

U.S. DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND
REHABILITATIVE SERVICES
REHABILITATION SERVICES ADMINISTRATION
WASHINGTON, D.C. 20202

INFORMATION MEMORANDUM
RSA-IM-01-18
DATE: December 18, 2000

TO : STATE VOCATIONAL REHABILITATION AGENCIES (GENERAL)
STATE VOCAITONAL REHABILITATION AGENCIES (BLIND)
REGIONAL REHABILITATION CONTINUING EDUCATION
PROGRAMS
CLIENT ASSISTANCE PROGRAMS
PROTECTION & ADVOCACY OF INDIVIDUAL RIGHTS
STATE REHABILITATION COUNCIL
RSA SENIOR MANAGEMENT TEAM

SUBJECT: Development of National Registry for the Deaf-Blind

The Helen Keller National Center (HKNC) is a national rehabilitation program authorized by the Helen Keller National Center Act, as amended (HKNC Act), to provide services for youth and adults who are deaf-blind. Recent amendments to the HKNC Act authorize the HKNC to establish and maintain a registry of individuals who are deaf-blind in order to assist the Center in providing services to this population.

Historically, the deaf-blind population has been underreported. Although the definition of an "individual who is deaf-blind," contained in the HKNC Act (see attached), has been commonly accepted by State vocational rehabilitation (VR) agencies, this population is reported inconsistently on the RSA-911. For example, in FY 1998, only 456 individuals nationally were reported as being "deaf-blind," using codes 290-298; an additional 27 were listed with "deaf-blindness" as a secondary disability, 153 indicated "blindness" as major and "deafness" as secondary and 19 reported "deafness" as major and "blindness" as secondary.

In order to develop and provide adequate services to this population, the HKNC has determined that an accurate census is necessary and plans to establish a voluntary national registry for individuals who are deaf-blind. All personal information contained in the registry will be kept confidential and will not be released to anyone outside of the HKNC without the individual's specific written consent.

Enclosed are a letter from Joseph McNulty, Director of HKNC, asking for your assistance in identifying individuals who may want to be included in this registry and a blank registry form. Please circulate these items to key people within your organization who can distribute them to individuals who are deaf-blind and/or their parents or guardians. Although registration is voluntary, if an individual chooses to register he or she must provide, at a minimum, his/her name, address, date of birth and some indication of deafness and blindness. Return completed registration forms to the HKNC.

The Rehabilitation Services Administration (RSA) encourages your support in distributing these materials to those individuals who may wish to be included in the HKNC registry. Be sure to inform these individuals that registering with the HKNC is completely voluntary. Grantees are responsible for complying with requirements in their applicable program regulations governing confidentiality of personal information; therefore, grantees should not release personal information to the HKNC, on behalf of individuals who are deaf-blind, without first receiving the individual's informed written consent.

INQUIRIES TO: Joe D. Cordova, Director
Division for the Blind and Visually Impaired

CITATION: Helen Keller National Center Act, 29 USC 1901 et seq.

/s/
Fredric K. Schroeder, Ph.D.
Commissioner

cc: CSAVR/NCSAB
NCIL
NAPAS

Attachment #1

The HKNC Act defines an "individual who is deaf-blind" as being an individual:

- (A)(i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions;
 - (ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and
 - (iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation; or
- (B) who, despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives; or
- (C) meets such other requirements as the Secretary may prescribe by regulations.

(29 USC 1905(2)).

Attachment #2

To Whom it May Concern:

The Helen Keller National Center is a national rehabilitation facility funded by the federal government to provide services for youths and adults who are deaf-blind. Recently, our mandate was broadened to allow us to develop and maintain a registry of persons who are deaf-blind.

Information obtained by the registry will be used to generate statistical information that will be used in the following ways:

1. It will be shared with adult service programs so they will be better prepared for serving youths and adults who are deaf-blind.
2. It will be shared with teacher and interpreter preparation programs to prepare professionals to work with this population.
3. It will be used for program planning for transition age youth (14-21 years of age) as they transition out of the educational system.
4. It will be shared with state and federal governments as they develop priorities for program funding.

We invite individuals who are deaf-blind, parents, guardians and service providers who work with individuals who are deaf-blind of any age to fill out the enclosed registry form and return it to us. Be assured that all personal information will be kept in the strictest confidence.

If you have any questions, please contact me at 516-944-8900, ext. 270.

Sincerely,

Joseph J. McNulty
Director

Enclosure: Registry form