APPENDIX 28. SURVEY OF THE PUBLIC INFORMATION NEEDS OF DISADVANTAGED AND SPECIAL POPULATIONS

In early September 2000, NCLIS conducted an informal survey of 9 organizations that represent, or advocate on behalf of, special populations including disabled or disadvantaged individuals to determine their policies, programs and practices relating to public information dissemination. The survey instrument and the survey results are provided below.

NCLIS SURVEY OF THE PUBLIC INFORMATION NEEDS OF DISADVANTAGED AND SPECIAL POPULATIONS[125]

Conducted by F. Woody Horton and Sarah T. Kadec, NCLIS Consultants

SURVEY INSTRUMENT[126]

Several committees of the U.S. Congress have asked the U.S. National Commission on Libraries and Information Science (NCLIS) to recommend reforms to the Nation's laws, policies, programs, and practices governing the dissemination of government information to the public. The study comes about essentially because of the advent of the World Wide Web, and the rapidly accelerating federal agency actions to migrate their government information products for the public from ink-on-paper formats and mediums to the new electronic formats and mediums, especially the Internet. The Government Paperwork Elimination Act (GPEA), recently enacted by the Congress and signed into law, also mandates the transferal of transactions between the government and the people from traditional paper-based to electronic modes.

The Commission is already deeply into this study, and is very pleased to be receiving the active participation and involvement of a great many information and policy experts, associations, library groups, public interest groups, and others; four panels and a Board of Experts have been at work since late June. A final report will be sent to the Congress and the President by December 15, 2000. Background on the study can be found at www.nclis.gov/govt/assess/assess.html.

One of the most important "stakeholder groups" that heavily depends on government information are what are sometimes called "special need clientele" organizations, or, in other cases, organizations that represent memberships that are "disadvantaged" or handicapped in one respect or another. For example, memberships comprised of individuals or groups which are, in some manner, physically, emotionally, financially handicapped, or by virtue of their remote residency (e.g. rural areas), or by virtue of their minority status (e.g. gender, age, race, religion, ethnicity, etc.) unable to identify, much less search online and retrieve the information once found, the government information resources they need to cope with their special information needs or their particular disadvantages or handicaps. In both cases, the associations or societies which represent such individuals and/or groups have special information needs that are not otherwise being fully and adequately served by normally available

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[125] Available at http://www.nclis.gov/govt/assess/assess.appen28.pdf.
[126] The survey instrument is also available at http://www.nclis.gov/govt/assess/special.html.

public information services. *Congress wants to know what changes are needed to strengthen its public information infrastructure to better serve them.*

We are contacting you to ask for your assistance in a survey which we are conducting of a cross-section sampling of just a few associations, societies, and similar groups whose memberships and/or constituencies fall within one of the above categories. Woody Horton and Sarah Kadec are co-coordinating this study. If neither of them, nor Judy Russell, the NCLIS Deputy Director, has already contacted you, they soon will. However, please feel free at any time to telephone Horton or Russell at 202-606-9200. Kadec can be reached at (757) 259-0358.

We are asking you to do two things.

First, we would like to know about any published information or literature that deals with this challenge. Perhaps, for example, an article has been recently written that is published in either book or journal article form by one of your own members, for which you can provide us a citation. Or perhaps your organization has a web site which has such information available and accessible through the Internet, in which case we would also appreciate learning the URL address.

Second, we would like you to respond to the following questions and, if you provide a "yes" answer to any of them, kindly furnish us with a hard copy of the material (or call our attention to the web site containing the information if it is in electronic form):

1. Does your organization have any published policies and/or programs for providing government information (federal, state, local, or tribal) to your membership (e.g. how to access such information, where to go, whom to see, and so forth)?

2. What information do you not now receive from government that your membership/clientele often need or want?

3. What kind of government information resources does your association, society, or other kind of organization, most heavily depend on to meet the needs of its membership/clientele?

4. What changes in the government's laws, policies, programs, or practices governing the dissemination of information to the public might you recommend, which NCLIS, in turn, might be able to recommend to the President and the Congress in its final report?

In addition to the above, perhaps you would be interested in writing a special 'white paper' for the Commission's study. We could then provide the paper to our Panel 3, which is dealing with the information needs of the various individuals and groups outside of government, such as yours. Perhaps you have a "success story" to tell us, where your group has established a creative or innovative information service, system, or network to help its members search for, find, and then obtain and use government information. We would like to know about such a valuable resource so that we might, through our final report, share the idea with others.

We would much appreciate receiving this information by October 1st, or even earlier if possible, because of our very tight study deadline. Electronic responses can be sent to whorton@nclis.gov. Faxed responses can be sent to (202) 606-9203. Mailed responses should be sent to the below address.

The Commission wishes to thank you in advance for your willingness to assist us in this important endeavor. We believe the final results could be very valuable to you and your memberships/clienteles.

US NCLIS
1110 Vermont Avenue, N

Suite 820
Washington, DC 20005-3552

SURVEY RESPONSES FROM ASSOCIATIONS AND OTHER ORGANIZATIONS

Introductory Note

As a part of its effort to examine government public information dissemination, NCLIS believed that it was absolutely necessary to be very concerned with those individuals and groups in the general population who may have physical, emotional, or other problems in searching for, retrieving, or using government information available to them electronically. Sometimes the problems were directly related to a disability condition. Sometimes the problems were related to geographic location, such as rural Americans. Sometimes the problems had to do with state-of-the-art of the technologies being employed that are as yet inadequate to fully and effectively deal with the problem.

Nine different groups were contacted. They represented two types of organizations:

- The organization, such as a professional association, either was a direct membership society which represented a certain disadvantaged group and its membership counted those individuals in its ranks as members.

- The organization was not a direct membership kind of group, but, rather, worked toward the resolution of the problems of a certain disadvantaged group through lobbying and other public interest activities, or through other means such as leveraging financial resources, through philanthropic activities, and so forth.

Responses were received from seven of the nine groups contacted. Several of the groups did not reply specifically to the four questions, but, instead, discussed various critical issues that they believed that their clienteles face in accessing government information in electronic form. Both the responses to the NCLIS questions, and their comments, are summarized below.

Summary of Responses

1. Does your organization have any published policies and/or programs for providing government information (federal, state, local, or tribal) to your membership (e.g. how to access such information, where to go, whom to see, and so forth)?

American Association on Mental Retardation (AAMR).[127] Currently collaborating on the development of RADAR (Focused Research and Reporting on Critical Development Disability Issues), with bi-weekly "Radar" reports in an online data warehouse. The system is similar to one at the Substance Abuse and Mental Health Services Administrations (SAMHSA).

Association for the Advancement of Retired Persons (AARP).[128] Maintains the Ageline database of articles and book summaries. This database is licensed to several search services, and it will be added to the AARP web site later this year. AARP seeks to inform citizens of government benefits through its Public Benefits Outreach.

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[127] Its website is at http://207.201.142.179/index.shtml.
[128] Its website is at http://www.aarp.org/.

Columbia Lighthouse for the Blind (CLB).[129] This organization is concerned with visually impaired people and particularly their ability to find employment. It has entered a strategic partnership with the Colorado-based audio bookstore ReelBooks Internet Inc., to develop an e-commerce business operated by employees who are blind and visually impaired. ReelBooks.com provides online training and employment opportunities. Its employees receive hands-on training in Internet technology, technical support, and customer service.

National Library Service (NLS) for the Blind and Physically Handicapped (within the Library of Congress).[130] Yes, the NLS Collection Building policy, including discussion of the NLS' responsibility for making library materials available for the blind and physically handicapped U.S. citizens living in the U.S. or abroad.

National Organization on Disabilities (NOD).[131] Discussions are underway to develop a program to reach business and volunteer groups needing information on how to most effectively serve people with disabilities.

Self Help for Hard of Hearing People Within the National Center on Assistive Technologies (SHHHP).[132] No input.

TDI.[133] No input.

2. What information do you not now receive from government that your membership/clientele often need or want?

AAMR. Information on key issues relating to developmental disabilities (abuse, housing, aging, employment, and transportation).

AARP. No input.

CLB. Information on e-commerce and acquiring valuable career skills that increase future job marketability.

NLS. Public popular consumer information documents that come from various federal agencies, and time-sensitive documents.

NOD. Information on the "how-to" part of disability work.

SHHHP. No input.

TDI. Anything and everything must have sound, text, or captions to meet the needs of those who are deaf, hard of hearing, late-deafened or deaf-blind. This includes streaming videos and web sites that "talk," etc.

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[129] Its website is at http://www.clb.org/.
[130] Its website is at http://lcweb.loc.gov/nls/nls.html.
[131] Its website is at http://www.nod.org/.
[132] Its website is at http://www.shhh.org/.
[133] TDI was formerly known as Telecommunications for the Deaf, Inc. Its website is at http://www.tdi-online.org/.

3. What kind of government information resources does your association, society, or other kind of organization most heavily depend on to meet the needs of its membership/clientele?

AAMR. Vital policy, financial, research, and service information on issues and trends in mental health and substance abuse services.

AARP. Social Security, Medicare, and Medicaid information is obtained through AARP web site links to government and other sites.

CLB. No input.

NLS. Public popular consumer information documents, and research and statistical information from various federal information referral centers.

NOD. Basics on the ADA and other legislation.

SHHHP. Section 508 of the Rehabilitation Act. – Electronic and Information Technology, and guidance on accessible web sites included in the WWW Consortium.

TDI. No input.

4. What changes in the government's laws, policies, programs, or practices governing the dissemination of government information to the public might you recommend, which NCLIS, in turn, might be able to recommend to the President and the Congress in its final report?

AAMR. No input.

AARP. Move from offering simple, passive access to government information to actively getting it into the hands of individual who need it. Resolution of the problem of degradability and technical vulnerability of information in electronic formats. An agency of government should implement solutions to the impermanence of digital information. Universal access is necessary before government can cease traditional publishing efforts, the situation will improve, but not necessarily for everyone in society.

CLB. Support for providing employment opportunities for the blind and visually impaired residents of the Washington, D.C. area.

NLS. Of the government information readily available to the public, how much of it is in accessible formats such as audiotape, Braille, and computer diskettes for special needs population. The federal government should have an office where any agency could get training on providing accessible formats, specialized software they need to adapt it to their needs, and the monthly charges imposed for access.

NOD. Web-based way to search through government materials that have to do with the "how-to" part of disability work.

SHHHP. No input.

TDI. No input.

Additional Notes important to these groups include:

The NLS provided the following comments based on a document entitled *Computer and Internet Use Among People with Disabilities*, published by the Disability Statistics Center, University of California, San Francisco.[134] People with disabilities perhaps stand to gain the most from the new technologies, which are important tools with which to gain greater independence and social integration, yet they have among the lowest rates of use. Many are poor and cannot afford a computer capable of navigating the Internet. There is a need for lower-cost computing and access, simpler user interfaces, and a concerted program of education along with training and support in the use of hardware and software.

SHHHP referred the Commission to the Target Center at the Department of Agriculture, where free workshops on accessibility and the Internet are provided. Specifically the Commission was reminded of a Section 508 workshop at the IDEAS Conference held at the Department.

Detailed Responses

American Association on Mental Retardation (AAMR).

We have just received a grant of national significance to establish "RADAR:"

Radar Project Summary/Abstract

AAMR, a credible, well-respected organization concerned about intellectual and other developmental disabilities, will collaborate with The Lewin Group, (TLG), an experienced, respected, international health care consulting firm with proven competence in database development and management, to develop RADAR: Focused Research and Reporting on Critical Developmental Disability Issues. The RADAR System will be modeled after a similar system that was developed by TLG for the Substance Abuse and Mental Health Services Administration (SAMHSA). The SAMHSA system has been operating for three years and provides the agency with vital policy, financial, research, and service information on issues and trends in mental health and substance abuse services.

AAMR and TLG firmly believe our entire network would benefit greatly, if similar information were available to all stakeholders in the mental
retardation/developmental disabilities network. Furthermore, implementation of the Roadmap to the Future demands the capacity to identify and track developmental disabilities issues, activities, and trends at the national, state, and local levels.

The AAMR/Lewin Team will work with all developmental disability stakeholders to develop the content of the RADAR "early alert" Internet database system. Representatives from the developmental disabilities network, including individuals with disabilities and family members, will form a RADAR Advisory Council to guide development of keywords and provide overall project monitoring.

RADAR activities in the first year will focus on designing, testing and building the online Data Warehouse. On a weekly basis RADAR personnel will monitor the general news media and specific trade press related to developmental disabilities to collect nationwide information on key issues. A few examples of potential issues to be tracked include abuse, housing, aging, employment, and transportation. The information, gathered from more than 150 sources, will be summarized into bi-

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[134] H. Stephen Kaye, *Disability and the Digital Divide*, Abstract 22, San Francisco: Disability Statistics Center, University of California, San Francisco, July 2000; http://www.dsc.ucsf.edu/UCSF/pdf/ABSTRACT22.pdf.

weekly "RADAR" reports, which will be stored in the online Data Warehouse. All stakeholders, even the general public, will be able to access the Data Warehouse via the Internet. They will be able review the current report or search past entries. At the end of the first year of the RADAR initiative, the database content, ease of access and system utilization will be evaluated. In the second year, the technological accessibility for individuals with disabilities and their families will be reviewed.

With Advisory Council input, necessary modifications will be made to the RADAR System. In the third year, database content should be substantive and RADAR personnel will be able to focus on data mapping and trend analyses while continuing data collection activities.

Prepared by:
Doreen Croser, AAMR

Association for the Advancement of Retired Persons (AARP).

I have asked some of my colleagues to respond to different parts of your memo, so you may be receiving some additional material by email related to your information request.

My own responses in this memo should be taken as my own opinions, not necessarily reflective of official AARP policy.

As a former government documents librarian (at the regional depository library at the University of Maryland, College Park) I strongly support your inquiry into ways of improving the dissemination of U.S. government information to the public. The depository library system, laudable for the intentions behind it and for the hard effort invested in it, really has not resulted in universal public use (as opposed to access) of federal information resources; nor has that system been effective at including all U.S. government publications within its scope. Many of those publications are in fact only available through commercial products that supplement depository library collections (such as the CIS Index\Abstracts microfiche collections). The searchability and home access that the Internet makes possible allows for the government to move from offering simple, passive access to government information to actively getting it into the hands of individuals who need it.

That said, the problem of the degradability and technical vulnerability of information in electronic formats has still not been resolved. Some depository libraries have government documents in paper copy that were produced in the early 1800s. In contrast, the digital formats of the 1960s and 1970s--including IBM punch cards--are unreadable by the common computing hardware in use today. The economic incentive for government agencies to move from print to electronic publishing formats is strong, as is the benefit of searchability and timeliness that comes with digital information. Archiving that information for future reference, however, is complicated by the fact that magnetic media decay and digital formats and hardware change unpredictably. Is there any agency of government prepared to find and implement solutions to the impermanence of digital information?

An additional problem is that access to digital information is by no means universal yet throughout the U.S. and the world. The savings occur if government can cease traditional publishing efforts in favor of digital ones, but that will inevitably mean closing off access to government information to large areas of the citizenry. Aside from the issue of the cost of computer ownership and communication, there is the issue of training in the use of computers as information machines. Most of us learn to read in school, and many of us can do so with no more complicated "hardware" than our eyes. Moving entirely to digital information means making information access and use dependent upon a high level of education, facility in using computer hardware that continues to change from year to year, and the

money and savvy to either have the equipment at home or know how to get at it conveniently. Granted, this situation will improve--but not necessarily for everyone in our society.

The organization for which I currently work, AARP, is deeply involved with advocacy and information programs around Social Security, Medicare and Medicaid issues, among others. Our own Web site links to government and other sites related to these issues. Interpreting the issues and details surrounding these programs is one of the things AARP seeks to do in its own publications and programs.

Public Benefits Outreach, in which the organization seeks to inform senior citizens of government benefits for which they may be eligible but of which they may be unaware, is another of AARP's concerns.

After today I will be out of the office until October 3rd, so, unfortunately, I will not be able to respond to any follow-up questions you may have about this response.

Prepared by Hugh O'Connor
Association for the Advancement of Retired Persons

Columbia Lighthouse for the Blind (CLB)

(From *Digital Voices* -- September 25, 2000)

Region's New Economy Can't Exclude the Blind and Visually Impaired

As the president and chief executive officer of an organization providing programs and services to 20,000 visually impaired people in the Washington, D.C. area, I find it staggering that, even in the face of the current labor shortage, 70 percent of blind, working age adults in the United States remain unemployed. Initiatives designed to improve this unacceptably high unemployment rate and bridge the "digital divide" are urgently needed ["Initiatives for Disabled Unveiled," *National News*, September 22].

Recent advances in adaptive and assistive technology, such as screen magnification software and software that converts text into speech, can help to bridge this divide. Assistive technology is revolutionizing professional opportunities for the blind and visually impaired community, specifically in the communications and information services industry. This technology enables individuals who are experiencing vision loss to acquire and retain the skills necessary to achieve economic independence and allows visually impaired persons attempting to re-enter the workforce to develop marketable career skills. People who are blind and visually impaired can turn to the Columbia Lighthouse for the Blind to receive training in this technology.

In order to demonstrate to other local employers how easily, effectively and efficiently this technology can be integrated into the workplace, the Columbia Lighthouse for the Blind recently entered into a strategic partnership with the Colorado-based audio bookstore Reel Books Internet, Inc., to develop an e-commerce business that is operated by employees who are blind and visually impaired.

The resulting website, ReelBooks.com, is an online audio bookstore designed to provide training and employment opportunities consistent with the region's "new economy." In addition to learning about e-commerce and acquiring valuable career skills that increase their future job marketability, the blind

and visually impaired employees working for ReelBooks.com receive hands-on training in internet-driven technology, technical support and customer service.

The ultimate goal of this venture is to provide savvy, well-trained employees to other tech companies in the Washington, DC area, as well as to offer valuable retail service in the rapidly expanding market of audio books.

The official launch of ReelBooks.com will be held on Capitol Hill Thursday, September 28 from 5:00 - 7:00 p.m. in room B-369 of the Rayburn House Office Building. I invite Members of Congress, local business and community leaders and the residents of the Washington, DC area to attend the launch and show their support for providing employment opportunities for the blind and visually impaired residents of the metropolitan Washington, DC area.

Prepared by:
Dale Otto
President & CEO
Columbia Lighthouse for the Blind

National Library Service for the Blind and Physically Handicapped (NLS)

1. Does your organization have any published policies and/or programs for providing government information (federal, state, local, or tribal) to your membership (e.g. how to access such information, where to go, whom to see, and so forth)?

Yes, we have enclosed a copy of the NLS Collection Building policy and other related documents. We also included Sources of Braille Reading Material and NBA Suggestions for Producing Large Print Materials, 2000.

2. What information do you not now receive from government that your membership/clientele often need or want?

Public popular consumer information documents that come from various federal agencies and time-sensitive documents.

3. What kind of government information resources does your association, society, or other kind of organization, most heavily depend on to meet the needs of its membership/clientele?

Public popular consumer information documents that come from various federal agencies, and research and statistical information from various federal information/referral centers.

4. What changes in the government's laws, policies, programs, or practices governing the dissemination of information to the public might you recommend, which NCLIS, in turn, might be able to recommend to the President and the Congress in its final report?

The questions that we would ask you to pose "If it's readily available to the public, how are you providing it in special format? Who is the person to contact who will help provide the special format material for the various agencies? We would ask you to consider recommending:
•   that a contact always be trained to help each agency;

- that the reforms include flexibility to allow for the dissemination of government information in accessible formats such as audiotape, braille and computer diskettes on an as needed basis for special needs population; and

- that the federal government always have an office where any agency can get training on providing accessible formats. For example, the U.S. Senate and U.S. House of Representatives have a special information needs office that helps each senator and representative respond to clients. Somewhere there should be an office to liaison with all executive department agencies to assure training and to help the agencies respond to special needs populations.

Finally, the passage of Section 508 of the Rehabilitation Act will make accessing government information via the Internet easier and more feasible for special needs populations, especially those with visual impairments. However, we encourage your committee to take note of a statement from the document *Computer and Internet Use Among People with Disabilities* published by Disability Statistics Center University of California, San Francisco:

> People with disabilities are perhaps the single segment of society with the most to gain from the new technologies of the electronic age. Yet they have among the lowest rates of use of these technologies. As a result, the potential benefits of computers and the Internet to the disability community are a long way from being realized.
>
> The problem is largely one of access. Many people with disabilities are poor and can little afford a computer capable of navigating the Internet, the specialized software they might need in order to adapt it to their needs, and the monthly charges imposed for access to the Internet. Many people with disabilities, whether elderly or not, lack an awareness of the potential benefits of this technology, an understanding that, for themselves especially, a computer and an Internet connection could become not a toy, but an important tool with which to gain greater independence and social integration.
>
> The advent of lower-cost computing--including the free computers that come with an extended subscription to an Internet service provider--may help to make this technology more available. Simpler user interfaces,
> which would encourage use by people who are less comfortable with the technology, might also help people with disabilities to overcome any resistance they might have to exploring the Internet. But it seems clear that, in order to clarify the benefits that this technology can offer to the population with disabilities, a concerted program of education will be needed, along with training and support in the use of the hardware and software, before significant progress is made in closing the enormous gaps in technology access that have been identified in this report.

The full report is available from Disability Statistics Center, University of California, San Francisco, Box 0646, Laurel Heights 3333 California Street, San Francisco, CA 94143-0646 or from their website: <http://www.dsc.ucsf.edu/>.

Prepared by (Mrs.) Freddie L. Peaco,
Government Information/Volunteer Specialist

National Organization on Disabilities (NOD)

I've asked a couple of people in the office now, and the general consensus is that we don't have the appropriate experience attempting to locate government publications for any specific constituency to

answer your survey. we are not of grass-roots organization -- and thus have relatively little contact with people from "disadvantaged communities". We are in the process of attempting to become more Web focused ourselves, however, and there is some discussion about trying to access materials that certain constituencies might have a need for, and link to them from a central location. If we did so, the constituencies that we would primarily be trying to reach are business and volunteer groups, looking for information on how they can work most effectively to serve people with disabilities, as well as get the basics on the ADA and other legislation. That said, we would love to have an easy, Web-based, way to search through government materials -- especially materials that have to do more with the "how-to" part of disability work.

Sorry that we cannot help you further. Other groups you might consider contacting are The American Association of People with Disabilities, the American Association of Retarded Citizens (the Arc) -- they have a governmental affairs office here in D.C.

Prepared by Taylor Hines
National Organization on Disabilities

SHHH National Center on Assistive Technologies

Thank you for contacting the "stakeholder" group of people with disabilities. I represent people with hearing loss via SHHH (Self Help for Hard of Hearing People). I will give you a quick answer now and perhaps we can respond in depth later.

I recommend that you go to the Access Board website and read as much as you can about rules for Section 508 of the Rehab Act—Electronic and Information Technology, which includes federal government obligations regarding your WWW questions. I also recommend that you specifically visit the website of the World Wide Web Consortium regarding guidance for accessible web sites. Please let me know if you can't find these websites.

Prepared by David Baquis, Director
SHHH National Center on Assistive Technology