



Satellite Broadcast Resource List

The “Department of Health and Human Services Programs Supporting Caregivers across the Lifespan” Satellite Broadcast is presented by the New Freedom Initiative (NFI) Subcommittee on Caregiving. NFI is a government-wide effort directed at eliminating the barriers that prevent people with disabilities from participating fully in community life.

Through this broadcast we want to bring greater awareness and understanding of the programs that help caregivers, providers, and partners in the Department of Health and Human Services. We hope this compilation aids in this effort.

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New Freedom Initiative

President Bush announced the New Freedom Initiative on February 1, 2001, as part of a nationwide effort to remove barriers to community living for people with disabilities. The New Freedom Initiative is a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life.

New Freedom Initiative Website

<http://www.hhs.gov/newfreedom/>

This website contains information on the New Freedom Initiative.

New Freedom Initiative Subcommittee on Caregiving

http://www.hhs.gov/od/about/fact_sheets/fs4_caregiving.html

This web page, housed on the HHS Office of Disability website, contains background information on the New Freedom Initiative Subcommittee on Caregiving.

Administration on Aging

The mission of the Administration on Aging is to assist elderly individuals maintain their independence and dignity in their homes and communities through comprehensive, coordinated, and cost effective systems of home and community-based long-term care across the U.S. AoA works in close collaboration with the Aging Network of states, Area Agencies on Aging, and local community service provider agencies – the most visible, trusted community resources for information access and services.

National Family Caregiver Support Program (NFCSP) “Resource Room”

<http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>

The Caregiver Resource Room is where families, caregivers, and professionals can find information about the National Family Caregiver Support Program, including: where you can turn for support and assistance, and providing services to caregivers.

National Family Caregiver Support Program State Contacts

http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/state_by_state/FCSP_state_Contact_Directory.doc

This document will link you to NFCSP Project Directors in each state.

National Family Caregiver Support Program (NFCSP) State Websites

http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/state_by_state/CG_State_Websites.doc

This document will link you to NFCSP websites in each state.

National Family Caregiver Support Program (NFCSP) Fact Sheets

<http://www.aoa.gov/prof/aoaprogram/caregiver/overview/fact.asp>

NFCSP develops fact sheets on topics of interest to caregivers and professionals. Fact Sheet titles include:

- Just In Case - Emergency Readiness for Older Adults and Caregivers
- Adult Day Services - How Can They Help You
- Caring for Someone with Developmental Disabilities
- Care Receiving: Creating Partnerships in Self Care
- Caring for Someone in the Last Years of Life
- Communicating Better with Health Professionals
- Resolving Conflicts Related to Family Caregiving
- Consumer Direction: Home and community Based Services
- Working Caregivers: Finding a Balance
- Grandparent Resources
- Home Modifications and Assisted Devices
- Taking Care of Yourself
- Grandparents and Other Relatives Raising Children

- Transportation Issues to Consider
- Transportation Tips for Caregivers
- Caregiver Cooperatives – Voluntary Respite Services
- New Medicare Prescription Drug Coverage: A Message for People who Care for Someone with Medicare
- Financial Tips for Woman Caregivers
- Caregiver Tip Sheet

The Native American Caregiver Support Program (NACSP) Fact Sheets

<http://www.aoa.gov/prof/aoaprogram/caregiver/overview/fact.asp>

The Older Americans Act Amendments in 2000 also created the Native American Caregiver Support Program (NACSP). This webpage contains several American Indian and Alaska Native-specific fact sheets. Fact sheet titles include:

- Blackfeet Nation
- Central Council of Tlingit and Haida Indian Tribes
- Confederated Salish and Kootenai Tribes
- Culturally Appropriate Caregiving: A Native Caregiving Model
- Jamestown S’Klallam Tribe
- Kupuna Caregiver Support Program
- Oneida Tribe of Indians of Wisconsin
- Rosebud Sioux Tribe
- South Puget Intertribal Planning Agency

Conducting Local Assessments: Locating the Needs of Elders

<http://www.med.und.nodak.edu/depts/rural/nrcnaa/research/index.html>

The purpose of this study is to compare Native American elders to the general U.S. population to determine the extent of existing social and health differences. A survey instrument was constructed using questions from nationally administered questionnaires that comparisons might be made with data from the nation. Data is collected on: General health status, Indicators of chronic disease, Indicators of activity limitations, Indicators of vision and hearing, Tobacco and alcohol use, Diet and exercise, and Social supports.

Eldercare Locator

<http://www.eldercare.gov/>

The Eldercare Locator is a public service of the U.S. Administration on Aging and is the first step to finding resources for older adults in any U.S. community. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.

Alzheimer’s Disease Demonstration Grants to States (ADDGS) “Resource Room”

<http://www.aoa.gov/alz>

The Alzheimer’s Resource Room is where families, caregivers, and professionals can find information about The Alzheimer’s Demonstration Program, including: where you can turn for support and assistance, and providing services to caregivers.

Aging and Disability Resource Centers (ADRC)

http://www.aoa.gov/prof/aging_dis/aging_dis.asp

The Aging and Disability Resource Center (ADRC) Grant Program, a cooperative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS), was developed to assist states in their efforts to create a single, coordinated system of information and access for all persons seeking long term support to minimize confusion, enhance individual choice, and support informed decision-making. Since 2003 43 states have received ADRC initiative grants.

Own Your Future Website

http://www.longtermcare.gov/LTC/Main_Site/Planning_LTC/Campaign/index.aspx

The Own Your Future Campaign is a project, started in January 2005, to increase consumer awareness about, and planning ahead for, long-term care. The project's core activities are state based direct mail campaigns supported by each participating state's Governor, and targeted to households with members between the ages of 45 to 70. Campaign materials include a Long-Term Care Planning Kit and state specific information and resources.

Administration on Developmental Disabilities

The Administration on Developmental Disabilities (ADD) is the U.S. Government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, known as the DD Act. ADD, its staff and programs, are part of the Administration for Children and Families, of the U.S. Department of Health and Human Services.

The Developmental Disabilities Act

<http://www.acf.hhs.gov/programs/add/ddact/DDACT2.html>

requires ADD to ensure that people with developmental disabilities and their families receive the services and supports they need and participate in the planning and designing of those services. The DD Act established eight areas of emphasis for ADD programs; Employment, Education, Child Care, Health, Housing, Transportation, Recreation, and Quality Assurance. ADD meets the requirements of the DD Act through the work of its four programs:

State Councils on Developmental Disabilities (SCDD)

<http://www.acf.hhs.gov/programs/add/states/ddcs.html>

Each state has a Developmental Disabilities Council that functions to increase the independence, productivity, inclusion, and community integration of people with developmental disabilities. DDC activities demonstrate new ideas for enhancing people's lives through training activities, through community education and support, by making information available to policy-makers, and by eliminating barriers.

Protection and Advocacy Agencies (P&A)

<http://www.acf.hhs.gov/programs/add/states/pas.html>

Each state has a Protection and Advocacy (P&A) System to empower, protect, and advocate on behalf of persons with developmental disabilities. The P&As are independent of service-providing agencies and offer information and referral services for

legal, administrative, and other remedies to resolve problems for individuals and groups of clients. P&As enhance the quality of life of people with developmental disabilities by investigating incidents of abuse and neglect and discrimination based on disability. The P&As also provide an annual opportunity for the public to comment on the objectives, priorities, and activities of the system. This gives clients and others in the community an opportunity to voice their concerns and needs to the P&A.

University Centers for Excellence in Developmental Disabilities Education, Research and Services (UCEDD)

<http://www.acf.hhs.gov/programs/add/states/ucedds.html>

UCEDD is a grant program providing support to a national network of University Centers to support interdisciplinary training, exemplary services, technical assistance, and information/dissemination activities. University Centers positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities. University Centers have four broad tasks: conduct interdisciplinary training, promote community service programs, provide technical assistance at all levels (from local service delivery to community and state governments), and conduct research and dissemination activities.

Projects of National Significance (PNS)

<http://www.acf.hhs.gov/programs/add/pns/pns.html>

The PNS program awards grants and contracts that promote and increase the independence, productivity, inclusion and integration into the community of persons with developmental disabilities. These projects focus on the most pressing issues for people with developmental disabilities across the country. These projects may involve research, technical assistance, projects which improving supportive living and quality of life opportunities, projects to educate policymakers, and efforts to create interagency Federal collaboration.

Centers for Medicare & Medicaid Services

The mission of the Centers for Medicare & Medicaid Services (CMS) is to ensure effective, up-to-date health care coverage and to promote quality care for beneficiaries, which will be accomplished by continuing to transform and modernize America's health care system.

The Official Medicare Website for Consumers

<http://www.medicare.gov>

The medicare.gov website provides information and tools to inform consumers and assist caregivers in helping a loved one with their Medicare health benefits and choices. Don't forget Medicare's open enrollment is November 15 to December 31 every year. Go to www.medicare.gov on the web to:

- See what Medicare plans are in your area.
- Find doctors who participate in Medicare.
- See what Medicare covers, including preventive services.
- Get Medicare appeals information and forms.

- Get information on the quality of care provided by nursing homes, hospitals, home health agencies, plans, and dialysis facilities.
- Look up helpful telephone numbers for your area.
- View Medicare publications.

MyMedicare.gov

<http://www.MyMedicare.gov>

Medicare's secure online service for accessing personal Medicare information. People with Medicare and their caregivers can use this website to track the individual's health care claims, eligibility information, preventives services used, and keep the individual's Medicare information in one convenient place.

Medicare Publications

<http://www.medicare.gov/Publications>

CMS develops a wide range of publications on Medicare and other related topics, including:

Medicare Basics: A Guide for Caregivers

<http://www.medicare.gov/Publications/Pubs/pdf/11034.pdf>

Medicare Basics highlights eight decision points related to the health or overall well-being of an older person. For each of these decision points, you'll find basic information about Medicare and suggestions on finding more detailed information.

When Employees Become Caregivers: A Manager's Workbook

<http://www.medicare.gov/Publications/Pubs/pdf/11035.pdf>

A Manager's Workbook guides employers in how to make eldercare and Medicare information available to caregiving employees at little or no cost.

*Please note, the first page is the order form to send to AARP to request hardcopies

State Health Insurance Assistance Program (SHIP)

<http://www.medicare.gov/contacts/Static/SHIPs.asp?dest=NAV%7CHome%7CRelatedWebsites%7CSHIPs>

The State Health Insurance Assistance Program, or SHIP, is a national program available in every state that offers free one-on-one counseling and assistance (over the telephone or in-person) to people with Medicare and their caregivers.

CMS Caregiver Partnerships and Caregiver Workgroup

http://www.cms.hhs.gov/Partnerships/12_Caregiver.asp#TopOfPage

CMS formed a Caregivers Workgroup in 1999, composed of caregiver organizations, beneficiary advocacy groups, providers, insurers, employers, and other organizations with an interest in care giving. This group meets quarterly and discusses how Medicare information can better be communicated to this population and what the members of this group can do to make that happen.

Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees

<http://www.hcbs.org/files/91/4525/FTFPaper.pdf>

This paper is one in a series addressing major topic areas in the Systems Change for Community Living Grants Program. It describes the activities of 19 Grantees who received grant funding in fiscal years 2003 and 2004 CMS, and six Grantees funded in fiscal year 2002 by the Maternal and Child Health Bureau (MCHB)/Health Resources and Services Administration (HRSA). The purpose of the grants is to support the development of Family to Family Health Information Centers to assist families of children with special health care needs to obtain the wide range of services and supports they need. This paper describes grant activities, implementation challenges, and accomplishments. Its primary purpose is to provide information that states and stakeholders will find useful when planning or implementing similar initiatives.

Innovative Strategies for Strengthening Family to Family Health Information and Education Centers

http://www.hcbs.org/files/96/4754/F2F_PromPrac.pdf

Following a brief overview of the Family to Family Centers are examples of grantees' implemented strategies to strengthen their Center, grouped by theme. Additional information and background on these practices was also obtained by reviewing grantees' Web sites and their annual grant reports. After each example, contact information is included so readers may easily learn more about particular practices.

Department of Veterans Affairs

The Department of Veterans Affairs is the federal agency dedicated to meeting the needs of veterans of their families through providing excellence in patient care, veterans' benefits, and customer satisfaction.

Clinical Programs & Initiatives

<http://www1.va.gov/health/clinical.html>

This website lists VA clinical programs and initiatives that support veterans and their families.

Health Resources and Services Administration

The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable. HRSA provides national leadership, program resources and services needed to improve access to culturally competent, quality health care.

Family-To-Family Health Information Centers

<http://www.familyvoices.org/projects/f2f.php>

Family-To-Family Health Information Centers are state-based, family-run centers providing technical assistance and parent support to families of children with special health care needs. They develop partnerships with those organizations serving these children and their families in order to assist families get community based resources

and monitor the issues families have with services, financing and agencies. These centers have been funded by MCHB and the Centers for Medicare and Medicaid.

Family Voices

www.familyvoices.org

Resource Catalogue: <http://www.familyvoices.org/catalog.php>

Family Voices, a national grassroots network of families and friends, advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision makers at all levels of health care; and supports essential partnerships between families and professionals. Family Voices is also the home of The National Center for Family/Professional Partnerships. This site has information that includes information for advocates, caring for your child and health care financing issues.

Friday's Child Newsletter

<http://www.familyvoices.org/pub/fc/index.php>

Friday's Child is a bi-weekly e-newsletter containing information for existing and emerging family leaders on topics such as leadership, mentoring, partnering and team building. Each issue provides news and resources from the Family Voices network and the broader community of families and friends of children and youth with special health care needs.

"What Does Normal Mean?"

To Order - Contact Adelita Martinez at amartinez@familyvoices.org or call: (888) 835-5669.

The film-makers and the producers, two of whom have sons with disabilities, created a film that illustrates how inclusion can succeed and learning environments improve when school administrators, teachers, families, and disabled students and their friends work together. The cost is \$50 for individuals and family-run organizations plus shipping and handling and \$100 for schools, agencies, institutions, businesses plus shipping and handling.

The Employee Benefit Study for Families of Children with Special Health Care Needs

Workplace Benefits for Families with Special Needs: A Guide for Employees

http://massgeneral.org/children/professionals/ccahp/empl_benefit_study/pdf/EmployeeGuide.pdf

The purpose of this guide is to educate working parents about employer sponsored benefits and supports. It addresses the kinds of benefits and policies that may be available and describes ways to access these benefits, particularly Health Care Benefits, Work-Life and Employee Assistance Programs, and Flexible Spending Accounts.

Children with Special Needs and the Workplace: A Guide for Employers:

http://massgeneral.org/children/professionals/ccaahp/empl_benefit_study/pdf/EmployerGuide.pdf

This guide explores how the care of a child with a chronic condition or disability can impact an employee's work life and describes ways in which employers can address the workplace needs of these employees.

Helpful Workplace Benefits for Families of Children with Special Needs

<http://www.familyvoices.org/pub/projects/HelpfulEmployeeBenefits.PDF>

This document highlights supportive programs and policies that were identified by families in their roles as productive employees and good parents.

Health and Ready To Work National Center

www.hrtw.org

The website has resources for agencies, providers, families and youth related to transition, including state-specific SSI Information. See "A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs", PEDIATRICS Vol. 110 No. 6 December 2002 on this web site.

HHS Office on Disability

The Health and Human Services Office on Disability was created in October 2002 in response to President Bush's New Freedom Initiative (NFI). The office oversees the implementation and coordination of disability programs, policies and special initiatives pertaining to the over 54 million persons with disabilities in the United States.

Office on Disability Fact Sheet

http://www.hhs.gov/od/about/fact_sheets/fctsht0305.html

This fact sheet contains additional information on the Office on Disability (OD) as well as a list of featured programs, including "Caregiver/Workforce Challenges for Persons with Disabilities," which is an OD-led workgroup identifying the strengths, gaps, and opportunities in HHS caregiving-related programs to enhance the human capacity to promote community living for people with disabilities.

Indian Health Service

The Indian Health Service (IHS), an agency within the Department of Health and Human Services, is responsible for providing federal health services to American Indians and Alaska Natives. The IHS is the principal federal health care provider and health advocate for Indian people, and its goal is to raise their health status to the highest possible level.

Indian Health Service Website

<http://www.ihs.gov/>

National Alliance for Caregiving

The National Alliance for Caregiving is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers.

National Alliance for Caregiving Website

<http://www.caregiving.org/>

The National Alliance for Caregiving website has a multitude of resources for professionals and family caregivers.

National Cancer Institute

The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

National Cancer Institute Website

<http://www.cancer.gov/>

The National Cancer Institute has produced three booklets on issues affecting caregivers of relatives with cancer. They include:

- [When Someone You Love Is Being Treated for Cancer](#)
- [When Someone You Love Has Advanced Cancer](#)
- [Facing Forward When Someone You Love Has Completed Cancer Treatment](#)

National Institute on Aging

The National Institute on Aging (NIA), which is part of the National Institutes on Health, leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. NIA's mission is to improve the health and well-being of older Americans through research.

So Far Away: Twenty Questions for Long-Distance Caregivers

<http://www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/>

Published by the National Institute on Aging, this booklet is organized in a question/answer format. Each of the 20 commonly asked questions has a brief, stand-alone answer.

Caregiver Guide – Tips for Caregivers of People with Alzheimer's Disease

<http://www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm>

This guide, published by the National Institute on Aging, provides strategies caregivers of people with Alzheimer's disease can use to deal with difficult behaviors and stressful situations.

Caring for Someone with Alzheimer's Disease

<http://nihseniorhealth.gov/alzheimerscare/toc.html>

This website, offered by the National Institute on Aging, is an interactive guide on how to care for loved one with Alzheimer's disease. It focuses on: Home Care, Residential Care, Safety Issues, and Caregiver Support.

United States Department of Agriculture - Cooperative Extension System

The Cooperative Extension System, also known as the Extension Service of the United States Department of Agriculture [USDA](#), is the largest non-formal educational program in the world and is implemented across the United States to help people use research-based knowledge to improve their lives. The service is provided by the state's designated [land-grant universities](#). In most states the educational offerings are in the areas of agriculture and food, home and family, the environment, community economic development, and youth and 4-H. The Cooperative State Research, Education, and Extension Service (CSREES) USDA administers funding for [Smith Lever Act](#) services in cooperation with state and county governments and land-grant universities.

The Cooperative Extension System is uniquely positioned to reach out to caregivers and their families- to inform and educate them about the myriad issues, challenges, and opportunities related to population aging. Current work in this area focuses on research, education, and outreach to individuals, families, and communities preparing for or experiencing the impact of population aging and associated transitions in the family life course. Most notably, the system provides educational information and resources to address caregiving needs from a multidisciplinary perspective, utilizing expertise in such areas as nutrition, financial security, health, and housing to address family caregiving and related aging issues. The Cooperative Extension Systems offers many educational resources for caregivers:

eXtension

www.extension.org

This is an educational partnership of more than 70 universities to help improve life every day with access to objective, research-based information and educational opportunities. Currently in development, the site has already launched several Communities of Practice including the eXtension Personal Finance site

http://www.extension.org/personal_finance which has relevant information for caregivers. A Family Caregiving Community of Practice will be launched on eXtension in the fall of 2007.

AgrAbility Program

AgrAbility is a consumer-driven USDA-funded program that provides vital education, caregiving assistance, and support to farmers and ranchers with disabilities. Through the combined dedication and expertise of the Cooperative Extension System and nonprofit disability organizations, AgrAbility helps thousands of determined individuals overcome the barriers to continuing their chosen professions in agriculture.

http://www.csrees.usda.gov/nea/ag_systems/in_focus/workforce_if_agrability.html Visit the <http://www.agrabilityproject.org/stateprojects.cfm> link and click on your state to see the resources available to you.

Cooperative Extension System Publication on Aging Issues

http://www.csrees.usda.gov/nea/family/pdfs/aging_resources.pdf

In collaboration with CSREES, Cooperative Extension System faculty have contributed information and resources to the development of the 2006-2007 Cooperative Extension System Resources, Contacts, and Collaborations: Aging Issues, with resources and contacts on aging issues organized by state. This e-publication includes the name and contact information for each of the partner institutions, as well as more detailed contact information for the heads of the aging education programs. This publication is updated annually.

Powerful Tools for Caregiving

<http://www.uwex.edu/ces/flp/caregiving/education/powerfultools/index.cfm>

Powerful Tools for Caregivers (PTC) is an educational program designed to support family caregivers of older adults in a way that enhances their well being as they care for others. Extension is rapidly becoming the lead agency for dissemination of *Powerful Tools for Caregivers* to expand the *Powerful Tools for Caregivers* program in all 50 states so that there are Master Trainers and Class Leaders in all states.

Wisconsin Alliance for Family Caregiving

<http://www.uwex.edu/ces/flp/caregiving/index.cfm>

The Wisconsin Alliance for Family Caregiving is a statewide non-profit organization with the mission of providing education, support, and resource to professionals who work directly with family caregivers.

League of Experienced Caregivers

www.familycaregivers.uwm.edu

The League of Experienced Family Caregivers (LEFC) is a registry of family members who care for their spouses, parents, or other elderly relatives and who want to help other families by sharing information about their experiences as caregivers.

Partners in Caregiving

<http://citra.org/Assets/documents/PIC%20final%20manual%20las%20edits.pdf>

Cornell Institute for Translational Research on Aging resource on support of and education with caregivers and families lead to improved elder care.

Other Caregiving Resources

The State of the States in Family Caregiver Support: A 50-State Study

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1220

This report profiles the experience of all 50 states and the District of Columbia since the passage of the National Family Caregiver Support Program in providing publicly funded support services to family and informal caregivers of older people and adults with disabilities.

Womenshealth.gov: Caregiver Stress

<http://www.womenshealth.gov/wwd/caregiving.cfm?style=module>

Womenshealth.gov is the federal government source for women's health information.