recommendations. They further agreed to collectively examine these areas through other forums, such as a working group to develop recommendations concerning relative foster care.

IV. Background

The recommendations in each of the nine topic areas above — legal relationship options and legal assistance; financial assistance; affordable housing; health and mental health; respite services; education and special education for the children; outreach and information; data collection; and messaging — emanated from symposium discussions of corresponding background papers prepared by experts in the field and distributed in advance to symposium participants. Those papers covered topics critical to grandparents and other relatives raising children. The papers helped focus and stimulate good discussions and thoughtful recommendations. This section begins with a brief look at the demographics, causal factors, and general issues facing relative-headed families. It then includes the discussion of needs, current responses, and areas of unmet need from each of the background papers.

Overarching Background

DIVERSE FAMILIES

Throughout the U.S., about 4.4 million children are living in households headed by grandparents. An additional 1.5 million children are living in households headed by other relatives, such as aunts or uncles. More than 2.5 million of these children live in grandparent- and other relative-headed households with no parent present.³

The children in these families span the racial, ethnic, socioeconomic, and geographic spectrum. Data show that more Whites are being raised by grandparents and other relatives than Blacks, but higher percentages of Black children are being raised by their grandparents and other relatives. A child

who lives with a grandparent or other relative as head of the household is more likely to be living in poverty than a child whose parent is head of the household; about 16 percent of children whose parents are head of the household live in poverty, whereas approximately 21 percent living with grandparents and almost 25 percent living with other relatives do. Children are living with grandparents and other relatives throughout the U.S., but the highest percentage is in the South.⁴

As for the caregivers, their poverty status, race, ethnicity and — of course — where they live mirror that of the children in their homes. Twenty-nine percent of grandparent caregivers are Black; 17 percent are Hispanic; 3 percent are Asian; 2 percent are American Indian and Alaska Native; and 47 percent are non-Hispanic White. Nineteen percent of grandparent caregivers have incomes below the poverty level.⁵

Thirty-nine percent of grandparent caregivers have raised their grandchildren for five or more years. Seventy-one percent are under age 60.⁶

CAUSAL FACTORS

The factors causing these caregivers to raise children can happen to anyone, and, for that reason, there is this great diversity among the families. Some of the most common factors include parental substance abuse, military deployment, incarceration, death, poverty, HIV/AIDS, teenage pregnancy, and mental illness.

MOST FAMILIES NOT IN THE FOSTER CARE SYSTEM

The vast majority of relative-headed

families are not in foster care in the formal child welfare system. Only about 131,000 of the children being raised by grandparents and other relatives are in foster care.⁷ Although this number represents about one-fourth of all children in foster care, it is only about one-eighteenth of all the children being raised by grandparents and other relatives with no parents in the home. If less than half of the 2.5 million children being raised by relatives with no parents in the home were to enter foster care, they would completely overwhelm the system. Translated to dollars, if even one million children being raised by relatives (less than half) were to enter foster care, it would cost taxpayers more than \$6.5 billion each year.⁸

For those families in foster care, access to services, such as school enrollment, is typically easier than for those not in the formal system. The state generally has legal custody of the children in foster care, so caseworkers and judges ease entry into schools and receipt of medical care. In order to support the caregivers outside the system and their tremendous contributions towards keeping families together, access to services needs to be improved dramatically.

not want to go through the expense, delay, and trauma of suing the birth parents for such a relationship. Without a legal relationship, caregivers may have trouble enrolling the children in school, obtaining special education services, consenting to medical and mental health treatment, getting financial assistance and health insurance coverage, and finding affordable housing suitable for the children. Alternatives — like educational and medical consent laws — for those families not wanting legal relationships need to be expanded throughout the country.



MANY LACK LEGAL RELATIONSHIPS AND HAVE PROBLEMS ACCESSING SERVICES

One of the reasons access issues are prevalent outside of foster care is because many of these children do not have a legal relationship, like legal custody or guardianship, with their caregivers. They lack such a relationship for many reasons. Often their caregivers may have difficulty finding an affordable lawyer or they may

Legal Relationship Options and Legal Assistance

NEEDS

To obtain a legal relationship to the children they are raising, grandparents and other relatives face different concerns than non-related caregivers raising children. For example, a grandmother may not want to sue her daughter for adoption, thereby causing the birth mother to become the sibling and the grandmother to become the parent. Moreover, some cultures do not believe in adoption, but rather have a tradition of caring for extended families.

Even to obtain a less permanent option than adoption, the families must go to court. The U.S. Supreme Court has long found that parents have a fundamental right to make decisions concerning their children's care, custody, and control. Because of this right, in order for a grandparent or other relative to be awarded legal custody, guardianship or adoption of a child, the first step is to prove that the parent is unfit. This is a significant hurdle that can be very threatening to family dynamics.

Some states are creating legal relationship options that address these concerns. Open adoption, standby guardianship, and de facto custody are a few of these innovations. This section describes the various options. It also discusses the difficulties in obtaining affordable legal assistance, once a decision is made that a legal relationship is needed or wanted.

Please note that there are potential financial ramifications with each legal relationship option. Some of those

consequences are discussed below in the financial assistance section.

CURRENT RESPONSES

RELATIVE FOSTER CARE

Relative foster care is not an option for all or even most grandparents and other relatives raising children. A child must be removed from the birth parent's home for abuse or neglect before a family member can become a relative foster parent. Sometimes the state places the child with the relative and then completely steps out of the picture or provides very little supervision or funding. In other instances, the state may decide to obtain legal custody of the child and license the relative to care for the child. Although licensed relative foster parents typically receive monthly financial assistance, some relatives do not want to become licensed. They may not want to be subject to oversight by a court and government agency and face the possibility that the child could be removed at any time and placed elsewhere.

LEGAL RELATIONSHIP OPTIONS

The legal relationships presented below may be options for children exiting foster care or outside of foster care. For those families who do not want to establish a legal relationship, consent and power of attorney laws are available in several states. All of the following options are presented in general terms. Because this area of the law is created at the state level, how these options are defined and which ones are available can vary significantly.

ADOPTION

One of the most critical differences between adoption and other options is

that it severs all of the birth parents' rights and responsibilities. The relative caregiver becomes the parent in the eyes of the law. This fact makes access to services on behalf of the child much easier. It also means that the birth parents cannot simply reappear one day and go to court to reclaim parental rights and responsibilities.

Open or Cooperative Adoption: About one-third of the states have this option available.⁹ As part of an adoption, the relative caregiver, birth parents, and child develop an agreement for post-adoption contact with the birth parents. In some states, siblings may also be given contact privileges through the agreement. If a party breaches the agreement's terms, courts can order remedies to enforce it. Invalidation of the adoption, however, is never a possible remedy.

GUARDIANSHIP

The most significant distinction between adoption and guardianship is that guardianship does not sever the birth parents' rights and responsibilities. Parents typically retain the rights to visit the child and consent to adoption and/or name change; they also keep the obligation to financially support the child. The guardianship designation allows caregivers to access services on behalf of the child that otherwise might prove unattainable. Unlike an adoption, the guardianship can be terminated if the parents go back to court and ask.

Standby Guardianship: This option exists in about 18 states.¹⁰ It allows a terminally ill parent to name a standby guardian to take over the day to day care of a child in the event of a triggering event, such as incapacity, without the parent's rights being terminated. These laws were originally designed in response

to the AIDS crisis.

LEGAL CUSTODY

Legal custody is a similar status to guardianship, but is usually granted by a different court that has different procedures. Depending on the state, the status of "guardian" may give access to more services and rights than that of "legal custodian." Consider, for example, how many times one reads or hears the phrase "parent or guardian" without any mention of "legal custodian."

Because of difficulties with bringing legal custody cases and proving that parents are unfit, some states have enacted innovative laws that may help relative caregivers. These laws essentially provide that if a relative has been raising a child for a significant period of time, the first step in proving his or her case is met. Then, the relative can go on to prove that he or she should be awarded legal custody because it is in the child's best interests.

De Facto Custody: Kentucky was a pioneer in this area when it passed the nation's first de facto custody law in 1998.¹¹ A de facto custodian is defined as the primary caregiver and financial supporter of a child who has resided with that person for at least (1) six months if the child is under age three, and (2) one year if the child is at least age three. If the judge finds that the person is a de facto custodian, he or she has the same standing as a parent in the legal custody dispute. Custody is then determined based on the best interests of the child. There is no need to prove that the parents are unfit. Indiana has a very similar law.¹² Minnesota also has a de facto custody law, but it requires that the caregiver prove there was a "lack of demonstrated consistent participation by a parent,"



which essentially means they are unfit.¹³

New York's Approach: New York's new law does not provide for de facto custodians, but it defines a previously undefined term of physical custody that makes it possible for a relative to seek legal custody.¹⁴ A New York trial judge in a legal custody dispute between a parent and a non-parent must find an "extraordinary circumstance" before deciding legal custody. Extraordinary circumstances include an extended disruption of custody. The length of the disruption had not been defined prior to this law. This led to different outcomes depending on the judge. The new law defines the disruption to be at least two years. Therefore, if a child has resided in a grandparent's home for two or more years, judges must decide legal custody based

on the best interests of the child. For less than two years, judges have discretion to find an extended disruption.

CONSENT AND POWER OF ATTORNEY LAWS

In some states, relative caregivers who do not want or have a legal relationship to the children in their care have laws that make it possible to access medical treatment and educational services on behalf of the children without going to court. About 17 states have educational consent laws or some form of open enrollment law, which effectively allow children being raised by relatives to attend public school free of charge.¹⁵ More states, about half, have some form of medical consent law.¹⁶ Both types of laws differ in various ways, including whether the parent must give consent authority in writing. The medical consent laws also vary in terms of what types of treatment are covered. Some laws only include immunizations or physical health care, whereas others, like California's, include mental health and dental care.

Another option for those caregivers without a legal relationship may be a power of attorney. Parents complete a form or handwritten document that states what type of authority they are giving the caregiver. Some states allow parents to use power of attorney to confer school-related and medical decision-making authority. Tennessee recently enacted such a power of attorney law.¹⁷ Like consent laws, these documents can be

easily revoked by the parents; furthermore, institutions, such as schools and hospitals, may not accept them despite the existence of a law stating they should.

LEGAL ASSISTANCE

Once a decision is made that a legal relationship is needed or wanted, finding an affordable lawyer can be difficult, if not impossible. There are some no- and low-cost alternatives available. AAAs, legal aid clinics, local law schools, and bar associations may provide legal assistance. Referral services may be available through AARP Legal Services Network and local programs, including support groups. A few states have kinship navigator programs, which provide referral services and legal assistance through partnerships with local law schools and legal aid clinics. However, the availability of these direct and referral services, like the legal options, varies dramatically from state to state.

Another problem frequently exists with legal assistance. Many judges and lawyers do not know about laws in their own states that are specifically directed at grandparents and other relatives raising children. Also, these professionals can be unaware of and/or insensitive to the needs of relative-headed families.

NEEDS NOT ADDRESSED

The innovative legal options available in some states are useful first steps. However, many states still do not have the legal alternatives that the families need. For example, many states lack comprehensive consent laws that would allow relatives who do not want a legal relationship to access necessary services on behalf of the children. Despite the need, there is no clear guidance at the national level to provide models to states interested in enacting these laws. If useful laws do exist in a particular state, lawyers and judges might not know they do. Educating these professionals is very important, as is making more lawyers available to the families through referral services and volunteer activities.



Financial Assistance

NEEDS

Sometimes a grandparent or other relative caregiver is retired and living on a fixed income. Sometimes he or she is working, but needs help finding and paying for quality child care. Relative caregivers almost never anticipated that they would be raising the children in their care and thus may need financial assistance to meet the needs of the children, at least initially. On the other hand, not all relative caregivers need financial assistance.

CURRENT RESPONSES

There are several potential sources of financial assistance for relative caregivers: (1) Temporary Assistance for Needy Families (TANF);¹⁸ (2) foster care; (3) adoption assistance; (4) subsidized guardianships; and (5) child support payments. Each of these sources of support has advantages and disadvantages. Caregivers, as well as those who work with them, need to evaluate which options are available in a given case and which best meet the needs of a particular family. In addition to these supports, social security benefits or tax credits may be available to help certain relative-headed families.

TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF)

As the name suggests, Temporary Assistance for Needy Families (TANF) provides temporary assistance to families with very low incomes. Each state determines the income eligibility for its TANF program. States also determine the amount of assistance to be provided to

families.¹⁹ There are two basic types of grants a relative caregiver can receive under TANF. The first is a “child-only” grant, which considers only the needs and income of the child. Because few children have income of their own, almost all relative caregivers can receive a child-only grant on behalf of the children in their care. Unfortunately, child-only grants are typically quite small and may be insufficient to meet the needs of the child. In 2001, the average grant was about \$7 per day for one child, with only slight increases for additional children.²⁰

The second type of TANF grant for which relative caregivers may be eligible is a “family grant.” One of the purposes of TANF is “to provide assistance to needy families so that children may be cared for in their own homes or in the homes of relatives.”²¹ Thus, relative caregivers who meet the state’s income criteria are eligible to receive a grant that addresses their needs, as well as those of the child. Although these grants are larger than the child-only grants, federal law imposes a 60-month time limit and work requirements on such grants.²² Thus, TANF family grants may not be appropriate for retired relative caregivers or for caregivers who will need assistance for more than 60 months.

FOSTER CARE PAYMENTS

In addition to TANF, grandparents and other relatives caring for children may be eligible for assistance through the child welfare system. In most states, relative caregivers can receive foster care payments on behalf of the children in their care if the children are involved in formal foster care. However, some children are ineligible for such help because grandparents or other relatives stepped in

before the child was abused or neglected and thus kept the child out of foster care. Additionally, foster care is intended to be temporary, while permanent plans are made for the child in accordance with the Adoption and Safe Families Act of 1997 (ASFA).

Foster payments are typically higher than the TANF child-only payment a grandparent or other relative could receive on behalf of the child in their care. In fact, the foster care payment is almost always higher than a TANF family grant. Foster payments also multiply (e.g. double, triple) as the number of children cared for increases.

States or counties make foster care payments to foster parents on behalf of children in their care. Sometimes the payments are funded solely with state or county dollars. Sometimes the child is eligible for the federal foster care program, and states may seek federal funds to cover a portion of the costs associated with those children. Generally, federal foster care payments under Title IV-E of the Social Security Act are available only for very poor children.²³

Eligibility for the federal foster care program is important because it may impact the amount of financial assistance available to relative caregivers. Under federal law, a relative who is a licensed foster parent for a child who is Title IV-E eligible must receive the same foster care payment as a non-related foster parent.²⁴ All states, except California and Oregon, use state or local funds to provide foster care payments to licensed, relative foster parents caring for children who do not meet the IV-E income criteria. In addition, states may provide assistance, with state or local funds, to unlicensed relatives

caring for children in foster care. In some states, however, unlicensed relative foster parents are simply referred to TANF for assistance.²⁵

ADOPTION ASSISTANCE PAYMENTS

Adoption assistance payments may be available to relative caregivers who choose to adopt the children in their care. All states provide adoption assistance on behalf of certain children who are adopted from the child welfare system.²⁶ States may receive federal reimbursement, through Title IV-E, for a portion of the adoption assistance payments made on behalf of very poor children who have “special needs.”²⁷ “Special needs” are defined by the state, but generally include characteristics or conditions that make it difficult to place the child with adoptive parents without a subsidy.²⁸ As with foster care, Title IV-E eligibility can make a difference in the amount of the subsidy available and in whether other benefits, like eligibility for Medicaid, come with the subsidy.

SUBSIDIZED GUARDIANSHIP

For relative caregivers who do not want to adopt the children in their care, legal guardianship can provide the rights and authority needed to properly care for children.²⁹ Guardianship itself does not address the need for financial assistance,³⁰ but 34 states and the District of Columbia now offer financial assistance for guardians.³¹

Subsidized guardianship programs vary from state to state. Most are available only for relatives who obtain legal guardianship of children who have been in the foster care system for some period of time. These programs typically require that reunification and adoption be

ruled out as options before guardianship assistance is available. Subsidized guardianship programs may require criminal background checks and home studies. In some states, subsidies for guardians are available only when the children are of a certain age. In a few states, subsidized guardianships are available only for children with special needs or for children who meet certain income tests. Typically, subsidized guardianships are subject to only minimal oversight, such as an annual report to the court or an annual meeting with the child welfare agency. The amount of the subsidy varies from state to state. Usually, the subsidy amount is somewhere between the amount of a TANF child-only grant and a foster care payment.³² Federal dollars are generally not available to provide guardianship subsidies, but seven states have waivers from the federal government to use Title IV-E funds to provide such subsidies.

CHILD SUPPORT PAYMENTS

Until a court has terminated parental rights, a parent generally remains financially responsible for his or her children. Every state has a child support enforcement agency that typically helps custodial parents collect child support from non-custodial parents. However, this office can also assist grandparents and other relatives who wish to obtain child support on behalf of the children in their care.³³ The amount of the support is based on the needs of the child and on the resources and abilities of the parent(s) to pay. Some relative caregivers do not want to pursue child support because they are uncomfortable initiating what can become an adversarial process that might result in the child's parent(s) having their driver's license or business license

revoked or being incarcerated for failure to comply with child support orders. Caregivers may also fear that initiating child support collection will provoke the parents into a child custody battle. Sometimes grandparents and other relative caregivers who are caring for children because the children's parents were violent are fearful that the child support process will lead to additional violence. These relatives may choose not to pursue child support collection.

However, when grandparents or other relatives are receiving TANF benefits on behalf of a child, they must assign their rights to child support to the state. In most states relative caregivers must cooperate with the child support agency unless they can demonstrate that seeking child support is potentially harmful and they have "good cause" not to cooperate.³⁴ In such cases, child support collection will not be pursued or will be pursued in ways that protect the safety of the caregiver and the children. Relative caregivers who receive federally funded foster care payments may be required by the child welfare agency, where appropriate, to sign over their rights to child support and to work with the child support agency.³⁵ Here too, though, good cause exceptions may be made. Under current law, most of the child support collected for children receiving TANF or foster care payments is kept by the state to recoup the costs of providing assistance. However, states may pass through to relative caregivers any or all of the child support collected. Generally, only a modest amount is passed through, often no more than \$50 per month.

SOCIAL SECURITY BENEFITS

The Supplemental Security Income (SSI)

program provides benefits for individuals who are elderly, blind or have disabilities and who have limited income and assets. SSI is an important source of assistance for grandparents and other relative caregivers satisfying these criteria. This program, administered by the U.S. Social Security Administration (SSA), also provides cash benefits to children who are blind or have other serious disabilities. For a child to qualify for benefits, he or she must be under 18 and meet the SSI disability, income, and asset criteria. Under a recent U.S. Supreme Court decision, *Washington v. Keffler*,³⁶ child welfare agencies that petition for SSI on behalf of children in their custody who are living with a relative foster parent can, in certain circumstances, receive and keep all or a portion of the child's SSI payments to cover the costs of providing for the child.

Children being raised by grandparents may be eligible for social security dependent benefits under *Old-Age Survivors and Disability Insurance (OASDI)* if the child's parent is collecting retirement or disability insurance benefits or if the parent was fully insured at the time of his or her death. Generally, these benefits are available for children under age 18. Grandparents and other relatives can apply for benefits on behalf of the child based on the work record of the child's parent. If a child is not receiving dependent benefits based on a parent's work record, the child may qualify for dependent benefits based on his or her grandparent's work record. Generally, the grandparent must be raising the child because the child's parents are deceased or disabled. Additionally, the child must have begun living with the grandparent before the age of 18 and have received at least one-half of his or her support from

the grandparent for the year prior to the grandparent becoming eligible for benefits. Children raised by relatives other than grandparents may qualify for dependent benefits only if they are legally adopted by the caregiver.

TAX CREDITS

The *Earned Income Tax Credit (EITC)* may be available for certain low or moderate income relative caregivers who are working. This tax credit is refundable so that even workers who do not earn enough to pay taxes can get cash from the U.S. Internal Revenue Service (IRS). The amount of the credit depends upon the income earned and upon the number of qualifying children in the family. Qualifying children include a worker's sons, daughters, stepchildren, grandchildren, brothers, sisters, stepbrothers, and stepsisters, as well as any descendants of these relatives. Such children must have lived with the working relative for more than half the year or have been placed with this relative by a child welfare agency. The children must be under age 19 or under age 24 if they are full-time students, although children of any age who have permanent disabilities are considered qualifying children.

The *Child Tax Credit* of \$1,000 per child may also be available to some relative caregivers. This credit can generally be claimed for sons, daughters, stepchildren, grandchildren, brothers, sisters, stepbrothers, stepsisters, as well as any descendants of these relatives, who are under age 17 and are dependents of the taxpayer. Unlike the EITC, the child tax credit is only partially refundable.

The *Child and Dependent Care Tax Credit* may be available to grandparents and

other relative caregivers who incur child care expenditures in order to work. This credit is generally available for dependent children under age 13 or older children who are not mentally or physically able to care for themselves. The credit is based on actual child care expenditures, up to a certain maximum. This credit is not refundable and thus will be of little use to relative caregivers who do not pay taxes.

In addition to these federal tax credits, some state and local jurisdictions also offer similar tax benefits.

NEEDS NOT ADDRESSED

Although there are several potential funding streams to which grandparents and other relatives can turn for financial assistance in raising children, two of the major programs (TANF and foster care) were not designed with relative caregivers in mind. For example, when the TANF program was created in 1996, the rhetoric was about getting able-bodied parents to work, not requiring a retired grandmother to go back to work so that she can receive financial assistance to care for a child she is keeping out of the foster care system. The notion of offering temporary support in such cases is contrary to the ASFA goals of building safe, loving, permanent homes for children.

Similarly, foster care was not designed for relative-headed families. Unlike non-related foster parents, grandparents and other relatives often have no warning

before the children are on their doorstep. While safety concerns are equally important for children living with relatives and non-relatives, conducting background checks, home studies, training, and other licensing requirements all take time and can delay access to financial supports for relatives suddenly caring for children. In addition, as with TANF, foster care is intended to be temporary, not permanent.

Subsidized guardianship programs can often be used to bridge the gap between foster care and TANF. The financial support offered in these programs may create a realistic alternative to TANF, foster care, or adoption, one that provides stability and permanency for the child, while also providing flexibility for the caregivers if the situation of the child's parent improves. At the present time, however, most of the subsidized guardianship programs are available only for children who have been in foster care. They do not help grandparents and other relatives who have intervened before abuse and neglect occurred. Finally, even when financial assistance is available through TANF, foster care, adoption assistance, subsidized guardianship, child support, tax credits, or social security, relative caregivers often do not know the supports are available, nor do they know how to access them.

Affordable Housing

NEEDS

Obtaining safe and affordable housing is a serious concern for many grandparents and other relative caregivers, especially older ones who did not expect to be raising children in this stage of their lives. Many of these caregivers live on fixed incomes, often in small apartments and houses that are not suitable for children. If they live in public senior housing, where children are not allowed, they are often subject to eviction if the children are discovered.

While few studies have been completed on the housing issues affecting grandparents and other relatives raising children, data extrapolated from the 2000 Census provides the following national statistics on grandparent caregivers who were renters:

- Over 26 percent of grandparent caregivers were renters. (617,569)
- 17.4 percent spent 50 percent or more of their income on rent.
- 48.1 percent spent 30 percent or more of their income on gross rent (includes rent and estimated monthly costs of utilities and fuel paid by renter).
- 28.2 percent were living in overcrowded conditions (more than one person per room,—by Census definition).
- More than 8,000 were without some essential kitchen or plumbing facilities.
- More than 60 percent of qualifying renters were not receiving housing subsidies.³⁷

LACK OF HOUSING APPROPRIATE FOR INTERGENERATIONAL FAMILIES

The lack of affordable housing is an issue for many Americans, but grandparents and other relatives face certain unique barriers related to their particular circumstances, varied ages, and the usually unexpected experiences which led to their family arrangement. Like many in need of housing, grandparent- and other relative-headed families have been affected by the substantial decrease in the availability of quality, affordable housing units during the last decade.³⁸ The dearth of reasonably priced, large, three or more bedroom units is an increasing problem as the public housing system increasingly relies on the Section 8 voucher program for the provision of housing to low-income people.³⁹ When assisted housing is available, often it is not designed with relative-headed families in mind and does not include special features for both older people and children. Furthermore, available housing rarely has services to help with the multiple barriers grandparent- and other relative-headed families often encounter.

OCCUPANCY STANDARDS

HUD standards indicate that, as a general rule, an occupancy policy of two persons per bedroom is reasonable; however the policy allows some flexibility and takes into account special circumstances. Policies that appear to be aimed at limiting the total number of children rather than the total number of people are suspect.⁴⁰ Relative caregivers who are foster parents may face even stricter occupancy standards due to child welfare requirements. For caregivers living in Section 202 elderly housing, which limits the maximum size of housing units to two bedrooms, it may be difficult to accommodate children. These families,

however, should not be faced with immediate eviction if the children's presence puts them in violation of the occupancy standards. Section 202 regulations indicate that the rental assistance payment with respect to the relevant unit will not be reduced or terminated until the eligible household has been relocated to an appropriate alternate unit.

BARRIERS RELATED TO MISPERCEPTION OF FAMILIAL STATUS

While there are some statutory and policy obstacles facing grandparent-headed families, many of the real barriers are caused by lack of training and education. Many housing providers fail to understand the needs of these families, and staff often unwittingly misinterprets HUD policy related to familial status because of notions of what constitutes a family. As a result, otherwise eligible families are often turned away by public housing authorities.

Many housing authorities are unlawfully requiring relative caregivers to have legal custody or guardianship of the children in their care in order to qualify for assisted housing. The Fair Housing Act prohibits discrimination on the basis of familial status. This protection is not limited to individuals who have legal custody of the children in their care. It includes the designee of a parent or other person with custody. Furthermore, analyses of HUD housing programs by the National Housing Law Project, memos from regional HUD offices, and at least one federal court decision, *Hann v. Housing Authority of Easton*, have found restrictive definitions of family to be in violation of the Fair Housing Act. To make the policy clear to local housing actors, local jurisdictions should address grandparent

custody issues in their public housing administrative plan, Section 8 administrative plan, and consolidated plan.⁴¹

The Section 8 Family Unification Program (FUP) is another housing opportunity that is underutilized by grandparent-headed households because of the interpretation of what constitutes a family. FUP is a program that gives priority Section 8 vouchers to families who are at risk of losing custody of their children because of their housing situation. Currently grandparent- and other relative-headed families are not consistently treated as families who would qualify for this program. Clarification that this program should allow grandparents and other relatives raising children to use these vouchers, regardless of whether they have formal legal custody of the children, would help the program continue to meet its goal of preventing children from entering foster care due to the housing conditions of a family member.

Regardless of the specific language of FUP and other housing laws, grandparents and other relatives will continue to be unlawfully turned away from existing affordable housing opportunities unless frontline housing staff and the relative caregivers themselves are educated on the legal custody issue as it relates to assisted housing.

AGE RESTRICTIONS

Also among concerns is the perception that children are not allowed in elderly housing. Despite the fact that the Fair Housing Act prohibits discrimination against families because of children, there is widespread belief, even among housing experts, that children are barred from Section 202 elderly housing.

However, the HUD *Handbook of Occupancy Requirements of Subsidized Multifamily Housing Programs* explicitly states that owners may not exclude otherwise eligible elderly families with children from elderly properties. It further directs that owners cannot exclude families with children or develop policies with the purpose or effect of prohibiting children.

The only exception to this policy comes from the Housing for Older Persons Act, which allows individual development owners or managers of privately owned seniors-only housing buildings to legally exclude families with children in buildings where at least 80 percent of the units are occupied by at least one person who is 55 years of age or older. In such cases, owners of these buildings are not required to make them child-free developments, but do have the choice to legally exclude children.

Despite the flexibility of HUD's policy related to children in senior housing, grandparents and other relatives raising children continue to fear eviction when children come to live with them in senior housing. In essence, many of the age restriction barriers are due to ignorance of actual policy, rather than the HUD policy itself.

CURRENT RESPONSES

The first housing complex specifically designed for grandparents and other relatives raising children opened in October 1998 in Boston, Massachusetts, in response to the need for affordable housing for these families. Developed by two local nonprofit organizations,⁴² GrandFamilies House was created through a mixture of public and private financing, including Section 8 vouchers and federal HOME housing program funds.

GrandFamilies House comprises 26 two, three, and four bedroom apartments that have safety features for both older adults and children and extensive communal program space. The House offers an on-site resident services coordinator, a live-in house manager, education services, and assistance accessing and traveling to outside services. Through a partnership with YWCA-Boston, on-site preschool and school-age programs are offered in addition to educational workshops, intergenerational community events, holiday celebrations, and respite outings for grandparents.

Since the development of GrandFamilies House, two projects in Buffalo, New York, have been developed. One project rebuilt public housing and designated ten units for grandparent-headed families with accompanying case management services. The other program is included in a housing complex for seniors and families. The complex includes six "granny units," some of which are single level and handicap adaptable.

Many organizations have contacted these projects for information on how to replicate their programs. Groups in at least fifteen states are in various stages of researching and/or building similar programs. Many of those interested, however, are facing barriers related to finances and lack of information about best practices. In response to the multiple requests for housing assistance, GU worked with a team of experts on housing issues, and on the needs of relative-headed families, to develop language and conduct education around the housing legislation for grandparents raising children called LEGACY — Living Equitably: Grandparents Aiding Children and Youth. The legislation included five

major provisions to assist with housing needs, three of which were passed and signed into law in December 2003 as part of the American Dream Downpayment Act. The provisions that became law call for HUD to develop and distribute grants for demonstration projects to create housing for grandparents and other relatives raising children; provide training to housing officials on issues facing relatives raising children; and work with the U.S. Census Bureau to conduct a national study of the housing needs of relatives raising children and make recommendations based on the study.

NEEDS NOT ADDRESSED

ASSISTANCE FOR HOMEOWNERS

Much of the research and housing assistance currently available to grandparent- and other relative-headed families are for families who rent their homes. Yet, little assistance is available for grandparents who own their single family homes, but whose homes are too small due to the arrival of their grandchildren. To address the housing needs of family caregivers of older individuals, Congress created the Elder Cottage Housing Opportunity Program (ECHO). As the ECHO program is currently configured, funds can be used for the initial purchase and placement costs of small, free-standing, and barrier-free housing units for older relatives to live near their families. This program could be adapted to allow for the addition of bedrooms to small caregiver homes to accommodate children who come into caregivers' care unexpectedly.

CAREGIVERS UNDER 62

While the LEGACY law calls for grants to develop housing demonstrations specifically for grandparent- and other

relative-headed families, the law requires that these grants come from the Section 202 elderly housing program. This means that at least one member of the family in these units must be 62 years or older to qualify. Since the vast majority of relative caregivers are under 62, many needy families will be excluded from these projects.

EDUCATION AND IMPLEMENTATION OF LAWS

Although the LEGACY housing provisions previously described were signed into law in December 2003, as of December 2004 HUD has failed to take significant steps toward their implementation. Co-sponsors of the bill have written HUD to clarify the congressional intent for all three provisions to be implemented simultaneously and for the demonstration programs to use 2004 funds appropriated for elderly housing, but HUD has not followed through. Furthermore, research shows that other laws relevant to housing issues facing grandparents and other relative caregivers are often interpreted incorrectly. Currently there is no coordinated effort to educate and train caregivers and key housing professionals on the array of issues and policies related to housing for caregiver families.

RESEARCH AND INFORMATION SHARING ON MODEL PROGRAMS AND BEST PRACTICES

Although there is interest in the development of housing specifically for grandparent- and other relative-headed families, there is little data on key aspects of such housing and information on how to develop effective programs. The lessons learned from GrandFamilies House in Boston should be shared with parties interested in doing further development.

Health and Mental Health

NEEDS

A number of children being raised by grandparents and other relatives have serious physical and mental health problems that require immediate attention and sometimes long-term treatment. Research shows that these children exhibit a variety of physical, behavioral, and emotional problems to a greater degree than the general population of children, often due to the difficult situations that caused them to be placed in the care of a grandparent or other relative.⁴³

The problems may have started at birth, such as low birth weight, drug addiction, Fetal Alcohol Syndrome, HIV/AIDS, and other physical and emotional disabilities. Other problems include Attention Deficit Hyperactivity Disorder (ADHD), adjustment and attachment disorders, and learning disabilities. Experiencing multiple living arrangements is often stressful and compounds any emotional disorders developing in childhood.

The challenges relative caregivers face in getting help to the children often exacerbate these problems. One in three children living in grandparent-maintained homes in 1996 had no health insurance (as compared with one in seven children in the overall child population).⁴⁴ Given the absence of their parents, these children are more likely to be without private health insurance, which most frequently attaches to the parents' employer. Relative caregivers may have private health insurance and often can add the children to their policy if they adopt them. However, they often are

unable to cover the children they are raising without adopting them.⁴⁵

Grandparents and other relative caregivers frequently do not know about the range of supports available through public health insurance programs, such as Medicaid or the Children's Health Insurance Program (CHIP), the mental health system, or special education programs available to both preschool and school age children. Or, they may be intimidated and frustrated by the burdensome requirements attached to these various service systems.

This lack of access to needed health care impacts these children not just now, but all too often, for a lifetime. Many adult diseases begin in childhood. The leading causes of death among adults – cancer, stroke, and heart disease – often have their antecedents early in life. There are also other conditions that plague grandparents, such as osteoporosis, shingles, and arthritis that can be greatly diminished or even eliminated by modifying or managing health behaviors during childhood.

Grandparent caregivers often face a range of physical and mental health concerns themselves. They may be unable to attend to their own medical needs due to a lack of child care, respite care or adequate health insurance. They are frequently stressed because they are caring for children at a time in their lives when they did not expect to be. They are often socially isolated from their peers. They may be burdened by a sense of shame and guilt about their own adult children who are unable or unwilling to parent. Grandparent caregivers report health problems like depression, diabetes, hypertension, insomnia, and gastric distress.⁴⁶

CURRENT RESPONSES

There are many special efforts underway in states and communities to help relative caregivers get the health and mental health services that they and the children they are raising need. In addition to specific treatment, supportive services such as counseling, support groups, and respite care are useful to both the children and their caregivers. Outreach and education are essential.

ACCESSING MEDICAID AND CHIP

All 50 states and the District of Columbia have policies that allow grandparents and other relative caregivers who do not have adequate private health insurance to apply for Medicaid and CHIP coverage on behalf of the children they are raising. In enrolling children or determining eligibility for CHIP or Medicaid, most state policies do not require relative caregivers to have court-ordered legal custody or guardianship, do not count the income of relative caregivers in determining eligibility, do not require caregivers to submit proof of the absent parent's income, do not require caregivers to prove their blood relationship to the child or their status as full-time caregiver, and do not require the child to have resided in the state or in the home of the relative caregiver for a certain period of time.⁴⁷

To ensure that these policies are implemented appropriately, some states have made special efforts to educate staff, providers, and health outreach workers about the eligibility of children being raised by grandparents and other caregivers for CHIP and Medicaid, and about the importance of reaching and informing the caregivers. Some states, such as Arizona, have passed legislation

that directs the public agency with responsibility for Medicaid and CHIP to inform grandparents and other relative caregivers of health insurance opportunities and to expedite the eligibility process. State efforts to streamline and shorten applications and to offer a mail-in application have made it easier for relative caregivers to apply for assistance for the children they are raising. Outreach efforts to engage community-based organizations, called “facilitated enrollment” in New York, can also lead to more applications for children in relative-headed families.

Recognizing that pediatricians can play a critical role in reaching out to children who qualify for CHIP and Medicaid but are not yet enrolled, the American Academy of Pediatrics has partnered with the Federal Maternal and Child Health Bureau on an initiative designed to decrease these children's risk of preventable health problems. The program, “Reaching Children: Building Systems of Care,” provides a unique opportunity for pediatricians, other health professionals, community agencies, and local stakeholders to implement grassroots partnership initiatives to improve enrollment of uninsured children within their communities. Among the 14 partnership initiatives funded through this program is a health clinic in Florida that serves a large Hispanic and migrant worker population. That program has an outreach worker available in the waiting room to talk with families and determine if they have insurance. The outreach worker is both bilingual and a social worker and readily able to develop rapport with families to gain trust, enroll children in health care, and make other referrals for service. An initiative in Texas partners

several community organizations, including Head Start and child care agencies, to provide screening and information on CHIP and Medicaid enrollment.

TARGETING OUTREACH TO THE FAMILIES

A number of states have made special efforts to spread the word about Medicaid and CHIP to relative-headed families.

Both the Ohio and New Jersey Kinship Navigator Programs help relatives raising children access a full range of federal and state benefits and services for which they are eligible, including health care. In other states, Medicaid and CHIP programs have partnered with state agencies serving seniors, networks of support programs for relative caregivers, AARP offices, or faith-based organizations working with relative caregivers to get program information out. Medicaid and CHIP staffs have been out-stationed in Social Security offices and other locations serving seniors.

Information is distributed through meals on wheels, senior centers, and special senior health fairs. There also has been outreach to tribal elders and caregivers living on Indian reservations.

Other states have prepared brochures specifically for relative caregivers informing them about their children's eligibility for CHIP and Medicaid, as well as how to apply, and encouraging them to take advantage of the program. Both Georgia and Utah have publicized the eligibility of children in relative-headed families for CHIP. Other states have made changes in their applications so that caregivers are specifically mentioned along with parents.

Some states have made special efforts to send nurses, nursing students, agency staff, or other emissaries into the

community to inform relative caregivers about their children's eligibility for CHIP or Medicaid. Child health advocates and other children's advocates in some states also have included programs serving relative caregivers in their outreach efforts. Support groups for grandparents and other relatives often include an information segment on health insurance.

ACCESSING APPROPRIATE MENTAL HEALTH SERVICES

If relative caregivers are to get the mental health services the children need, they must be helped to recognize such needs and to get appropriate mental health screening, assessments, and treatment.⁴⁸ Those working with caregivers need to know about Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit and how to help children get the mental health screens to which they are entitled. It is also helpful to bring representatives from early childhood programs, schools, and mental health centers together with caregivers, so they can help caregivers access the Early Intervention Programs under Part C of the Individuals with Disabilities Education Act (IDEA), Part B of IDEA, and other programs. Pediatricians have been instrumental in increasing mental health services for children. For example, in North Carolina and Vermont, special efforts are being made to engage them in helping children access mental health services. Some school-based health centers provide comprehensive medical and mental health screening and treatment for students. Relative caregivers may also get help by connecting with the Federation of Families for Children's Mental Health, which is run by and for families whose children and grandchildren have mental health problems.⁴⁹

SECURING MEDICAL CONSENT

Twenty-four states have addressed the problem of relatives not being able to give consent to medical care for the children they are raising by passing medical consent laws. In these states, parents can sign a consent form authorizing grandparents and other relative caregivers to obtain medical treatment for their children even if the caregivers do not have legal custody or guardianship.⁵⁰ Some states have power of attorney laws or similar laws that may be used to authorize a designated third party to consent to medical care on a child's behalf. State laws vary, however, in the type of parental permission that is required.

NEEDS NOT ADDRESSED

Children's Defense Fund conducted a survey in 2000 to assess the ability of grandparents and other relative caregivers to access health insurance coverage under Medicaid and CHIP on behalf of the children they are raising. The survey highlighted effective strategies for increasing enrollment in Medicaid and CHIP, such as those described above, and also provided a useful snapshot of enrollment barriers affecting children in relative-headed families. Some of these and other barriers to health and mental health care are summarized below.

Restrictive State Policies: Despite the flexibility of most state Medicaid and CHIP enrollment policies, a small number of states continue to maintain policies that require court-ordered legal custody or guardianship or that count the caregiver's income in determining whether a child meets the eligibility guidelines for Medicaid and CHIP. Some states require proof of relationship and full-time caregiver status. Such requirements

discourage, delay, and, in some cases, prevent eligible children in grandparent- and other relative-headed families from obtaining health insurance coverage under Medicaid and CHIP.

Inconsistent Policy Implementation: In many states, inclusive health policies for children being raised by relatives are not implemented properly. Caregivers often are given incorrect information, asked for burdensome documentation, or discouraged from applying at all because they do not have legal guardianship. Most often these problems arise because those responsible for enrollment are unaware of the policies that apply to children being raised by relatives; frequently there is no attention in training or in written policies to the specific needs of relative-headed families. Policies may also be applied inconsistently across counties. Negative attitudes among frontline staff may discourage grandparents and other relatives, who may already be concerned about applying for government services, from applying for Medicaid and CHIP.

Caregivers Overlooked in Outreach Efforts: Relative caregivers are seldom specifically mentioned in informational brochures and other outreach materials or application forms for Medicaid and CHIP. "Parent" is used frequently in describing who is eligible to apply, with little if any attention given to how relatives and other caregivers who are not parents might apply.

Other General Barriers: There are additional barriers that are applicable to all families, including relative-headed families, trying to enroll their children in Medicaid or CHIP. These include the perceived stigma associated with applying for government programs, the reluctance of caregivers to share personal

information about their family situations, some families' mistrust of government programs, confusion about medical child support requirements, unnecessary waiting periods for CHIP coverage, and lack of communication between Medicaid and CHIP programs that prevent children ineligible for one from qualifying for the other. As with many families whose children receive Medicaid coverage, relative caregivers may have trouble finding health care providers who will accept Medicaid. Unfortunately, inadequate Medicaid reimbursement often correlates with a scarcity of Medicaid providers. Medicaid reimbursement rates are about two-thirds of Medicare reimbursement rates for seniors, which providers find inadequate compared to commercial rates. Medicaid, although providing some insurance for 24 percent of children through age 18,⁵¹ has a justified image of low, slow, or no payments. However, many providers see patients with no or low reimbursement on a daily basis.

Special Barriers to Mental Health Care:

Relatives raising children with special mental health needs face some of the greatest barriers in getting the care their children need. Technically, Medicaid's EPSDT benefit requires a comprehensive medical screen for all Medicaid-eligible children and youth through age 20, which includes an assessment of both physical and mental health development. Medicaid is also required to cover the cost of all "medically necessary" services that are found in a child's health screen, including care for mental health needs. Comparable mental health benefits may also be available to children in some of

the states with a combined Medicaid and CHIP program for children. In states that run separate CHIP programs, however, mental health benefits often are limited to what is typically found in private health insurance plans. When children are screened for mental health needs under EPSDT and follow-up treatment is provided, it can be very comprehensive and individually focused. Unfortunately, despite Medicaid's mandate, many children are not even screened for mental health conditions under EPSDT and do not receive treatment when the need is identified. A national survey conducted in 2000-2001 found that nearly half the states had not addressed mental health concerns at all in their comprehensive EPSDT screens.⁵²

Related Medical Consent Issues: Once grandparents and other relatives have health insurance for the children they are raising, they still frequently face difficulties authorizing medical treatment for the children if they do not have legal custody or guardianship. Because of malpractice and liability issues, health care providers may refuse to treat a child without the consent of a parent or legal custodian or guardian even when the child has insurance to cover the cost of the health care. In emergencies, however, both common and statutory laws generally have supported the physician or health care professional in caring for a child in the Emergency Department without the consent of a parent or guardian. Additionally, the American Academy of Pediatrics recommends that appropriate medical care for children with an urgent condition should never be withheld or delayed because of problems with obtaining consent.⁵³

Respite Services

NEEDS

Caregiving can be a very rewarding experience for relative caregivers. On the other hand, they face a myriad of issues as they struggle to keep their families together. Concerns about health insurance coverage and accessing health and mental health benefits, the need to make decisions with or without a legal relationship to the children, as well as advanced age can lead to physical and mental health problems. Studies have shown that grandparents are likely to neglect their own health by skipping or postponing medical appointments as they strive to meet the needs of the children in their care. In a recent survey, caregivers identified exhaustion, poor eating habits, sleep deprivation, and failure to exercise as symptoms of the demands and stresses of caregiving.⁵⁴ Chronic health problems have been reported in studies of Hispanic, Caucasian, and African-American grandparents raising grandchildren.⁵⁵ Family caregivers also face increased risk of excessive use of alcohol, cigarettes or other drugs.⁵⁶ These challenges can be especially overwhelming when relatives care for children who have mental or physical disabilities.

The benefits of respite care are clear.⁵⁷ Turning over their caretaking duties to others for a time ensures that caregivers get the rest they need in order to resume the care of their children. A tired caregiver has an even more difficult time facing what can seem like the endless challenges of caregiving. A break allows time for rest or social activities and a “recharging of batteries.” Respite, when clearly defined and easily accessible, creative, and flexible, can help caregivers face their caregiving responsibilities.

CURRENT RESPONSES

COMMUNITY-BASED PROGRAMS

Community-based interventions, in the form of support groups, have proven to be a source of assistance and support for relative caregivers. These groups have recognized the challenges faced by caregivers and their need for supportive programming that provides a break from caregiving responsibilities.

Brookdale’s Relatives As Parents Program (RAPP) has used creative approaches to provide caregivers with time off. Some of the lessons learned are that it may be difficult for caregivers to seek help; that it may take caregivers time to accept help and enjoy time away from their children; and that respite is possible any time programs provide activities for children. Here are some examples of types of activities that can lead to respite opportunities.

1. CHILD CARE

Child care, provided in or out of the home, is the traditional and most recognized form of providing time off for relative caregivers. When offered during support group meetings, conferences, workshops, and seminars, child care is an important way of ensuring that caregivers have time away from their children. Child care may also be offered by giving caregivers the opportunity to drop kids off and go shopping or to a movie or activity of their choice. It can be provided through collaboration with social work interns, staff, teens, and trained volunteers. No matter what avenue is used, if caregivers know that the children are well cared for they are free to enjoy and benefit from their support group meetings or other activities.

EXAMPLES OF CHILD CARE ACTIVITIES⁵⁸

Vouchers: Some programs provide vouchers that can be used to pay for child care. Some allow caregivers to choose the providers, others offer a list of possible providers, and still others contract with a specific child care agency.

“Swap” child care programs are those where caregivers take turns caring for each other’s children.

2. CHILDREN’S ACTIVITIES

Any time activities are provided for children, caregivers get some time off. If caregivers feel that the children enjoy programs and services, they will bring them to the programs and, in effect, allow themselves to get a break. Some groups have tried to introduce caregivers to respite by having a children’s activity and inviting the caregivers to stay and observe the interaction between the children and respite workers. The hope is that once caregivers know that the children are in good hands, they may accept, and even enjoy, time away from their children. If

children enjoy the activities provided, that may, in itself, be an incentive for the caregiver to access other social, educational, and supportive services offered that will result in much-needed time off.

EXAMPLES OF CHILDREN’S ACTIVITIES

Art classes, parties, camps, movie nights, field/day trips, after-school programs; tickets to sports events, circuses, concerts and shows; safe, fun events for the many children who are learning disabled; and regular therapeutic activities for children that include play therapy and help with coping, social skills, grief, psycho-education, and self-esteem.

Collaborations with local museums, libraries, zoos, schools, YM/YWCAs, Boys and Girls Clubs (kids can be dropped off for certain times and supervision is provided by trained staff), Cooperative Extension Services, parks, and other recreational providers are key to the creation and expansion of children’s activities that lead to caregiver respite.

EXAMPLES OF RELATIVE CAREGIVER ACTIVITIES

Concerts and musical performances; dinner shows; breakfast, brunch and lunch outings; plays; shopping/day trips; “Grandparents Night Out;” and “Grandparents Day” recognition ceremonies and celebrations all spell relief.

Creative programs include:

Prom Night: An annual semi-formal event for grandparent caregivers. They dress up, dance, and have dinner surrounded by others who are also caring for children.

Yearly Grandparent Recognition Ceremonies: Caregivers are recognized with lunch or dinner, music, and recognition certificates. These ceremonies may take place in restaurants, senior and community centers, picnics, local parks, and sports arenas.

3. RELATIVE CAREGIVER ACTIVITIES

Planned social activities at least once a month, with fellow relative caregivers, lessen isolation and can be one of the most rewarding experiences for them. Any activity that focuses on the relative caregiver and that is done with a group of caregivers who are going through the same challenges results in a special occasion for all.

4. INTERGENERATIONAL ACTIVITIES

Sometimes respite opportunities that provide a fun event for both relative caregivers and the children they raise are the most successful. The events are a good way to ensure that caregivers and their children enjoy time together without worrying about homework and chores. Supervision for the children may be offered to allow caregivers the opportunity to relax and connect with other caregivers.

RESPIRE COALITIONS

Respite Coalitions provide community-based networks of accessible respite services for individuals with special needs such as developmental and physical disabilities, emotional and behavioral disorders, chronic illnesses, Alzheimer's disease and related health concerns, medical frailty, and for those at risk of abuse or neglect. Most of these focus on the frail elderly; only a few provide services specifically for grandparents and other relatives raising children. Here are some examples:

Oregon's Lifespan Respite Program helps counties develop and implement community-based lifespan respite care networks and helps caregivers locate respite services in their communities. The Oklahoma Respite Resource Network (ORRN) also provides respite for families and individuals and specifically includes grandparents and other relative caregivers.

EXAMPLES OF INTERGENERATIONAL ACTIVITIES

Holiday parties, day trips for grandparents and children, annual picnics, boat trips, nature walks, and family and respite weekends that involve programs for children while grandparents relax or enjoy educational activities and reunite with the children at night are all wonderful activities. Potluck dinners before support group meetings are always welcomed by both caregivers and children and provide a much-needed meal before the meeting.

Family Fun Night: A monthly family celebration with food, door prizes, and lots of intergenerational activities. Celebrations include pool parties, fall festivals, holiday crafts, picnics in the park, and Grandparents Day.

Family Spa Night: An evening of relaxation and respite for caregivers and children that includes spa services such as massages, manicures, haircuts, foot soaks, yoga, stress management techniques, and a sampling of health foods while children enjoy separate, structured activities.

LEGISLATION

I. THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

The National Family Caregiver Support Program (NFCSP) was enacted as part of the reauthorization of the Older Americans Act in 2000. The program calls for all states, working in partnership with AAAs and local community-based providers, to offer five categories of supportive services, including respite care, to family caregivers of adults aged 60 years and older and grandparents and other relative caregivers aged 60 years and older who are caring for children. A maximum of 10 percent of the funds allocated for NFCSP activities can be utilized for grandparents and other relatives raising children.

2. THE LIFESPAN RESPITE CARE ACT OF 2003

Proposed legislation, like The Lifespan Respite Care Act of 2003 (the Act), seeks to expand and enhance respite care services to family caregivers and to improve statewide dissemination and coordination of respite care. As of December 2004, the Act has been incorporated into the Ronald Reagan Alzheimer's Breakthrough Act of 2004 (S. 2533/H.R. 4595). The Act would establish grant programs to assist family caregivers to access affordable, quality respite care; encourage states to enact state and local lifespan respite programs; and improve coordination and dissemination of information on respite services.

NEEDS NOT ADDRESSED

Although the NFCSP recognizes the need and importance of respite for grandparents and other relatives raising

children, the program limits services to those who are aged 60 and older. Government agencies, advocates, and practitioners must struggle to determine how to provide respite and other services to the vast majority of grandparent caregivers who are under age 60. Also of concern is that some caregivers may be unable to access other state respite programs due to income or other eligibility guidelines and must therefore forgo this much-needed resource.



Accessing Education and Special Education for the Children

NEEDS

LIMITATIONS TO SCHOOL ENROLLMENT

In many states, grandparents and other relatives who are raising children without a legal relationship, such as legal custody or guardianship, face limitations and may not, according to school district policy, enroll children in school or make educational decisions on their behalf. These policies are not supportive of relatives raising children, prohibit and delay children from attending school, and impede relatives from contributing to the educational success of the children they are raising. With changes in “traditional families,” and the increased number of children cared for by grandparents and relatives, policies must be supportive of relatives’ efforts to provide for the needs of these children.

Entry into a school is typically based on “residency” within that school district. Many school districts question the validity of a child’s residency when they do not live with a parent. In these situations, district policy may force a relative to obtain guardianship or provide other documents to validate the student’s residency. Although some states do not require guardianship for enrollment, they do place burdens upon relatives by requiring them to provide numerous documents, such as the child’s immunization and health records that can only be obtained by parents or guardians. These requirements are meant to legitimize the reasons children are living with relatives, as well as discourage the practice of sending children to live with relatives for the sole purpose of attending

a particular school or avoiding tuition charges. Such requirements often, however, unwittingly prevent children from attending any school.

RESTRICTED ACCESS TO SPECIAL EDUCATION

Many children raised by relatives need special education services for a variety of reasons ranging from drug exposure to abuse or neglect. Although not required by federal law, many states require caregivers to have guardianship of children in order to obtain special education services on their behalf and participate in Individualized Education Plans (IEPs). Relatives are often intimidated by the special education process and unaware of their rights and the rights of the children.

EXCLUSION FROM PARENTAL ACTIVITIES

Many school districts define “parent” restrictively and exclude grandparents and other relatives raising children from involvement in parental activities, such as parent-teacher conferences.

CURRENT REPOSES

LAWS ALLOWING SCHOOL ENROLLMENT

Some states have enacted legislation to address the concerns of school districts and also meet the needs of relative-headed families where enrollment is concerned. Provisions vary from state to state and may allow relatives to enroll children in school by signing affidavits or submitting other notarized documents.

In California, caregivers may enroll children in school as well as consent to medical treatment through the use of one affidavit. North Carolina caregivers are given the authority to enroll children in school and also make “educational decisions” on their behalf. In Indiana, the

student's legal residence is where the student resides, not where the parent does.

Other states that have passed educational consent laws include Connecticut, Delaware, Hawaii, Louisiana, Maryland, Ohio, Oklahoma, South Carolina, and Utah. In Massachusetts and Illinois, where guardianship is not statutorily required to enroll children in regular education, there is a lack of consistency within local school districts regarding enrollment requirements. In Illinois, some districts will accept a notarized affidavit, other districts require guardianship, and some require a power of attorney. In Massachusetts, guardianship is not required for enrollment; however, schools can require some other documentation, such as proof of residency and the child's immunization records.

DECLARING CHILDREN "HOMELESS"

Due to the restrictive enrollment policies embraced by many school districts, relatives are often forced to declare the child they are raising "homeless" under the Federal McKinney-Vento Homeless Assistance Act (the Act).

The Act states that homeless children and youth must have access to the same educational services provided to other students. The Act defines "homeless children and youths" as:

*"individuals who lack a fixed, regular, and adequate nighttime residence; and includes children and youths who are sharing the housing of other persons due to loss of housing, economic hardship or a similar reason..."*⁵⁹

The Act also defines "unaccompanied youth" as:

*"includes a youth not in the physical custody of a parent or guardian."*⁶⁰

FEDERAL LAW AND SPECIAL EDUCATION

Special education services are available to all qualifying children throughout the U.S., regardless of who cares for them. The regulations implementing the Individuals with Disabilities Education Act (IDEA) define "parent" to include grandparents and other relatives raising children:

(a) *The term parent means—*

- (1) *A natural or adoptive parent of a child;*
- (2) *A guardian but not the State if the child is a ward of the State;*

(3) A person acting in the place of a parent (such as a grandparent or stepparent with whom the child lives, or a person who is legally responsible for the child's welfare); or

- (4) *A surrogate parent who has been appointed in accordance with Sec. 300.515.*

(b) *Foster parent. Unless State law prohibits a foster parent from acting as a parent, a State may allow a foster parent to act as a parent under Part B of the Act if—*

- (1) *The natural parents' authority to make educational decisions on the child's behalf has been extinguished under State law; and*
- (2) *The foster parent—*
 - (i) *Has an ongoing, long-term parental relationship with the child;*
 - (ii) *Is willing to make the educational decisions required of parents under the Act; and*
 - (iii) *Has no interest that would conflict with the interests of the child.*⁶¹

Grandparents and other relative caregivers therefore have the authority

under federal law to participate in IEP meetings and sign the IEPs as parents. Some states and schools, however, may chose to require foster parents, even those that may be related, to petition a court to be a “surrogate parent” before being allowed to participate in an IEP meeting and sign the IEP.

Many parents and caregivers are unaware that special education services available under federal law include early intervention services for children ages birth to 3, as well as services for pre-school and school-aged children. The services for young children are available in each state, using funding available through Part C of the IDEA. Each state’s eligibility rules vary, but all should be serving children raised by relatives “informally,” i.e., without a legal relationship. Some early intervention programs serve infants and toddlers with disabilities. Others also serve children who have developmental delays or are “at risk” for those delays. Services that may be available include speech, physical, occupational, and feeding therapy. When a child turns 3, if he or she qualifies, special preschool education services are also available through the IDEA. For qualified children, special education services should be provided through age 21 or until they have graduated from high school, whichever comes first.

RELATIVE CAREGIVERS’ INVOLVEMENT IN “PARENTAL ACTIVITIES”

Title I of the federal Elementary and Secondary Education Act (ESEA) provides funding to schools in high-poverty communities to assist disadvantaged students. Title I, in part, provides funds to allow parents to be involved with their children’s education. The definition of

“parent” in the ESEA includes grandparents and other relatives raising children:

“The term “parent” includes a legal guardian or other person standing in loco parentis (such as a grandparent or stepparent with whom the child lives, or a person who is legally responsible for the child’s welfare).”⁶²

Therefore, grandparents and other relatives raising children should be included in all parental activities, such as parent-teacher conferences, provided under Title I of the ESEA.

NEEDS NOT ADDRESSED

If enrollment is allowed without obtaining guardianship or another legal relationship, relative caregivers may still be prohibited from signing permission slips and report cards, attending teacher conferences, participating in decisions regarding disciplinary action, obtaining support services, and authorizing medical treatment.

Federal law allows relative caregivers to obtain special education services for the children in their care and participate in parental activities. However, many states and localities are either unaware of or unwilling to implement these laws.

Outreach and Information

NEEDS

Grandparent and other relative caregivers are highly in need of accurate, easily accessible, timely information and assistance about legal, financial, support services, health, housing, education, and child-rearing issues. Information is very difficult to obtain, and these caregivers are overwhelmed when trying to “navigate the system.” While there is clearly a need for increased services in general, perhaps the needs for outreach efforts and information are the most urgent because caregivers are vastly unaware of existing supports and services that can be helpful to them right now. While there are some notable successful efforts to reach these caregivers, overall efforts to date have not adequately reached or informed them.

The AARP Grandparent Information Center (GIC) recently published a report, *Lean on Me: Support and Minority Outreach for Grandparents Raising Grandchildren* (12/2003). This report outlined the findings of research that included an environmental scan, focus groups with grandparent caregivers (both those in support groups and those not in support groups) and a survey of support groups. The results clearly indicate that grandparent caregivers are often isolated and unaware of information that can be very helpful – often essential – in raising their grandchildren. Those grandparents who do seek help are all too often given incorrect information that prevents them from accessing supports, benefits, and services for their grandchildren and themselves.

According to the AARP research, grandparent caregivers express the

greatest need for the following types of information:

- *Legal options* — this is a high priority issue for these grandparents. They are often in crisis situations, finding legal assistance too expensive or not available in a timely manner. Pursuing legal options and rights is very frustrating and confusing for grandparent caregivers.
- *Financial assistance* — the expense associated with raising grandchildren is enormous, and leaves many grandparents financially strapped. They are often unaware of sources of financial assistance, including public benefits, scholarships, free or reduced-fee services, health insurance, and housing assistance.
- *Support services or programs* — grandparents are dedicated to raising their grandchildren well, and seek programs to help them, as well as additional supports for themselves. Many are unaware that there may be financial assistance available to help them obtain these support programs/services.

CURRENT RESPONSES

Responses to the need for outreach, information, and referral have been quite varied. Each family, community or state is unique, requiring individualized information and assistance. There is no single way to go about successfully meeting these needs. A cookie-cutter approach does not work. However, some common types of tools have been successfully developed across the nation.

OUTREACH AND INFORMATION TOOLS AND SYSTEMS

These tools and systems of information and referral services are often referred to as “navigation.” In some cases navigation systems include an assistance component that goes a step beyond provision of information and referral.

Generally this assistance consists of in-person assistance in finding services, completing application forms, making appointments, and “walking through” the steps with the grandparent or other relative caregiver. Navigation or information systems and tools vary a great deal, and may consist of one or more of the following components:

- *Telephone Information and Referral* –

Warm-lines and hot-lines provide a phone number — often toll-free — grandparents or other relative caregivers can call to speak with someone and receive support and information/referral about services, benefits, and programs. Many grandparent resource centers provide telephone information and referral, as do many support groups. Other lines are housed in child welfare agencies, aging agencies, or human services offices. Hot-lines generally have a trained staff person or volunteer to answer the phone 24 hours a day. Warm-lines are generally staffed only during certain hours; relative caregivers can leave messages and receive calls back within a specifically designated time period. The New Jersey Navigator Program, which includes a statewide toll-free number that relative caregivers can call to receive information, is an excellent example of telephone information and referral. AARP also provides telephone information and referral through a toll-free number.

- *Resource Guides* – A print publication (some are also available on websites) may list helpful services, benefits, programs, agencies, support groups, etc. for a specific geographic region such as a state, county or city. Some guides are general and cover all issues facing grandparent and other relative caregivers. Others are more in-depth and focused on specific

issues such as legal choices. Examples of resource guides include the state of North Carolina’s recently published statewide guide to information, services, programs, and legal issues. The guide was produced by AARP North Carolina, North Carolina Cooperative Extension, and the North Carolina Division of Aging and Adult Services. Another example is a notebook full of information about pertinent agencies and organizations developed for the Southern Arizona region by the Grandparents Raising Grandchildren of Southern Arizona Coalition. The notebook is available in a three-ring binder, and is also available on the website of University of Arizona Extension. AARP state offices are working collaboratively with local AAAs to develop city or county guides in Missouri and Georgia.

- *Newsletters* – Many local support groups and aging agencies produce consumer-targeted newsletters for grandparents or other relative caregivers. The AARP GIC produces a free quarterly newsletter, The GIC Voice, which is available in English and Spanish.

- *Databases* – A systemized electronic database of helpful programs, agencies, support groups, etc. within a specified geographic region can be a resource for telephone or in-person information and assistance, and can be very helpful when available on a website accessed directly by relative caregivers. The AARP GIC has a national support database of agencies and support groups that relative caregivers and professionals can access directly from the website. Several state agencies post databases of support groups or agencies on their state websites as well.

- *Websites* – Various national, state, county or area organizations have

websites with guides, tip sheets, articles, databases, and important links to other agencies.

- **Events** – Workshops, forums, conferences, summits, and symposia that directly target relative caregivers are excellent venues for finding and reaching grandparents and other relative caregivers. These events not only provide education for caregivers, but they are venues for various agencies to distribute pertinent information.

- **State Fact Sheets for Grandparents and Other Relatives Raising Children** – One notable information/navigation tool is the state fact sheets (for every state and the District of Columbia) that were developed in 2002 and updated in 2003 through a collaborative effort among eight national groups. The fact sheets contain state-specific information on programs, policies, and laws for the families. The information was updated by CDF, and AARP conducted focus groups to gain insight as to the effectiveness of the information, language, and format. AARP then created a new design for the fact sheets and made them available to all the original partners. All partners have the ability to post the state fact sheets on their websites, and they can be printed by anyone who wishes to distribute them.

- **National Publications** – Several national organizations have created information resources; most include references to other sources of pertinent information as well. While space will not allow mentioning all of these valuable information resources, a few examples follow:

- **CDF's Kinship Care Resource Kit**, which includes information about how

community and faith-based organizations can help relative-headed families through programmatic efforts, community organizing and advocacy. CDF also publishes Grandparents and Other Relative Caregivers Guides to Health Insurance, Child Care and Early Childhood Education, Raising Children with Disabilities, and Food and Nutrition Programs.

- **CWLA's recent *Sticking Together: Kinship Care and Financial Care***, a print guide to financial assistance and planning.

- **GU's series of fact sheets** available in print or from its website on topics such as the National Family Caregiver Program, housing, and subsidized guardianship programs.

- **The AARP Grandparent Information Center's** consumer-targeted publications about starting support groups, financial assistance, and health/safety.

- **The Children of Alcoholics Foundation's (COAF)** series of tip sheets, *The Ties that Bind*, which provides practical information and ideas for relative caregivers dealing with addictions in their families.

SUPPORT GROUPS

Support groups are an excellent outreach mechanism. While some think of support groups only as a source of emotional support, the provision of information through these support groups is the key to success. The AARP Lean on Me research report indicates that this "dual agenda" is what attracts most relative caregivers to these organized groups. They want to receive practical, helpful information. According to the

report, support groups are a fairly recent trend, with most coming into existence in the past ten years. Support groups provide information through guest speakers and also through the important “word of mouth” transmission of successful efforts by fellow caregivers.

The availability of seed funds from Brookdale has been a major impetus for the development of support groups across the nation. Other organizations that have become involved in developing support groups and assisting with their networking capabilities are Casey Family Programs, Cooperative Extension Services, AARP state offices, and GU.

NEEDS NOT ADDRESSED

FUNDING

In general, funds for outreach and information creation and delivery are vastly inadequate to address the current and future levels of need. Additional funding sources are needed at the local, state, and national levels specifically for outreach and information delivery mechanisms and systems. Most existing funders are not widely financing outreach efforts. While the National Family Caregiver Support Program has provided impetus for local-level outreach efforts, the funds that can be used for grandparent support are spread among respite, supportive services, and other activities. The amount of funding is so small that when spread out it cannot begin to adequately fund the outreach efforts that are needed.

LOCAL/COMMUNITY/NEIGHBORHOOD OUTREACH

Current outreach and information delivery efforts have developed, generally

as collaborative ventures, primarily in terms of national level, statewide information, AAAs’ planning and service areas (PSAs), counties, or cities. But many grandparents and other relative caregivers will only find that information if they have the initiative to go looking for it. They need to learn about information that will help them from sources close to them - in their neighborhoods and communities.

STATE OUTREACH CAMPAIGNS

Many states do not have organized and integrated state level outreach campaigns. Lack of funding and lack of a lead agency or organizing body are often cited as limitations.

PUBLIC AWARENESS

Despite the growing numbers of grandparents and other relatives raising children, the general public remains vastly unaware of the level of need. While there has been increased media interest, and attention and action among legislators, there is still great need for increased public awareness in order to stimulate the network of outreach and information creation and delivery. There also is a need for increased awareness among service providers so that they will readily provide caregivers the services for which they are eligible.

COORDINATED, INTEGRATED SYSTEMS

While various organizations create and implement outreach and information efforts, most systems are not integrated and/or coordinated. For example, the children and families administration in a state may have valuable information that would help relative caregivers, and the aging network may also have helpful

information. But the two systems rarely are well integrated or refer clients back and forth. The same may be true for local resources that are developed. State agencies may not know about the local resources, or other local areas may not know about them. This makes for unnecessary duplication of efforts and ineffective support for the caregivers.

CONSUMER-ORIENTED INFORMATION

While there are some excellent information sources in existence, many are written at reading levels that are too high and are not consumer-oriented in format. These resources may be helpful to professionals, but are less helpful to the consumer – the grandparent or other relative caregiver — who needs clear, concise, easily understandable information.

SPANISH AND NATIVE LANGUAGES

There is a lack of adequate and effective outreach efforts and information tools targeting Spanish speaking and Native American/Indian grandparent and other relative caregivers.



Data Collection

NEEDS

Community-based organizations that offer direct services to caregivers and public agencies that lead their states on policy and programmatic issues affecting grandparents and other relatives raising children need current, reliable data and research to translate the data into information. Collecting data and doing research is important. It also is important that public access to the data be easy and research findings be widely disseminated in a form that can be understood by non-technical audiences.

Differentiating types of sub-populations will assist in assessing current and future policy and programmatic responses. Existing research has begun to quantify and document the characteristics of a number of different family arrangements in which children are raised by grandparents and other relatives, including three-generation households headed by a parent, grandparent-headed households, and relative-headed households in which neither parent is in the home. Existing research has also differentiated children raised by relatives who have no contact with child welfare authorities, relative-headed families who have had contact but retain custody of the children, and relative-headed families caring for children who are in state custody.

Good quality nationally representative research can identify populations that are particularly at risk. Once these populations are identified, more effective outreach strategies can be designed to reach these groups. For example, recent findings from the American Community

Survey (ACS) indicate that the prevalence of grandparent caregiving among Native Americans aged 45 and over is comparable to that found among African Americans. However, few programs to date have focused on Native American grandparent caregivers.

Data from the National Survey of America's Families (NSAF) have begun to document the well-being of children raised by grandparents and other relatives in different types of family arrangements. The data show that such children face a number of challenges to their well-being and are faring worse than children raised by their birth parents. A related finding from NSAF data, however, documents that large numbers of children raised by grandparents and other relatives fail to receive the services and supports to which they are entitled.

To understand how and why different populations are faring differently, it is important to understand the impact of a wide range of federal and state policies. Three national surveys of state child welfare kinship care policies conducted by the Urban Institute have demonstrated how state agencies identify, assess, license, pay, and supervise kinship foster care homes. A national survey conducted by CDF documented how the needs of children raised by grandparents and other relatives are addressed in Medicaid and CHIP. One-in-three grandchildren in the care of grandparents lack health insurance, compared to one-in-seven American children overall.

With a clearer understanding of the problems facing grandparent and other relative caregivers, programs can be designed to address unmet needs. Of particular concern is the finding from the

ACS that more than one-third-of-a-million grandparent caregivers are living below the poverty line, yet only one-in-seven of these low-income grandparents are receiving public assistance. Programs also need to be designed for households raising multiple grandchildren and for those with disabilities. One-in-ten grandparent caregivers are raising three or more grandchildren. More than 40 percent of all grandparent caregiver households contain at least one member with a functional disability.

In-depth case studies of the situation of grandparents and other relatives raising children for individual communities will continue to be a valuable complement to nationwide data collection and research programs. These case studies can offer specific direction to community-based organizations that offer direct services to caregivers. The resources required to collect reliable community-level data, conduct analyses, and report results can be costly. Funding agencies may be reluctant to give grants to study the problem, preferring instead to support direct services to caregivers.

Research on support groups for grandparents and other relatives raising children can lead to a better understanding of the most effective ways to reach and assist these families. Best practices should be emphasized, including promotion and recruitment methods, start-up and sustaining strategies, and outreach to minority caregivers.

CURRENT RESPONSES

In recent years, the amount of data on grandparents and other relatives raising children has expanded significantly. Census 2000 included a three-part

question asking people aged 30 and over if they were “currently responsible for most of the basic needs of any grandchild(ren) under the age of 18 who live(s) in this house or apartment.” This question was included on the sample (long form) questionnaire mailed to one-in-six households in the U.S. Grandparent caregiving is relatively rare: only 1.5 percent of people 30 and over reported that they were grandparent caregivers. Nonetheless, this amounts to 2.4 million grandparent caregivers. In October 2003 the U.S. Census Bureau published a Census 2000 Brief: Grandparents Living With Grandchildren, by Tavia Simmons and Jane Lawler Dye. This brief includes an analysis of the characteristics of grandparent caregivers.

Census 2000 included a question on the short form mailed to every household asking the relationship of each person in the household to the person who owned or rented the housing unit (the householder). The response categories of the relationship question included “grandchild” and “other relative.” Of children under 18, 6.1 percent (4.4 million) were identified as the grandchild of the householder and 2.0 percent (1.5 million) as other relatives of the householder (not son or daughter). In February 2004 the U.S. Census Bureau published a Census 2000 Special Report, Children and the Households They Live In, by Terry Lugaila and Julia Overturf. This report includes an analysis of the characteristics of grandchildren and other relatives of the householder.

The ACS, conducted nationwide by the U.S. Census Bureau since 2000, includes the same grandparent caregiver question as Census 2000. Professors Meredith Minkler (University of California, Berkeley)

and Esme Fuller-Thomson (University of Toronto) have analyzed data about grandparent caregivers aged 45 and over from the 2000 ACS. This research was funded by a grant from the Retirement Research Foundation. In July 2004 the sample size of the ACS was expanded to approximately 3 million housing unit addresses. An expanded set of data products also is proposed for the ACS. These include new tables of specific subject data for grandparents and grandchildren.

Carrie Jefferson Smith, Deborah J. Monahan, and Eric Kingson of the Syracuse University School of Social Work have completed an evaluation of KinNET, the demonstration project designed to create a national network of support groups for relatives caring for children in and associated with the foster care system. As part of their evaluation Dr. Jefferson Smith and her colleagues developed a national profile of caregivers providing relative foster care within the GU support network, and identified best practices that are incorporated in a compact disk.

The National Survey of Child and Adolescent Well-Being (NSCAW) is the largest longitudinal study of children in the child welfare system ever conducted, and includes more than 600 children who are in kinship foster care placements.

NEEDS NOT ADDRESSED

The ACS does not collect any data about other relatives, such as aunts or uncles, who are caregivers for children under age 18.

More longitudinal studies are needed to follow families over time as they transition into and out of the grandparent and other relative caregiver role.

More research is needed to better understand the distinctions and similarities between the needs and concerns of children and caregivers in the formal and informal systems of care. Longitudinal studies would help to identify the costs and consequences (human toll and societal cost) of grandparents and other relatives raising children in the formal and informal systems. Longitudinal studies would also help to identify how the formal and informal systems intersect and how best to support and sustain caregivers and children.

While kinship care is generally accepted as the best placement option for children who must be removed from their parents' home, there has not been a single rigorous study conducted that demonstrates that children placed with relatives fare better than children placed in non-relative foster care. Moreover, there is no research to describe the types of children who will fare best in relative placements.

Messaging

NEEDS

While grandparents and other relatives have always stepped forward to raise children in need, the mainstream media's characterization of "kinship care" as an "emerging" social phenomenon is relatively new. As the number of relative caregivers has increased over the past decade and the social and family dynamics of these family relationships have changed, so have the ways in which the media portrays grandparents and other relatives – from beleaguered seniors overwhelmed by child-rearing responsibilities to dynamic community leaders and change agents. Media coverage of children living in relative-headed families varies from portraits of children irreparably "damaged" by irresponsible parents to romanticized images of children "rescued" by loving grandparents.

None of these images tells the whole story. Indeed, the needs and circumstances of relative-headed families are as complex and diverse as the families themselves. At the same time, however, the ability to understand and shape these images to better serve the needs of caregivers and the children they are raising is the cornerstone of any successful advocacy effort. Public perceptions of relative-headed families (and, more important, public support for policies that help them) are based on these media portrayals. Like it or not, newspapers, magazines, radio, television, the Internet, and other media outlets have become the principal mediators of social meaning, subtly shaping what the public thinks by organizing or "framing" information in a certain way.⁶³

What does it mean to "frame" an issue?

According to the FrameWorks Institute, a communications research nonprofit specializing in messaging social policy issues, "framing" describes "the subtle selection of certain aspects of an issue to cue a specific response." The way an issue is framed conveys to the target audience who is responsible for a problem and suggests potential solutions through "images, stereotypes, messengers, and metaphors." If advocates can effectively "frame" an issue, they can increase public support for their proposed policy solutions. Conversely, a negative "frame" can erode public support.⁶⁴

CURRENT RESPONSES

At the 1997 national expert symposium, conference participants recommended a coordinated effort to increase media coverage to enhance public understanding of the multiple barriers confronting relative-headed families. Seven years later, advocates for relative-headed families have been relatively successful in garnering media coverage – both of the problems relative caregivers face and of the valuable role they play in keeping children safe and families together. These advocates have been less effective in using the media to point the public towards specific policy solutions. Reporting has mainly focused on the struggles of individuals or on the benefits of specific programs, often without in-depth coverage of the policies and practices that could bring about broad-based reform on the national level. From a communications standpoint, the challenge for advocates for grandparents and other relatives raising children over the next five years will be to work more closely with members of the media to move beyond sporadic coverage and

introduce the public to the programs and public policy initiatives that will most benefit these families.

To this end, advocates must develop a coordinated, consistent, and positive message strategy that:

- *highlights the progress the grassroots movement has made through positive stories of grandparent-led groups and advocacy programs that have worked together to accomplish specific, measurable goals* (e.g., Under the leadership of a local RAPP group and the state office of AARP, the Mississippi GrandRally secured \$1 million in funding for expanded legal services).
- *educates the public about and increases public support for public policy solutions: specific programs, laws, and other model initiatives that will directly address the problems confronting relative-headed families* (e.g., expansion of a state's subsidized guardianship program to serve more than 300 additional families).

UNDERSTANDING COMMON FRAMES FOR THESE FAMILIES: A HISTORICAL PERSPECTIVE

In deciding how best to implement these overarching communications goals, a brief overview of existing media frames for grandparents and other relatives and the children they raise is helpful. In fact, news coverage of these families was relatively limited until December 1991, when U.S. *News and World Report* published the first national story on America's "Silent Saviors," the term it coined to describe the growing numbers of grandparents and other relatives unexpectedly raising a second generation of children.⁶⁵

U.S. *News and World Report's* focus on the issue, increased media coverage of the crack cocaine epidemic and "AIDS orphans," and the sharp increase in the number of grandparent caregivers spawned hundreds of similar articles in local newspapers and national magazines in the following several years. The vast majority of these formulaic stories were told through what could be best described as a "dream deferred" or "grandparent victim" frame. Primarily featured as human-interest pieces in newspapers' "Home Life" or "Living" sections, these articles typically focused on individual grandparents who had traded in their "golden years" for diapers, homework, and the unexpected responsibility of raising grandchildren.

As seen from the examples provided below, the press still relies heavily on the "dream deferred" frame after more than a decade of media coverage.

Los Angeles Times, December 1994: *"Like a lot of people in their late 50s and early 60s, Joan and Jerry McMillin had a retirement plan: Travel the country in a camper, grow old with friends, put some money aside for their grandchildren's education. Six years ago, those plans evaporated when their daughter was stabbed to death by her husband in front of their two children in an Orange County motel room."*

Indianapolis Star, February 2004: *"Their children were grown and Kenneth was close to the end of a 30-year accounting career. An idyllic retirement awaited. What they encountered was far different. Driven by family circumstances beyond their control, they inherited the task of raising two grandchildren. What was once a dream of retiring has all but evaporated."*

While rarely focusing on potential solutions to the problems facing relative-headed families, media coverage of these families remained relatively sympathetic throughout the early and mid-1990s. The

onset of the welfare reform debate and public discussions of the Adoption and Safe Families Act between 1995 and 1998, however, introduced a series of more negative portrayals of “dysfunctional” relative caregivers, poised to milk the public welfare system. As is so often the case when taxpayer dollars are at stake, media portrayals of caregivers during this time period predominately fell into two major categories: “deserving” and “undeserving” relative caregivers.⁶⁶

The “undeserving” caregivers, mainly those grandparents and other relatives receiving public support, especially through the foster care system, were sometimes portrayed in op-eds and news stories as “grandparents asking for a handout” to raise children they should be willing to care for without compensation. In a *New York Times* op-ed, for example, Doug Besharov, a fellow at the American Enterprise Institute, introduced the term “Aid to Relatives with Dependent Children,” subsequently picked up in press accounts, to describe parents who he feared would leave their children with grandparents simply to get a foster care stipend.⁶⁷ While damaging stereotypes of generational abuse and neglect have always been present in child welfare policy and social work practice circles, this period also brought renewed public attention to a disturbing old frame, “the apple doesn’t fall far from the tree.” In addition to series of sometimes venomous op-eds, this theme was also reflected in several articles that raised questions, even if they were later dismissed in the same piece, about whether grandparent caregivers who had “screwed up their own children” were really capable of raising their grandchildren responsibly.

At the other extreme, the “deserving” caregivers during the same period continued to be portrayed through the “dream deferred” or “grandparent as victim” frame — passive subjects of family and social circumstances beyond their control. Articles consistently began with a lengthy description of the problems grandparents faced and concluded with the caregiver’s statement that, despite the hardship, it is a privilege to raise their grandchildren⁶⁸ and an acknowledgment that they are not alone in their caregiving responsibilities.⁶⁹

On the whole, negative frames have been less common over the past several years, likely to surface mainly in the context of public financing debates, such as welfare reauthorization or highly publicized cases of child abuse or neglect by relative caregivers. After the terrorist attacks on September 11, 2001, the “grandparent hero” frame found resurgence in articles like this one in the *New York Times* in February 2002: “Mrs. Dunbar, 51, has already raised her own family, and seen them off to college and the business world. But when her daughter died in the terrorist attack on the World Trade Center, Mrs. Dunbar found herself part of a vast army of grandparents suddenly thrust into a second round of child rearing.”

Even more recently, thanks to a growing grassroots movement of grandparents and other relatives on the state and national levels, media have begun to explore these issues chiefly through the “grandparent leader” frame. By covering public events like the national GrandRally and state conferences across the country, most stories have included examples of caregivers and advocates pulling together to pressure policy makers to provide increased support for these families.

NEEDS NOT ADDRESSED

The following “frames” are based on the review of more than 500 articles on individual relative caregivers, programs, laws, and policy initiatives between June 1990 and May 2004. For easy reference, the more effective frames are presented side-by-side with their negative corollaries. The negative frames are included to provide a quick reference for re-framing the issues quickly and effectively.⁷⁰

POSITIVE FRAMES

Grandparent Leader/Grandparent Hero

- To draw attention to the need for better laws to protect [these] Grandfamilies, nearly a thousand grandparents (and supporters) trekked to Washington, D.C. this fall for the first-ever GrandRally. LSC's Equal Justice Magazine Winter 2003
- Quietly, heroic grandmothers like Ruth Rench are sacrificing their own needs and plans to provide their “rescued” grandchildren with that precious sense of security and love that is every child's birthright. They are also struggling to keep their grandkids from perpetuating a dangerous cycle. Newsweek Spring 1991

Unresponsive System (Square Peg)

- “System Doesn't Help Grandparents as Parents” Minneapolis-St. Paul Star Tribune 1/15/96
- “Grandparent Trap: Many Manage at Frightful Cost”: Newark Star Ledger 10/19/97
- “Raising grandchildren can isolate a person. You don't fit in anywhere.” Daily Oklahoman 1/1/04.

Keeping Family Together

- Mother Bouges simply wants her babies to stay together. All her babies. “I just hope I am here when Tabatha gets back,” she says [of her incarcerated granddaughter]: St. Petersburg Times, 2/10/04.
- “Like a gray-haired soccer Mom, she tools around in a tan station wagon, dropping off her grandchildren at school and picking up grandchildren at play.” Chicago Tribune, 5/2/04

NEGATIVE FRAMES

Dream Deferred/Grandparent Victim

- She spends much of her time doing laundry, feeding the baby, picking up toys, trying to keep up with the kids. . . that was something she expected when her own children were small. But it came as a big surprise the second time around. Wyoming Tribune-Eagle 4/5/04
- Harvard Study found that caring for children puts mothers, and especially grandmothers, at increased risk for heart disease.” Philadelphia Inquirer 12/3/04

Gaming the System

- Thanks to a biased social service system, welfare recipients anxious for more benefits, and gullible elected officials, the nation's burgeoning foster care system is being used to discourage adoption of at-risk children and keep them tied to abusive parents.” Seattle Post-Intelligencer 10/10/97.
- A little noticed provision in the Senate Republican welfare reform bill may encourage states to push the children out as well. The bill, coming to a vote as early as this week, inadvertently creates a financial incentive for states to take some children of welfare mothers and place them with relatives. Washington Post 6/11/95.

Apple Doesn't Fall Far from Tree/Undermining Traditional Family Roles

- Sometimes, grandparents end up raising their grandchildren because they didn't do such a good job of raising their children to begin with. . . Unfortunately, many grandparents end up repeating the same mistakes with grandchildren that they did with their own children. Dallas Morning News, 5/3/04.
- How can a child's mother become his sister and his grandmother his mom? By government edict in America's newest welfare trend, “kinship care.” Seattle Post-Intelligencer, 10/10/97.

POSITIVE FRAMES

Grandparents as Safety Net

- Grandparents who lovingly take on the burden of rearing their grandchildren in their “golden years” save the state and the nation big bucks by keeping children out of the formal foster care system. *Daily Mississippian*, 2/11/04
- Simply stated: give grandparents the tools to do the job that is being thrust upon them. It’s a job they readily accept out of a strong sense of familial responsibility and a genuine concern for loved ones. *Lexington Herald Leader* 3/5/04

Grandparents as Child Advocates

- To that end, hundreds of grandparents and other relatives raising children from more than 28 states met on Capitol Hill Wednesday to rally Congress’s support for their plight. The participants urged Congress to support legislation to give them permanent custody of the children they raise, to strengthen child welfare, health and mental health care programs, and to improve housing opportunities. *Biloxi Sun Herald* 10/17/03

Every Family

- “Grandparents Step Up to Raise Children: Trend That Crosses all Backgrounds Shows No Sign of Slowing.” *Sun-Sentinel* 5/20/02
- “The thing that’s interesting about grandparents and kinship care is we’re not talking about a homogeneous group,” he said. “No one situation fits. This issue crosses ethnic and socioeconomic boundaries.” *Washington Post* 6/27/03

NEGATIVE FRAMES

- “Some of these grandmothers are worn out, uneducated, and haven’t a clue as to what the emotional needs of these at-risk children are,” says a New York child welfare official. “For every grandmother doing a good job, there’s probably another who shouldn’t have these kids in her home, who fails to give them the stimulation they need to develop their minds.” *City Journal*, Autumn 1994

Moral Obligation to Raise Children

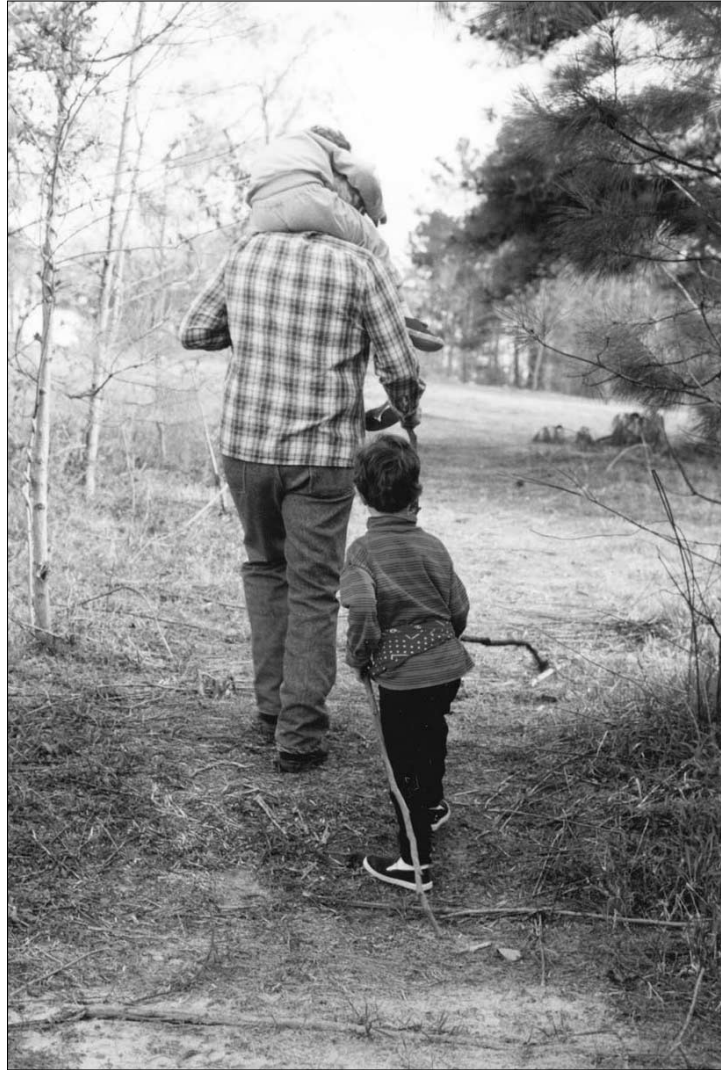
- Foster care legislation offers a mixed bag. Does subsidized guardianship/kinship care for children who have been in DSS custody pay families to fulfill their “moral obligation” to care for family members? *Greensboro News and Record* 5/12/97
- Mr. Grinker said in an interview recently that the kinship program was, in some respects “an example of good intentions gone awry” — a program that, he said, “pays relatives to do what they used to do for nothing.” *New York Times* 11/22/90

Grandparents’ Rights

- Government should intervene in the parent-child relationship only in extreme cases in which parents directly — or indirectly — abdicate their responsibility to rear and protect their children and put them at risk. Otherwise, society, including grandparents, should let parents do the parenting. *Salt Lake City Tribune*, 5/12/04

Urban, Minority Problem

- With an increasing number of Black parents in jail or strung out on drugs, more and more children are calling their grandmothers mama. About 52 percent of Black grandparents say they are the main caregivers for their grandchildren, according to a new Census Bureau report. *Broward Times* 11/7/03
- Together, they chug 1 1/2 gallons of milk. Not per week. Not even per day. That’s just for breakfast. The day starts early for Mary Outlaw, 67, and the 10 offspring who call her Grandma. Some are her grandchildren; some are the children of the first set of grandchildren she raised to adulthood. Some aren’t even her blood kin. *Tampa Tribune* 5/4/03



V. Conclusion

***A toast to a woman that raised a man
In popular demand all across the land
You're my lawyer, my teacher, my doctor, my friend
My mother, my father, you with me 'til the end***

LL Cool J's song "Big Mama" in honor of the grandmother who raised him

Grandmothers — like LL Cool J's — grandfathers, aunts, uncles, siblings and other relatives all over this country are stepping forward and keeping families together. Their love and devotion is making a tremendous difference in the lives of children. Without these caregivers' efforts, millions of children would be in the foster care system, overwhelming it and costing taxpayers billions of dollars. As a nation, we need to support these families and make it easier for them to access the necessary services that all children must have: an education and health care. Because of the circumstances that caused these families to form and the challenges of raising children when unexpected, affordable housing and supportive services like respite, support groups, and counseling are also of fundamental importance. During the last seven years, we have collectively made many positive changes. Please join us in our renewed work to spread a unified, strong message about these families; raise awareness about their strengths and challenges; conduct research to bolster our work; and reach out to educate the families and those working with them about available services. For ideas on how you can join in the national effort to implement this second intergenerational action agenda, please visit Generations United's website at www.gu.org or contact us at gu@gu.org or (202) 289-3979.

Endnotes

- 1 The terms “kinship” and “kinship care” are only used in this publication when referring to specific programs, publications, or research that use those terms. These terms generally mean grandparents and other relatives raising children. However, there is a lack of consensus on how these terms are defined, and, for that reason, more descriptive phrases such as “grandparents and other relatives raising children,” “relative-headed households” or “grandparent-headed households” are used, depending on what is meant.
- 2 Tavia Simmons and Jane Lawler Dye, *Grandparents Living With Grandchildren: 2000 – Census 2000 Brief*, (Washington, DC: United States Census Bureau, October 2003).
- 3 Terry Lugaila and Julia Overturf, *Children and the Households They Live In: 2000 – Census 2000 Special Reports*, (Washington, DC: United States Census Bureau, March 2004).
- 4 *Ibid.*
- 5 Tavia Simmons and Jane Lawler Dye, *Grandparents Living With Grandchildren: 2000 – Census 2000 Brief*, (Washington, DC: United States Census Bureau, October 2003).
- 6 *Ibid.*
- 7 U.S. Department of Health and Human Services, AFCARS, preliminary estimates as of March 2003.
- 8 This figure was calculated based on the federal share of the 2000 average monthly foster care maintenance payment, which was estimated at \$545.
- 9 *Arizona*: AZ Stat. 8-116.01; *California*: CA Family Code 8616.5 and CA Welfare and Institutions Code 366.29 (children in state custody); *Connecticut*: CT Statutes, 17a-112(children in state custody only); *Florida*: FL Stat. 39.811(7)(b); *Indiana*: IN Code 31-19-16; *Louisiana*: LA Children’s Code, 1269.1 et seq. (children in state custody only); *Massachusetts*: MA Stat Ch. 210, 6C and 6D; *Minnesota*: MN Stat. 259.58; *Montana*: MT Code 42-5-301; *Nebraska*: NE Statutes 43-162-165 (children in state custody only); *New Mexico*: NM Statutes 32A-5-35; *New York*: NY Social Services Law 383-c 5 (b) (children in state custody only); *Oregon*: OR Statutes 109.305; *Rhode Island*: RI Laws 15-7-14.1; *Washington*: WA Code 26.33.295; *West Virginia*: WV Code 48-4-12
- 10 *Arkansas*: AK Code, 28-65-221; *California*: CA Probate Code, 2105; *Connecticut*: CT Statutes, 45a-624; *Florida*: FL Statutes, 744.304; *Illinois*: IL Statutes, Chapter 755, section 5/11a-3.1; *Iowa*: IA Statutes, 633.560; *Maryland*: MD Code, 13-903 and 13-904; *Massachusetts*: MA General Laws, Ch. 201, section 2B; *Minnesota*: MN Statutes, 257B; *Nebraska*: NE Revised Statutes, 30.2608; *New Jersey*: NJ Statutes, 3B:12-67 to 3B:12-76; *New York*: NY Consolidated Laws, SCPA, 1726; *North Carolina*: NC Statutes, 35A-1370 to 35A-1382; *Pennsylvania*: PA Statutes, Title 23, sections 5601 to 5612; *Virginia*: VA Code 16.1-349 to 16.1-355; *West Virginia*: WV Code 44A-5-1-8; *Wisconsin*: WI Statutes 48-978; *Wyoming*: WY Statutes 3-2-108 and 3-3-301 et seq.
- 11 KY Statutes, 403.270
- 12 IN Code, 31-9-2-35.5 et seq.
- 13 MN Statutes, Chapter 257C
- 14 Chapter Law 657 of the NY Laws of 2003 (went into effect in January 2004)
- 15 *California*: CA Family Code, 6550 and 6552; *Connecticut*: CT Statutes, 10-253(d); *Delaware*: DE Code, Title 14, section 202; *Hawaii*: HI Statutes, 302A-482; *Indiana*: IN Code, 20-8.1-6.1-1; *Iowa*: IA Code, 282-18; *Louisiana*: LA Statutes, 9:975; *Maryland*: MD Code, 7-101; *Missouri*: MO Statutes, 167-151; *New Jersey*: NJ Statute, 18A:38-1; *New Mexico*: NM Statutes, 40-10B-15; *North Carolina*: NC Statute, 115C-366; *Ohio*: OH Statutes, 3313.64(11); *Oklahoma*: OK Statutes, Title 70, section 1-113(A)(1); *Rhode Island*: RI Laws, 16-64-1; *South Carolina*: SC Statute, 59-63-32; *Utah*: UT Code, 53A-2-201 (3) (A)

- 16 *Arkansas*: AK Statutes, 20-9-602; *California*: CA Family Code, 6550 and 6552; *Colorado*: CO Statutes, 25-4-1704; *Delaware*: DE Code, Title 13, section 707; *District of Columbia*: DC Code, 16-4901; *Florida*: FL Statutes 743.0645; *Georgia*: GA Code, 31-9-2; *Idaho*: ID Code, 39-4303; *Indiana*: IN Code, 16-36-1-5; *Kansas*: KS Statutes, 38-136 & 38-137; *Louisiana*: LA Statutes, 9:975; *Maryland*: MD Code, 20-105; *Mississippi*: MS Code, 41-41-3; *Missouri*: MO Statutes, 431.058 & 431.061; *Nevada*: NV Statutes, 129.040; *New Mexico*: NM Statutes, 24-10-2 (emergency medical attention) and NM Statutes, 40-10B-15 (school-related medical care); *New York*: NY Public Health, 2504; *North Carolina*: NC Statutes, 32A-34; *North Dakota*: ND Code, 23-12-13; *Oklahoma*: OK Statutes, Title 10, section 170.1; *Pennsylvania*: PA Code, Title 11, sections 2511-2513; *Texas*: TX Family Code, 32.001 et seq.; *Utah*: UT Code, 78-14-5; *Virginia*: VA Statutes, 54.1-2969
- 17 TN Code, 34-6-301
- 18 TANF replaced the former Aid to Families with Dependent Children (AFDC) program or “the welfare program”, as it was more commonly known.
- 19 Mark Greenberg and Steve Savner, *The Final TANF Regulations: A Preliminary Analysis* (Washington, DC: Center for Law & Social Policy, May 1999); Administration for Children and Families Office of Family Assistance, *Helping Families Achieve Self-Sufficiency: A Guide on Funding Services for Children and Families Through TANF*, (Washington DC: Department of Health and Human Services, 1999, available at: <http://www.acf.hhs.gov/programs/ofa/funds2.htm>).
- 20 Craig W. Abbey, *Welfare Reform: TANF Cash Benefits*, (Washington, DC: Congressional Research Service, March 2001). See also, the Center for Law & Social Policy’s and Center on Budget and Policy Priorities’ State Policy Documentation Project at www.spdp.org.
- 21 42 U.S.C. section 601.
- 22 Federal law prohibits using federal funds to provide assistance to families in which an adult has received TANF assistance for 60 months. Adult recipients must engage in work activities within 24 months of receiving assistance or sooner if states deem them ready to engage in work. States are required to have 50 percent of their families participating in specified work activities for a certain number of hours per week. The number of hours depends upon the age of the youngest child in the home and upon whether the family is a two-parent family or a single-parent family. 42 U.S.C. sections 602, 607, 608
- 23 Eligibility for Title IV-E requires that (1) the child be removed from his or her home pursuant to a court order or voluntary placement agreement, (2) the state or local child welfare agency is responsible for the child’s placement and care, (3) the child meets the Aid to Families with Dependent Children (AFDC) eligibility criteria at the time of removal or within the six months prior to removal and (4) the child is placed in a licensed or approved foster home or child care institution. The AFDC criteria include a requirement that the child be living with a parent or specified relative and that he or she meet the income and resource limits in place in that state on July 16, 1996. If a voluntary placement agreement is used, the child can be eligible for federal foster care assistance for more than 180 days only if there is a court determination that such placement is in the best interest of the child. 42 U.S.C. section 672.
- 24 *Youakim v. Miller*, 440 U.S. 125, 99 S.Ct. 957, 59 L.Ed. 2d 194 (1979).
- 25 See Amy Jantz, Rob, Geen, Roseana Bess, Cynthia Andrews, & Victoria Russ, *The Continuing Evolution of State Kinship Care Policies*, (Washington, DC: The Urban Institute, 2002) for a review of state policies regarding foster care payments for relatives.
- 26 Jeanette Wiedemeier Bower, *Forever Families: A Policy Analysis of Adoption Subsidy Programs in the United States*, (St. Paul, Minnesota: North American Council on Adoptable Children, July 2002).
- 27 The child may either meet the AFDC criteria and removal criteria described in note 8 or the criteria for the Supplemental Security Income program (Title XVI of the Social Security Act).
- 28 42 U.S.C. section 673

- 29 See the previous section of this publication for discussion of the rights and responsibilities associated with various legal relationships.
- 30 The child's parents generally remain obligated to pay child support while the child is living with a guardian. However, many of the circumstances that lead a grandparent or other relative to raise a child also make it unlikely that the parent can and will provide such support.
- 31 MaryLee Allen, Mary Bissell, and Jennifer Miller, *Expanding Permanency Options for Children: A Guide to Subsidized Guardianship Programs*, (Washington, DC: Children's Defense Fund and Cornerstone Consulting, 2003).
- 32 *Ibid.*
- 33 Federal law does not require that the relative caregiver have legal custody of the child to collect child support. However, some states have imposed that requirement.
- 34 42 U.S.C. section 608.
- 35 42 U.S.C. section 671(a)(17).
- 36 *Washington v. Keffler*, 537 U.S. 371, 123 S.Ct. 1017, 154 L.Ed. 2d 972, 2003 Lexis 1735 (2003).
- 37 Fuller-Thomson, E. and Minkler, M. (2003). Housing issues and realities facing grandparent caregivers who are renters. *The Gerontologist* 43:92-98.
- 38 Kaufman, S. and Goldberg-Glen, R. (2000). A comparison of low-income caregivers in public housing: Differences in grandparents and non grandparent needs and problems. In B. Hayslip and R. Goldberg-Glen (Eds.) *Grandparents Raising Grandchildren: Theoretical, Empirical and Clinical Perspectives*. NY: Springer Publishing Co. pp. 369-382.
- 39 Sand P. (2001). Generations united under one roof: A briefing paper on housing barriers for grandparents raising grandchildren. Unpublished paper.
- 40 *Ibid.*
- 41 *Ibid.*
- 42 Boston Aging Concerns- Young & Old United, Inc (BAC-YOU) and the Women's Institute for Housing and Economic Development.
- 43 Altshuler, S.J. (1998). Child Well-Being in Kinship Foster Care: Similar To, or Different From, Non-Related Foster Care, *Children and Youth Services Review* 20, 369-88. Pruchno, R. (1999). Raising Grandchildren: The Experiences of Black and White Grandmothers, *The Gerontologist* 39, 209-31.
- 44 Lynne M. Casper and Kenneth R. Bryson, *Co-resident Grandparents and Their Grandchildren: Grandparent-maintained Families*. Population Division Working Series #26 (Washington, DC: United States Census Bureau, 1998)
- 45 *Ibid.*
- 46 Minkler, M. (1999). Intergenerational Households Headed by Grandparents: Contexts, Realities, and Implications for Policy, *Journal of Aging Studies* 13, 199-218.
- 47 For a fuller discussion of Medicaid and CHIP enrollment policies and practices, see Mary K. Bissell and MaryLee Allen, *Healthy Ties: Ensuring Health Coverage for Children Raised by Grandparents and Other Relatives*, (Washington, DC: Children's Defense Fund, 2001).
- 48 For additional information on mental health screening, assessment, and services, see Children's Defense Fund, *The Grandparent's and Other Relative Caregiver's Guide to Raising Children with Disabilities*, (Washington, DC: Author, 2002), available at www.childrensdefense.org/childwelfare/kinshipcare/guides.asp. or Children's Defense Fund, *Children's Mental Health Resource Kit*, (Washington, DC: Author, 2003), available at www.childrens-defense.org/childwelfare/mentalhealth/resourcekit/default.asp.
- 49 The Federation of Families for Children's Mental Health website, www.ffcmh.org, has a list of state and local chapters that can be helpful in connecting relative caregivers to services.

- 50 For further discussion of medical consent and power of attorney laws and references to relevant state laws, see the legal background section of this publication. See also the State Fact Sheets for Grandparents and Other Relatives Raising Children at www.childrensdefense.org/childwelfare/kinshipcare/fact_sheets/default.asp.
- 51 American Academy of Pediatrics, Division of Health Policy Research, Children's Health Insurance Status Medicaid/SCHIP Eligibility and Enrollment Characteristics of Medicaid-enrolled and Uninsured Children: State Reports, 2002. (Washington, DC: Author, October 2003).
- 52 Rafael M. Semansky, Chris Koyanagi, and Rita Vandivort-Warren, "Behavioral Health Screening Policies in Medicaid Programs Nationwide," *Psychiatric Services*, May 2003, 54(5): 736-739.
- 53 American Academy of Pediatrics, Committee on Pediatric Emergency Medicine, "Consent for Emergency Medical Services for Children and Adolescents," *Pediatrics*, 2003, 111:703-706.
- 54 Family Caregiver Alliance. 2003. *Taking Care of You: Self-Care for Family Caregivers*.
- 55 Minkler, M. & Roe, K.M., 1993. *Grandmothers as caregivers: Raising children in the crack cocaine epidemic*. California: Sage Publications. Burnette. Denise. 1996. *Assessing the Strengths and Needs of Grandparent Caregivers in Inner-City Latino Families*. Columbia University, NY. Poe. Lenora Madison. 1992. *Black Grandparents As Parents*.
- 56 Sumner-Mayer, Kim. 2004. *Thoughts on The Ties That Bind: A Toast... To Your Health*. Brooklyn Grandparent's Coalition, Keeping In Touch, Issue XI, 8-9.
- 57 For purposes of this paper, respite is the temporary or short-term care of a child with or without a disability that enables a relative caregiver to be relieved of caregiving responsibilities for a short or extended period of time and can be provided in-home, out of home, or in an emergency.
- 58 The respite examples cited in this section are those currently provided by Brookdale Foundation Relatives As Parents Programs (RAPPs).
- 59 42 U.S.C. section 11434a(2)(A)(B)(i)
- 60 42 U.S.C. section 11434a(6)
- 61 34 C.F.R. section 300.20
- 62 20 U.S.C. section 7801(31)
- 63 Susan Nall Bales, *Effective Language for Communicating Children's Issues*, Coalition for America's Children with the Benton Foundation (Washington, DC: 1999).
- 64 The FrameWorks Institute website has a variety of resources to help advocates effectively frame social issues at <http://www.frameworksinstitute.org>.
- 65 Linda M. Creighton, *Silent Saviors*, U.S. News and World Report, December 16, 1991.
- 66 See also, *Telling New Stories About Children's Issues*, Issue No. 6, Kids Count E-Zines, FrameWorks Institute 1/22/04 based on a study that found that people want to be generous with those in need but believe many take advantage of the system.
- 67 Doug Besharov, *How to Help Welfare Mothers*, The New York Times, November 13, 1996.
- 68 "I feel like I am coming out of the most difficult period of my life. Still, I consider it a privilege to see my grandchildren have excellent care." Wyoming Tribune-Eagle 4/5/04. "I love this little boy. He is my whole life and I am lucky to have him." Daily Oklahoman 1/1/04. "It's a lot of work, but I wouldn't change a thing," she says of raising her granddaughter. St. Petersburg Times 1/2/04; "We're blessed with magic." Detroit News 3/19/98
- 69 "I just want grandparents to know they are not alone." St. Petersburg Times 1/2/04. "But most of all, they find that they're not alone." Lewiston Morning Tribune 5/2/04.

⁷⁰ For more information about how to message social issues effectively, the following organizations are helpful:

FrameWorks Institute advances the nonprofit sector's communications capacity by identifying, translating, and modeling relevant scholarly research for framing the public discourse about social problems. The organization designs, commissions, manages, and publishes communications research to prepare nonprofit organizations to expand their constituency base, to build public will, and to further public understanding of specific social issues. Especially helpful are FrameWorks E-Zines, 3 to 5 page explorations of a technique or topic that analyzes framing problems and opportunities. 1776 I Street, NW, 9th Floor, Washington, DC 20006; 202-833-1600 or www.frameworksinstitute.org.

Connect for Kids helps adults make their communities better places for families and children by providing an alternative news source on the Web with solutions-oriented coverage of critical issues for children and families. Its goal is to go far beyond the personal stories that dominate family coverage in most news outlets by bringing together meaningful information, success stories, and ideas for action. Sign up for the Connect for Kids Weekly, which takes a comprehensive look at children and the news to bring you new data, new reports, and new challenges facing children and families. 1625 K Street, NW, 11th Floor, Washington, DC 20006, 202-638-5770 or www.connectforkids.org.

The Communications Consortium Media Center is a public interest media center dedicated to helping nonprofit organizations use media and new telecommunications technologies for public education and policy change. CCMC was created in 1988 by veteran nonprofit communications and media specialists who understood that effective communications strategies are essential in order to turn ideas into public policy. 1200 New York Avenue, NW, Suite 300, Washington, DC 20005-1754, 202-326-8700 or www.ccmc.org.

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AARP is a nonprofit, nonpartisan membership organization dedicated to making life better for people 50 and over. AARP provides information and resources; engages in legislative, regulatory and legal advocacy; assists members in serving their communities; and offers a wide range of unique benefits, special products, and services for members. These include AARP *The Magazine*, published bimonthly; AARP *Bulletin*, the monthly newspaper; AARP *Segunda Juventud*, the quarterly newspaper in Spanish; NRTA *Live and Learn*, the quarterly newsletter for 50+ educators; and the website, www.aarp.org. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

The AARP Grandparent Information Center (AARP GIC) provides national and local level information and referrals for grandparents, program practitioners, researchers, policymakers and the general public. The AARP GIC offers a free quarterly newsletter for grandparents raising grandchildren, various print publications, and a national Support Database available on the website www.aarp.org/grandparents.

CONTACT INFORMATION:

AARP Grandparent Information Center
601 E Street, N.W.
Washington, D.C. 20049
Phone: (888) OUR-AARP (1-888-687-2277)
Fax: (202) 434-6474
Email: gic@aarp.org
www.aarp.org/grandparents

American Academy of Pediatrics

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The American Academy of Pediatrics (AAP) and its member pediatricians dedicate their efforts and resources to the health, safety, and well being of infants, children, adolescents, and young adults. The AAP has 60,000 members in the United States, Canada, and Latin America. Members include pediatricians, pediatric medical subspecialists, and pediatric surgical specialists. More than 34,000 members are board-certified and called Fellows of the American Academy of Pediatrics (FAAP). The AAP has chapters in every state. The mission of the American Academy of Pediatrics is to attain optimal physical, mental, and social health and well being for all infants, children, adolescents, and young adults. To this purpose, the AAP and its members dedicate their efforts and resources.

CONTACT INFORMATION:

American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Phone: (847) 434-4000
Fax: (847) 434-8000
E-mail: kidsdocs@aap.org
www.aap.org

The Brookdale Foundation Group

The Brookdale Foundation Group consists of The Brookdale Foundation, The Glendale Foundation, and Ramapo Trust. Each entity, which is totally distinct with separate Officers and Boards of Directors

or Trustees, was originally endowed by the Schwartz Family and shares a common outlook and purpose. Although Henry, Irving, Robert, Benjamin, and Arnold Schwartz are all deceased, their vision and compassion remain the driving force as we focus on the needs and challenges of America's elderly population.

The Relatives As Parents Program (RAPP), initiated in 1996 by the Foundation, was created to promote the creation and expansion of services to grandparent caregivers and other relatives raising children. RAPP has evolved into a comprehensive, nationwide community approach of providing high quality services to relative caregivers and their families. RAPPs provide services to relative caregivers and their families in 42 states. In addition, 35 State Public Agencies in the RAPP National Network serve as a focal point for addressing programmatic and policy issues statewide.

CONTACT INFORMATION:

The Brookdale Foundation Group
950 Third Avenue, 19th Floor
New York, NY 10022
Phone: (212) 308-7355
Fax: (212) 750-0132
www.brookdalefoundation.org



Casey Family Programs' mission is to provide and improve—and ultimately to prevent the need for—foster care. Established by United Parcel Service founder Jim Casey, the Seattle-based national operating foundation has served children, youth, and families in the child welfare system since 1966. The founda-

tion operates in two ways. It provides direct services, and it promotes advances in child welfare practice and policy.

Casey collaborates with foster, kinship, and adoptive families to provide safe, loving homes for youth in its direct care. The foundation also collaborates with counties, states, and American Indian and Alaska Native tribes to improve services and outcomes for the more than 500,000 young people in out-of-home care across the U.S.

Drawing on four decades of front-line work with families and alumni of foster care, Casey Family Programs develops tools, practices, and policies to nurture all youth in care and to help parents strengthen families at risk of needing foster care.

CONTACT INFORMATION:

Casey Family Programs
1300 Dexter Avenue North
Seattle, WA 98109-3542
Phone: (206) 282-3330
www.casey.org



The Child Welfare League of America (CWLA) is an 83-year-old national, non-profit membership organization devoted to protecting children and strengthening families. It unites almost 1,100 public and private agencies, community based and regionally organized, that serve over three million children, youth, and their families every year across the United States. A 49-member elected board of directors provides governance and oversight. With

headquarters in Washington, DC, CWLA also operates regional offices in Baltimore, Boston, Chicago, Denver, Los Angeles, and Reston, Virginia.

Through its membership, CWLA advocates for high standards of practice, sound public policies, and quality services. Its mission is to provide guidance, training, technical assistance, research, and consultation to its member agencies and the field of child welfare, and to advocate in the public arena on behalf of vulnerable children and their families, as well as those who serve them. Goals include developing and promoting standards for the improvement of child welfare practice in the support, care, and treatment of children and their families; for the delivery of services; and for the administration of agencies; formulating, promoting, and advocating for public policies that benefit all children and their families; improving the field's ability to meet the needs of children and their families by increasing, serving, and strengthening CWLA member agencies; and ensuring that all agencies, services, and programs are conducted in a manner that respects and values the cultural and ethnic diversity of their constituents.

CONTACT INFORMATION:

Child Welfare League of America
50 F Street, N.W., 6th Floor
Washington, D.C. 20001
Phone: (202) 942-0282
Fax: (202) 737-3687
www.cwla.org



Children's Defense Fund
LEAVE NO CHILD BEHIND®

The mission of the Children's Defense Fund (CDF) is to **Leave No Child Behind®** and to ensure every child a Healthy Start, a Head Start, a Fair Start, a

Safe Start, and a Moral Start in life and successful passage to adulthood with the help of caring families and communities.

CDF provides a strong, effective voice for all the children of America who cannot vote, lobby or speak for themselves. We pay particular attention to the needs of poor and minority children and those with disabilities. CDF educates the nation about the needs of children and encourages preventive investment before they get sick or into trouble, drop out of school or suffer family breakdown.

CDF began in 1973 and is a private, non-profit organization supported by foundation and corporate grants and individual donations.

CONTACT INFORMATION:

Children's Defense Fund
Child Welfare and Mental Health Division
25 E Street, N.W.
Washington, D.C. 20001
Phone: (202) 662-3568
Email: childwelfare@childrensdefense.org
www.childrensdefense.org



Generations United (GU) is the national membership organization focused solely on improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. GU represents more than 100 national, state, and local organizations and individuals representing more than 70 million Americans. Since 1986, GU has served as a resource for educating policymakers and the public about the economic, social, and personal imperatives of

intergenerational cooperation. GU acts as a catalyst for stimulating collaboration between aging, children, and youth organizations providing a forum to explore areas of common ground while celebrating the richness of each generation.

As part of the National Family Caregiver Support Program (NFCSP), GU was awarded an Innovative Grant by the U.S. Department of Health and Human Services, Administration on Aging to establish the National Center on Grandparents and Other Relatives Raising Children (National Center) to support the implementation of the NFCSP and to focus on issues related to relative-headed families. The GU National Center seeks to improve the quality of life of grandparents and other relative caregivers and the children they are raising by addressing the unique needs of each generation. It provides a wide variety of resources, technical assistance, and training to service providers and professionals across the country, and educates policymakers on the importance of adopting intergenerational public policies and programs.

CONTACT INFORMATION:

Generations United
1333 H Street, N.W., Suite 500
Washington, D.C. 20005
Phone: (202) 289-3979
Fax: (202) 289-3952
Email: gu@gu.org
www.gu.org

Symposium Participants

The participants' affiliations listed below were at the time of the symposium in July 2004.

MaryLee Allen

Director, Child Welfare and Mental Health
Children's Defense Fund
Washington, D.C.

Kathy Barbell

Senior Program Director, Program
Operations
Child Welfare League of America
Washington, D.C.

Ana Beltran

Special Advisor
Generations United
Bellevue, Washington

Mary Bissell

Fellow
New America Foundation
Washington, D.C.

Dr. Mary Brintnall-Peterson

Program Specialist in Aging
University of Wisconsin Extension
Madison, Wisconsin

Kenneth Bryson

Program Analyst
U.S. Census Bureau
Washington, D.C.

Megahn Bufford

Grandparents as Parents (G.A.P.) Limited
South Bend, Indiana

Opal Bufford

CEO
Grandparents as Parents (G.A.P.) Limited
South Bend, Indiana

Donna Butts

Executive Director
Generations United
Washington, D.C.

Sandy Cross

Executive Director
Grand Central, Inc./
Kinship Care Resource Center
Philadelphia, Pennsylvania

Dr. Joseph Crumbley

Therapist and Kinship Care Consultant
Jenkintown, Pennsylvania

Adrienne Dern

Deputy Director
National Association of Area Agencies
Washington, D.C.

Kikora Dorsey

Senior Manager
Casey Family Programs
Seattle, Washington

Brent Elrod

Statewide Coordinator
Florida Kinship Center
Tampa, Florida

Jill Erickson

Division of Service & Systems
Improvement
Center for Mental Health Services
Rockville, Maryland

Cecilia Fiermonte

Assistant Director of Child Welfare
American Bar Association
Center on Children and the Law
Washington, D.C.

Rob Geen

Senior Research Associate
Urban Institute
Washington, D.C.

Amy Goyer

Coordinator, Grandparent Information
Center
AARP
Washington, D.C.

Rick Greene

Program Specialist
Administration on Aging
Washington, D.C.

Bernice Hutchinson

Director, National Family Caregiver
Support Project
National Association of State Units on
Aging
Washington, D.C.

Rutledge Hutson

Deputy Director, Child Welfare & Mental
Health Division
Children's Defense Fund
Washington, D.C.

Dr. Carden Johnston

President
American Academy of Pediatrics
Birmingham, Alabama

Linette Kinchen

Executive Director
GRANDFamilies Program of Chicago, Inc.
Chicago, Illinois

Deborah Langosch

Program Director
The Jewish Board of Family & Children's
Services
New York, New York

Jaia Peterson Lent

Public Policy Director
Generations United
Washington, D.C.

Jo Lightfeather

Manager, Library/Research/Clearinghouse
& Training Program
Minnesota Indian Women's Resource
Center
Minneapolis, Minnesota

Kristie Lund

Kinship Caregiver Project Coordinator
Relatives as Parents Project
Kent, Washington

Dr. Phillip McCallion

Director, Center for Excellence in Aging
Services and Associate Professor
School of Social Welfare
University at Albany
Albany, New York

Nichelle Mitchem

Director of Operations
National Center on Grandparents Raising
Grandchildren
Georgia State University
Atlanta, Georgia

Carol Moore

Kinship Care Coordinator
Mountain Empire Older Citizens
Big Stone Gap, Virginia

Pat Owens

Vice-President, National Committee of
Grandparents for Children's Rights
Member, Coalition to Protect Maryland's
Children
Thurmont, Maryland

Melinda Perez-Porter

Program Associate
The Brookdale Foundation Group
New York, New York

Rolanda Pyle

Director
Grandparent Resource Center
New York City Department for the Aging
New York, New York

Janet Sainer

Special Consultant
The Brookdale Foundation Group
New York, New York

Barbara Schwartz

Bureau Chief, Intergenerational Programs/
Program Coordinator, Grandparents
Illinois Department on Aging
Springfield, Illinois

Dr. Carrie Jefferson Smith

Associate Professor
Syracuse University School of Social Work
Syracuse, New York

Sheri Steinig

Special Projects Director
Generations United
Washington, D.C.

Chauncey Strong

Manager, Systems Improvement
Methodology
Casey Family Programs
Washington, D.C.

Geneva Ware-Rice

Child Welfare Specialist
Children's Bureau
Washington, D.C.



Generations United
1333 H Street, N.W., Suite 500W
Washington, D.C. 20005
Phone: (202) 289-3979
Fax: (202) 289-3952
Email: gu@gu.org
www.gu.org