

Before the
Federal Communications Commission
Washington, DC 20554

In the Matter of

Implementation of the Twenty-First Century)
Communication and Video Accessibility Act of) CG Docket No. 10-210
2010, Section 105, Relay Services for Deaf-Blind)
Individuals

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Comments in Response to Notice of Proposed Rulemaking

The National Coalition on Deafblindness appreciates the commitment and responsiveness to deaf-blind community shown by the Federal Communications Commission (Commission) reflected in the incorporation of comments from consumer and advocacy groups in this Notice of Proposed Rulemaking. The professionalism, hard work and diligent effort of the Commission is reflected in the Notice of Proposed Rulemaking. Your efforts are truly appreciated. We are pleased to offer the following comments.

II Background

American Association of the Deaf-Blind (AADB) Joint Commenters stated in their comments that consumers who are deaf-blind report great inconsistencies in their experiences with the current state Equipment Distribution Program (EDP) system. Eligibility criteria vary and covered equipment differs from state to state. The Coalition has heard many similar stories. In order for the Commission to meet the goal of bringing telecommunications service, Internet access service, and advanced communication to persons across the country who are deaf-blind, the distribution system must provide equal access to consumers regardless of where they live. The Coalition would prefer a regionalized or national system. If the Commission moves forward with the current EDP system, we hope there will be an option after the pilot program to explore other options based on the results of the evaluation. We implore the Commission to set up safeguards that ensure that persons across the country who are deaf-blind have equal access to National Deaf-Blind Equipment Distribution Program (NDBEDP).

We welcome the Commission's express intent to pilot the NDBEDP, but we have some significant concerns about the Commission's proposed approach. In general, we are concerned that the pilot, as described in the NPRM, does not include measures for evaluating its success, a sense of what specific issues about which the Commission intends to enquire, adequate provision for the involvement of national and/or regional organizations to inform the work of state EDPs which do not possess demonstrated or consumer-recognized expertise in service to people who are deaf-blind, and acknowledgement of the clear need for a coherent long-term structure that ensures consistency of results nationwide. Therefore, in any interim final rule, the Commission must clearly articulate the purposes and rationale for any pilot that the Commission determines is necessary to the NDBEDP's ongoing success. The pilot must be designed to fulfill these purposes while beginning to provide, as soon as possible, people who are deaf-blind with meaningful access to costly communications equipment through familiar, reliable and sustainable channels. Finally, the pilot must be evaluated using objective measures to the maximum extent possible. We therefore believe that, at a minimum, the pilot must:

- ✚ compare, on as equal a playing field as possible, a variety of models (program structures, equipment distribution mechanisms, and approaches to training and ongoing support) to inform the Commission's future final rulemaking;
- ✚ be of sufficient duration to allow for program start-up as well as the accumulation of a demonstrable record of successes and shortcomings of the various models piloted;
- ✚ actively seek direct consumer input as to the pilot's progress and ultimate evaluation;
- ✚ measure the administrative cost efficiency of each of the models piloted;
- ✚ recognize the relative geographic concentration and scarcity of populations of people who are deaf-blind nationally, and stress the importance of partnership and leveraged resources to meet such diverse demographic demands;
- ✚ test the relative effectiveness of state-by-state mechanisms versus more coordinated and/or centralized approaches;
- ✚ gather data on individual consumer satisfaction with service received through specific providers and, therefore, in each of the pilot's models; and

- ✚ assess each model's relative capacity and effectiveness in offering prompt, competent, and coordinated service to include program eligibility and enrollment, equipment distribution and training, and ongoing support and problem-solving.

Based on these foundational principles, we urge that the pilot:

- ✚ be three years in duration;
- ✚ commence with a three-month RFP process resulting in announcement by the Commission of grant awards to projects running during the remaining 33 months of the pilot;
- ✚ give preference to projects comprised of organizational partnerships and consortia whose members each satisfy participation criteria established by the Commission;
- ✚ offer grant awards to an array of models, from strictly nonprofit-organization-managed projects to consortia of state and private entities, to national and regional organizations with whom other state and private entities may subcontract;
- ✚ discourage application for participation by individual state programs where such programs' proposed projects lack formal relationship with out-of-state public or private entities;
- ✚ require applicants to declare and document expected administrative and other overhead costs in such applicant's response to the RFP and to periodically report on costs incurred throughout the pilot, along with data of number of clients served (i.e., provided with equipment, training, ongoing support, etc);
- ✚ invite proposals that would establish a single national network, administered centrally, to serve the needs of people who are deaf-blind throughout the country either directly or through the formalized relationships described above;
- ✚ allow individuals who are deaf-blind to receive equipment and/or services either from the state in which they live or from an alternative source even when the state in which the individual resides is operating a project funded under the pilot; and
- ✚ except entities funded under the pilot to educate parents of children with deaf-blindness about SEA/LEA responsibilities, as directed under IDEA, for the provision of equipment needed, including equipment used in the home, to meet the provisions of the child's IEP.

III Equipment Distribution Programs

10. The Coalition would favor a system in which EDPs should be subcontractors led by a national/regional NDEEDP funded entity with extensive expertise serving the deaf-blind community. At a minimum we recommend adding language that suggests that cooperative agreements are allowed for EDPs to subcontract with other entities in order to acquire needed expertise. Since the specific knowledge of technology for consumers who are deaf-blind is limited, we encourage the Commission to allow maximum flexibility for the EDPs to subcontract some or all of their responsibilities to one or more entities. These entities may or may not be located in their respective state.

11: As noted by the Commission, there is wide geographical diversity in the deaf-blind population. We support the concept of coordinated ventures. We recommend that the Commission also allow coordinated ventures across state lines. In many areas of the country it is easier for a consumer who is deaf-blind to access expertise in a neighboring state.

IV Consumer Eligibility

1. Definition

15. Since the Commission is bound by statute to use the definition of individuals who are deaf-blind in the HKNC Act, the Coalition concurs with the Commission on the need for a second prong of this definition. As noted by many commenters, a person who is deaf-blind may be able to understand speech in a 1:1 quiet setting but that same individual may not be able to understand speech if in a noisy environment. Similarly, a person who is deaf-blind may be able to read large print if lighting condition are optimal, but then may require braille in certain settings. A parent of a teenager from NY noted that her daughter “can read print but as fatigue sets in, she requires larger print and good lighting with good contrast”. These are all factors that influence the individual’s ability to function. We concur that “consideration of these functional capabilities is in keeping with Congress’s overall goal to ensure the availability of existing and emerging communication technologies for the deaf-blind population.” (FCC 11-3, p. 8) The Coalition commends the Commission’s concept of directing programs to apply definition in accordance with the underlying intent of the 21st Century Communications and Video Accessibility Act (CVAA) which includes consideration of functional capabilities. Adherence to this directive should be part of the assessment of the success of this pilot program

2. Verification

17: The Coalition commends the Commission's efforts to make the verification process less burdensome. We concur with recommendations offered by the AADB Joint Commenters to accept eligibility for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) as appropriate verification. We support the Commission's recommendation to accept verification by professionals including but not limited to: a vocational rehabilitation counselor, audiologist, speech pathologist, educator, hearing instrument specialist or physician. We recommend that the Commission develop a standard eligibility form that clearly states eligibility requirements. This form should include a statement that specifies that by signing this form the professional certifies that to the best of their knowledge the individual's disability satisfies the eligibility requirements for the NDBEDP. It is interesting to note that the verification process for the National Library Service for the Blind & Physically Handicapped of the Library of Congress, a program to provide machines and other equipment for 700,000 consumers who are blind, deaf-blind and have other disabilities, is also quite broad and flexible. <http://www.loc.gov/nls/eligible.html>

3. Income Eligibility

20: Recognizing the language in the legislation, the Coalition supports the Commission's recommendation to use an income threshold of 400– 500% of the FPG to be applied nationwide. Even this level will unfortunately exclude certain individuals who are deaf-blind because of their family situation and the high costs of their transportation, medical, home support and other needs. These extraordinary costs mentioned do not include consideration of the extensive adaptive technology needs people who are deaf-blind present.

We urge the Commission not to allow EDP to use a different income threshold. The Coalition believes that providing equal access to NDBEDP is paramount to meeting the stated goal of meeting the needs of persons across the country who are deaf-blind. Allowing EDPs to utilize different income thresholds would be tantamount to further limiting the rights of individuals who are deaf-blind in certain states.

The Coalition commends the Commission for their proposal to take into consideration both the high cost of specialized equipment and the unusually high costs of medical and other expenses associated with being deaf-blind.

As noted by several commenters, individuals who are deaf-blind often face extraordinary expenses due to their unique needs. These include costs related to specialized transportation, medical (deductible, co-payments and uncovered expenses), and support services. Among the student population, CHARGE Syndrome has become the leading syndrome that causes deaf-blindness. Individuals with CHARGE often face on-going medical issues that require medical equipment (g-tube, tracheotomy, etc.), liquid nutrition, braces for scoliosis, etc. While this equipment is usually covered by insurance, families and

young adults with CHARGE must pay deductibles and co-payments that add up to thousands of dollars annually. This can often leave families and individuals with very little discretionary income. One family from Ohio reports that “People who are challenged by deaf-blindness frequently also face complex medical challenges. We consider ourselves lucky. My husband has good private insurance. Last year we paid more than \$14,000 out of our pockets for medical costs. As we have a flex medical account, anything in excess of that is not tax deductible. Due to changes in our insurance this year, we have calculated that we will pay out approximately \$20,000 in medical costs in 2011.” A family from New York reports “In our own personal experiences with high out of pocket insurance costs, high co-pays and doctors that don't accept insurance but are greatly needed to follow my daughter, we have very high medical expenses related to her CHARGE syndrome and deaf-blind issues. We also live near a high cost city, so even though we have medical insurance, our out of pocket costs are great and make us think twice before we can purchase a very expensive piece of equipment, such as a CCTV for the home or a hand held CCTV device for shopping and independence purposes.”

21: The Coalition commends the Commission on their efforts to make verification of income less burdensome. We agree that individuals who participate in certain federal low income programs automatically be deemed eligible for NDBEDP. We suggest that eligibility for free lunch program also be considered.

4. Other Eligibility Requirements & Considerations

23: The Coalition agrees that in order to secure equipment through the NDBEDP the individual must have access to telephone or internet service. We urge the Commission to stipulate that access would include through a public library, public Wi-Fi, a friend, family, local non-profit or other source. Since many individuals who are deaf-blind are unemployed and with few financial resources, free access points must be included.

24: The Coalition commends the Commission on their directive to prohibit EDPs from requiring that equipment use be job related. Individuals who are deaf-blind, like those without disabilities, use technology in every realm of their lives.

25: If the onus of determining eligibility of consumers under the NDBEDP is on the authorized programs that distribute the equipment, the Commission must assure that the process to determine eligibility is applied equally across EDPs. We urge the Commission to offer written guidance and oversight to EDPs on determining eligibility so that access is equitable across states. The Coalition encourages the Commission to ensure that the process for determining eligibility is easy for the consumer. We urge the Commission to explore an on-line certification process.

V. Covered Equipment and Related Services

1. Scope of Specialized Customer Premises Equipment (CPE)

28. The Coalition strongly recommends that the Commission put in place safeguards that assure that access to equipment is equitable across state EDPs. We urge the Commission not to allow state EDP to decide which equipment to make available. As noted by the AADB Joint Commenters, consumers who are deaf-blind who have received equipment through the current EDP system have had very unequal treatment when access to equipment is dictated by the EDP rather than based on the individual's needs.

The Coalition has heard stories from our colleagues in both the AADB Joint Commenters and the Deaf-Blind Young Adults in Action that EDP have restricted access to the full capabilities of some technologies like smart phones. The Commission should assure that any entity that distributes equipment under the NDBEDP follow the spirit of the law that is bringing telecommunications service, Internet access service, and advanced communication to persons across the country who are deaf-blind. Each person with combined vision and hearing loss is unique, and their communication and technology needs are just as unique and individual to them. No two people can be expected to need or want exactly the same device.

According to Gayle Yarnall, founder of Adaptive Technology Consulting, "There are very few people who are totally blind and totally deaf. There are even less people who have been totally blind and totally deaf for their entire lives. Most people are some combination of hearing impaired and visually impaired. This means that the range of products, and needs, and learning styles vary greatly. Products will include anything from screen enlargement software to braille displays. Where one person will want to work with a screen reader using head phones to increase and concentrate the volume, another will want the combination of speech and braille. One person could access the internet using screen enlargement software and access the phone with a phone that can increase its volume. Adding a TTY to a phone system may be all someone needs, while someone else will need a Deaf-Blind Communicator."

There are dozens and potentially hundreds of different types of hardware, software, applications and peripherals that can be used by individuals who are deaf-blind. These continue to evolve, just as general technology moves forward with new features and models on a regular basis. It is critical that EDPs not be able to restrict specific types, brands or other forms of technology. The limitation on technology should be tied to what an individual who is deaf-blind can appropriately use for communication.

29: Since technologies evolve so rapidly, we recommend that the Commission build in great flexibility in the types of equipment covered under NDBEDP. Assessing the demand for various technologies during the pilot period would be useful in order to assure that EDPs are aware of the potential of existing and emerging technologies.

30: The Coalition urges the Commission to cover appropriate mainstream equipment under the NDBEDP. Many commenters noted that with adaptations equipment like smart phones can effectively and efficiently meet the communication needs of some consumers who are deaf-blind. The more that off-the-shelf equipment can be made accessible to consumers who are deaf-blind the greater access this group will have to advanced communication technology. In the long-term, if mainstream technology can be used by individuals who are deaf-blind, it will bring down the costs for consumers and significantly increase its availability.

As the Commission has acknowledged, reaching the varied population of people who are deaf-blind and eligible for services through the NDBEDP will be a challenge. It is quite likely that extensive outreach efforts will be required during the pilot period. Because the program may start off slowly, the Coalition believes that the Commission may not need to impose funding caps during the pilot period. Appropriate caps and time periods could be determined as a result of the lessons learned during the pilot program.

31: Similarly the Commission could study the appropriateness of allowing individuals to obtain replacement equipment every five years, and new software as needed. Again, the Coalition believes that funding caps on software may not be necessary during the pilot period. We understand the need to limit replacement equipment to a predetermined cycle, such as five years. We recommend that the Commission allow exceptions to this cycle if a new technology emerges with far greater capabilities than the older one or with greater accessibility than a previous model. In these instances individuals should have access to new equipment sooner than five years. Also, an individual who is deaf-blind should be able to receive more than one piece of equipment during the cycle if it is for a different function.

As an example, a mother from California writes “Telephone access for my daughter, who is, 29 years old and deaf-blind, is a vitally important lifeline. The specialized equipment she uses is not easy to come by. She started out as a child with large print TTY, and the day is coming rapidly when she will need Braille telecommunications equipment. It is also important to have portable Braille communication options away from home. Hearing and Sighted citizens take for granted they can place a call away from home. My daughter is not able to do that. She needs a technology evaluation to determine which portable Braille device will best suite her needs, and the specialized training from

someone fluent in ASL to accomplish the work. All Braille equipment is very expensive, and funding for individuals to purchase equipment and receive subsequent training is essential. It's been through the large screen TTY my daughter is able to have in depth conversations with her father and grandmother who are not fluent in ASL. Its how she makes appointments for herself, arranges her social and business life, calls for help if she needs it, and all the many things we all do via the phone.”

2. Research and Development

34: Given the very limited number of available technologies to assist those who are deaf-blind, particularly in the realm of telecommunications, the Coalition believes that it is critically important that the NDBEDP set aside some amount of funding to support and promote the research and development of new technologies for individuals with combined vision and hearing loss/deaf-blindness.

Many of the most current technologies that facilitate communication and are readily available to the general public were not designed with accessibility in mind. These products include, but are not limited to, computers and appliances such as the I Pad, Smartphones, and the iPhone. Such products do not enable ease of input or output and therefore significantly limit access to these technologies. Non-profit organizations in particular would benefit from support for some elements of their research and development and new product development. This would help accelerate the time period in which these devices come to market to improve accessibility to users who are deaf-blind. Based on the limited pool of venture and angel funding for new technologies, we believe that approximately \$1 million set aside per year of the pilot program for research and development would be helpful. Some of our members, including Perkins School for the Blind, are approached by people with creative technologies that do not make it to market because of a lack of investment capital. For some products the lack of \$250,000 to \$1,000,000 can make the difference for survival.

3. Individualized Assessment

36: The Coalition commends the Commission for recognizing how critical it is for NDBEDP funds to cover necessary training for individuals receiving equipment. The Veterans Administration also covers training associated with equipment provided to veterans who are blind or visually impaired.

http://www.va.gov/BLINDREHAB/BRS_Coordinated_Care.asp

The Coalition encourages the Commission to include provisions for the equipment distribution project to subcontract with qualified entities to assist with individualized assessments and training.

Arthur Gould writes "As a technology trainer for people with multiple disabilities including visual and hearing loss, I often find myself in a unique situation. I normally train people in their homes as their disabilities would be too restrictive to travel to any sort of training center. For a lot of my clients, I discover that with specialized software and customized training, having a computer allows the clients to not only maintain a communications link to the outside world, it improves the quality of their lives by having access to information. The age in which we live places a lot of value on information. There are multiple streams of information freely available to the public at large, but if you are visually impaired, mobility impaired, or hearing-impaired, your access to these information streams is extremely limited or totally prohibited. I have personally experienced the sense of loss by people living alone who are visually, hearing, or mobility impaired. It is a sense of almost total exclusion from the modern world. On the other hand, I have been privileged to take the training and the software out to some of these people, and "plug them in" to the age of information."

He further writes, "Imagine for a minute that the telephone is a barrier to communication. Then imagine the printed word is another barrier. Now picture a visually and hearing impaired grandmother using assistive technology on a computer to communicate with her grandchildren by e-mail. I have personally experienced amazing transformations on the part of people with multiple disabilities. I have seen through the use of this type of technology and specialized training; people rediscover their lives and even find new purposes to get behind. This technology and training is much more than connecting people to information. It's about improving our collective state by including everybody."

4. Installation and Training

39: The Coalition agrees with the Commission's assertion that there is a severe shortage of trained professionals. We believe that in order to meet the goals of the Act, there is a critical need to train professionals to assist consumers who are deaf-blind in all areas of the country. A national training effort that utilizes distance technologies where appropriate could begin to address this shortage. The Coalition would support the use of not less than \$1 million of the NDBEDP funds to support a national training project.

5. Maintenance, Repairs and Warranties

41: The Coalition concurs with the Commission that repair costs should be covered except those due to owner negligence.

6. Outreach and Education about NDBEDP

42: The Coalition concurs with the Commission that a portion of NDBEDP funds should be set aside for national outreach. In our experience, individuals who are

deaf-blind and associated with a program or agency, are relatively easy to reach. However, a majority of persons who are deaf-blind and eligible for this program may not be affiliated with programs or agencies. Making consumers aware of the NDBEDP will require a concerted effort. This outreach effort could also include the development of materials/website that demonstrates the variety of technologies that could be used by consumers who are deaf-blind. Outreach efforts must include agencies, providers, and families as well as individual who are deaf-blind. We recommend this amount not be less than \$500,000 per year.

VI. Funding

45: For the pilot period, the Coalition agrees with the Commission's intention to divide the remainder of the \$10 million allocation based upon population. The Commission should evaluate the effectiveness of this approach as part of the general evaluation of the pilot program.

Federal funds are available for certain equipment for students who are visually impaired through the "quota system" at the American Printing House for the Blind <http://www.aph.org/fedquotpgm/fedquota.htm>. This system allows APH to reallocate funds from one state to another if the funds are not utilized in certain areas. The Coalition recommends a similar system be considered to ensure all funds are used. We also recommend that funds be able to be carried over from one year to the next.

VII. Oversight and Reporting

49: The Coalition supports the Commissions' recommended process to monitor equipment distribution.

IX. Other Considerations

54: The Coalition recommends that the Commission create a specific advisory committee to help evaluate consumers' experiences during the pilot phase when such feedback will be critical in judging the effectiveness of the model.

56: The Coalition agrees that a clearinghouse of accessible products and accessibility solutions is vital. This could be combined with the national outreach effort.

58: The Coalition concurs with the Commission's assertion that NDBEDP funds should be supplemental to other equipment funding sources like IDEA or the Rehabilitation Act. Safeguards should be put in place to assure NDBEDP funds are not used for equipment that IDEA or Rehabilitation Act are required to

provide. However, the Coalition believes that adopting a rule that disqualifies from participation those individuals who are eligible or have received equipment through other sources would deny equipment to many eligible and deserving recipients.

For example a student who is deaf-blind and attends a residential school has access to all kinds of equipment in school and in her residence, but has very little access when she is home on vacations and in the summer. Her need for equipment has to do with communicating with friends and making social connections. This equipment would not be covered under IDEA.

The same would go for a young man who works as a delivery person in a hospital. He has the equipment he needs for work, but needs access to equipment at home for social networking. This equipment would not be covered by the Rehabilitation Act or his employer.

Pam Smith, the Coordinator of Adult Services at the North Dakota School for the Deaf stresses how very important it is for Deaf Adults (and students) to have an opportunity to socially network with their friends, peers and colleagues away from school and work. She wrote "Research has shown that those who have this opportunity are far less likely to suffer from depression and the isolation so often common for Deaf individuals in our rural Midwest where the numbers of Deaf individuals are limited." *This is at least equally true for individuals who are deaf-blind.*

A parent from Massachusetts writes, "As the father of a 23 year old deaf-blind male I'm very interested in the rulemaking. I especially agree that individuals need to have the same or nearly identical equipment at home as they may get on the job. There must be access to social networking at home and off the job. This would support an individual's right to learn on their own and establish the same relationships sighted and hearing people have access to."

A parent from Ohio writes "Equipment should go to all persons who are deaf-blind, regardless of age (beyond a minimum age, say five years old). By the time a child is five years old, he or she is learning to access the Internet and communicate on the phone, whether to call Grandma or learn the skills to dial 911. Every child who is deaf-blind has the right to develop the same skill set as every child who is not deaf-blind. To not provide equipment to every person, including children, is to subvert the intent of the Act and continue to isolate a population that is unnecessarily closed off in an age when technology is available to break down communication barriers."

In summary, the Coalition commends the Commission on their diligent efforts to establish an equipment distribution program that will meet the needs of a unique and under-served population of individuals who are deaf-blind. Thank you for the

opportunity to comment on these proposed rules. Please let us know if you have any questions or would like clarification on any of these comments.

Organizations who signed on:

American Foundation for the Blind
The Arizona Association of the Deaf-Blind
CHARGE Syndrome Foundation
Connecticut Deafblind Project
Helen Keller National Center
Maine Deafblind Project
Massachusetts Deafblind Project
National Family Association for Deaf-Blind
New Hampshire Deafblind Project
New York Parent Network
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