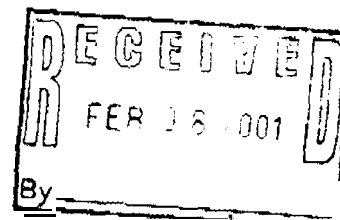


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U.S. DEPARTMENT OF EDUCATION
OFFICE OF **SPECIAL EDUCATION AND**
REHABILITATIVE SERVICES
REHABILITATION SERVICES ADMINISTRATION
WASHINGTON, D.C. 20202

*Bob***INFORMATION MEMORANDUM**

RSA-IM-01-18

DATE: December 18, 2000

TO : STATE VOCATIONAL REHABILITATION AGENCIES (GENERAL)
STATE VOCATIONAL 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.

Page 2

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



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 8 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

12-05-2000 3:07AM FROM HELEN KELLER 5169447302

P. 1

CURRENT SERVICES

Please choose from the list below up to 5 current services and indicate below each whether or not that service is adequate.

1. 2. 3. 4. 5.

Yes No Yes No Yes No Yes No Yes No

1. Activities of Daily Living	11. Job Placement	21. Speech, Language Therapy
2. Audiology	12. Low Vision	22. Supported Employment
3. Communication Instruction	13. Medical Services	23. Supported Living
4. Counseling	14. Occupational Therapy	24. Transportation
5. Education	15. Ophthalmology	25. Vocational Rehabilitation
6. Genetic Counseling	16. Orientation and Mobility/Travel Skills	26. Vocational Training
7. Independent Living	17. Personal Care Attendant	27. Home Care/Visiting Nurse
8. Infant Stimulation	18. Physical Therapy	28. Other (specify) _____
9. Interpreter Services	19. Recreation/ Leisure time	29. Other (specify) _____
10. Intervenor	20. Respite Care	

Using the same list (above), indicate up to 5 services needed by the individual that are not available

1. 2. 3. 4. 5.

EMPLOYMENT STATUS

- 1. Not employed - not seeking employment
- 2. Not employed - in job training
- 3. Seeking employment
- 4. Employed
- 5. Employed - seeking advancement
- 6. Retired
- 7. Not applicable
- 8. Unknown
- 9. Other (specify) _____

TYPE OF EMPLOYMENT

JOB TITLE (if applicable) _____

- 1. Homebound
- 2. Homemaker
- 3. Work Activity Program
- 4. Sheltered Employment
- 5. Supported Employment
- 6. Family/Self-employed
- 7. Competitive Employment
- 8. Not Applicable
- 9. Unknown
- 10. Other (specify) _____

PRIMARY LIVING ACCOMMODATIONS (check one)

- 1. With family
- 2. State institution
- 3. Foster care
- 4. Residential medical care program
- 5. Supported living
- 6. Supervised living (e.g., group home)
- 7. Independent
- 8. Unknown
- 9. Other (specify) _____

Primary Living Accommodations are:

1.88ttsfeary 2. Unsatisfactory 3. Unknown 1. Yes 2. No 3. Unknown

This form was completed by: _____ Date: _____

Last Name _____ - First Name _____

Relationship/Title _____ Agency _____

Address _____ Phone _____

City _____ State/Territory _____ Zip _____

Region DD Entered by: NOD Other Code

R Code C/D Date Entered:

Page 4, Revised 200 NOD (Latin Approach)

12-05-2000 3:04AM

FROM HELEN KELLER 5169447302

P. 5

CURRENT SERVICES

Please choose from the list below up to 5 current services and indicate below each whether or not that service is adequate.

1. 2. 3. 4. 5.

Yes No Yes No Yes No Yes No Yes No

1. Activities of Daily Living	11. Job Placement	21. Speech, Language Therapy
2. Audiology	12. Low Vision	22. Supported Employment
3. Communication Instruction	13. Medical Services	23. Supported Living
4. Counseling	14. Occupational Therapy	24. Transportation
5. Education	15. Ophthalmology	25. Vocational Rehabilitation
6. Genetic Counseling	16. Orientation and Mobility/Travel Skills	26. Vocational Training
7. Independent Living	17. Personal Care Attendant	27. Home Care/Visiting Nurse
8. Infant Stimulation	18. Physical Therapy	28. Other (specify) _____
9. Interpreter Services	19. Recreation/ Leisure time	29. Other (specify) _____
10. Intervenor	20. Respite Care	

Using the same list (above), indicate up to 5 services needed by the individual that are not available

1. 2. 3. 4. 5.

EMPLOYMENT STATUS

- 1. Not employed - not seeking employment
- 2. Not employed - in job training
- 3. Seeking employment
- 4. Employed
- 5. Employed - seeking advancement
- 6. Retired
- 7. Not applicable
- 8. Unknown
- 9. Other (specify) _____

TYPE OF EMPLOYMENT

JOB TITLE (if applicable) _____

- 1. Homebound
- 2. Homemaker
- 3. Work Activity Program
- 4. Sheltered Employment
- 5. Supported Employment
- 6. Family/Self-employed
- 7. Competitive Employment
- 8. Not Applicable
- 9. Unknown
- 10. Other (specify) _____

PRIMARY LIVING ACCOMMODATIONS (check one)

- 1. With family
- 2. State institution
- 3. Foster care
- 4. Residential medical care program
- 5. Supported living
- 6. Supervised living (e.g., group home)
- 7. Independent
- 8. Unknown
- 9. Other (specify) _____

Primary Living Accommodations are:

Seeking New Living Accommodations?

1. Satisfactory 2. Unsatisfactory 3. Unknown 1. Yes 2. No 3. Unknown

PERSONAL INFORMATION

Date: _____

Last Name: _____ First Name: _____

Relationship/Title: _____ Agency: _____

Address: _____ Phone: _____

City: _____ State/Territory: _____ Zip: _____

Region: DO:

R Code: C/D:

Entered by: Other Code:

Date Entered:

Page 4, Revised 3/99 MOD Letter Approach

12-05-2000 3:03AM FROM HELEN KELLER 5169447302

P. a

COMMUNICATION: A. Language

...the individual uses (check all that apply):

- 1. English
- 2. Spanish
- 3. American Sign Language (ASL)
- 4. Has not yet developed formal (conventional) language
- 5. Other (specify) _____

B. METHODS OF COMMUNICATION

Please indicate the primary method(s) which the person who is deaf-blind uses to communicate to others (informant) and by which information from others (receiver) if the person uses more than one method, please list the 5 that are most predominantly used.

- | | | | |
|---|--|--|---|
| <p>Expressive Communication</p> <p>1. <input type="checkbox"/></p> <p>2. <input type="checkbox"/></p> <p>3. <input type="checkbox"/></p> <p>4. <input type="checkbox"/></p> <p>5. <input type="checkbox"/></p> | <p>Receptive Communication</p> <p>1. <input type="checkbox"/></p> <p>2. <input type="checkbox"/></p> <p>3. <input type="checkbox"/></p> <p>4. <input type="checkbox"/></p> <p>5. <input type="checkbox"/></p> | <p>1. Behavior(s)</p> <p>2. Braille</p> <p>3. compute@</p> <p>4. Gestures/Pointing/Demonstration</p> <p>5. Hearing</p> <p>6. Manual Alphabet</p> <p>7. Pictures, including comm. board/book</p> <p>8. Print-on-palm</p> <p>9. Object cues</p> <p>10. Reading</p> <p>11. Sign: American sign Language</p> | <p>12. Sign: Signed English</p> <p>13. Speech</p> <p>14. Speechreading</p> <p>15. Tadoma</p> <p>16. Tactatouch</p> <p>17. Typing</p> <p>18. Voice Output Devices</p> <p>19. Writing</p> <p>20. Other (specify): _____</p> |
|---|--|--|---|

C. PROSTHETIC DEVICES

- 1. Hearing Aid(s)
- 2. Eye Glasses
- 3. Contact Lense(s)
- 4. Prosthetic Eye(s)
- 5. Orthopedic Prosthesis
- 6. Cochlear Implant(s)
- 7. Assistive Listening Device(s)
- 8. Other (specify): _____

SERVICES Is the individual currently receiving services? 1. Yes 2. No

Primary Service Provider/Agency _____

Mailing Address _____ City _____

State/Territory _____ Zip _____

Contact Person _____ Phone _____

TYPE(S) OF FACILITIES PROVIDING SERVICE(S)

Please enter the primary type of facility providing services, then list up to 2 additional types of facilities providing concurrent services.

Primary Facility: Additional Facility: Additional Facility:

- | | | |
|--|----------------------------------|---------------------------------------|
| 1. Infant Stimulation/Early Intervention | 7. Center for Independent Living | 13. Employment Program |
| 2. Education program | 8. Mental Health Program | 14. Vocational Rehabilitation Program |
| a. Post-secondary School | 9. Nursing Home | 15. Residential Program |
| b. Vocational Trade School | 10. Rehabilitation Center | 16. Program for the Blind |
| 5. Adult Day Program | 11. Senior Center | 17. Program for the Deaf |
| 6. Developmental Disability | 12. Medical Program | 18. Other (specify): _____ |

Setting of the Primary Facility

Please indicate the setting of the Primary Facility providing services, as listed above (choose only one).

- 1. Segregated
- 2. Mainstreamed
- 3. Inclusive
- 4. Home-based
- 5. Community-based
- 6. Other (specify): _____

ETIOLOGY/DIAGNOSTIC INFORMATION

A. Vision Loss
Please select up to 3 from the list below.
1. [] 2. [] 3. []

- 1. Accident/Trauma
2. Agenesis of Corpus Collosum
3. Albinism
4. Amblyopia
5. Anisidia
6. Anophthalmia
7. Anoxia (lack of oxygen)
8. Arthro Ophthalmopathy
9. Battered Child
10. Bell's Palsy
11. Brain damage
12. Cancer
13. Cataracts
14. Cerebral maldevelopment
15. Coloboma
16. Corneal scars
17. Corneal ulcers
18. Cortical blindness (CVI)
19. Cytomegic inclusion
20. Diabetes
21. Encephalopathy
22. Glaucoma
23. Ocular Histoplasmosis
24. HIV/AIDS
25. Hypermyopia
26. Hypertension
27. Keratitis
28. Leber's Optic Atrophy
29. Macular Degeneration
30. Microphthalmia
31. Multiple Sclerosis
32. Muscular Dystrophy
33. Myopic Degeneration
34. Neuroblastoma
35. Nystagmus
36. Optic Atrophy
37. Paget Disease
38. Phthisis Bulbi
39. Pituitary disorders
40. Retinal blastoma
41. Retinal detachment
42. Retinitis Pigmentosa
43. Retinopathy of Prematurity (ROP/RLF)
44. Rubella
45. Surgically acquired disease
46. Syphilis
47. Thyroid disease
48. Toxoplasmosis
49. Tumor
50. Viral infection
51. Unknown
52. Other (specify):

Comments:

B. Hearing Loss
Please select up to 3 from list below.
1. [] 2. [] 3. []

- 1. Accident/Trauma
2. Agenesis of Corpus Collosum
3. Anoxia (lack of oxygen)
4. Auditory Neuritis
5. Battered Child
6. Bell's Palsy
7. Brain damage
8. Cancer
9. Central Auditory Processing Disorder
10. Cerebral maldevelopment
11. Cerebral palsy
12. Congenital Syphilis
13. Cytomegic inclusion
14. Diabetes
15. Encephalopathy
16. HIV/AIDS
17. Hypertension
18. Labyrinthitis
19. Meniere's Disease
20. Multiple Sclerosis
21. Noise induced
22. Otitis Media
23. Otosclerosis
24. Ototoxic Drug Therapy
25. Paget Disease
26. Prematurity - complications of
27. Rubella
28. Sensorineural hearing loss
29. Syphilis
30. Tumor
31. Toxoplasmosis
32. Viral
33. Unknown
34. Other (specify):

D. Other Conditions: Please select up to 4 from the list below
1. [] 2. [] 3. [] 4. []
1. Alzheimer's
2. Battered Child
3. Bell's Palsy
4. Brain damage
5. Cancer
6. Cardiovascular disease
7. Cerebral Palsy
8. Cognitively delayed
9. Congenital heart disease
10. Cytomegic Inclusion
11. Dementia
12. Intellectual
13. Diabetes
14. Emotional Issues
15. Encephalopathy
16. Gastrointestinal conditions
17. Histoplasmosis
18. HIV/AIDS
19. Hypertension
20. Joint disorders
21. Meniere's disease
22. Multiple sclerosis
23. Muscular Dystrophy
24. Orthopedic conditions
25. Paget Disease
26. Pituitary disorders
27. Prematurity - complications of
28. Respiratory conditions
29. Seizure disorder
30. Spina Bifida
31. Surgically acquired disorder(s)
32. Syphilis
33. Hypert thyroid
34. Hypo thyroid
35. Thyroid conditions - other
36. Tumor
37. Urogenital Disorder
38. Viral Infection
39. Other (specify):

C. Syndromes
Please select up to 3 from the list below.
1. [] 2. [] 3. []

- 1. Apopt's
2. CHARGE
3. Christ-Sierrans-Touraine
4. Cockayne
5. Cogan
6. Down Syndrome (D21 Trisomy)
7. Fetal Alcohol syndrome
8. Goldenhar's
9. Hand-Schuller-Christian
10. Herpes-Zoster (or Hunt)
11. Hunter
12. Hurler
13. Inverse RP
14. Leber's Congenital Amaurosis
15. Laurence Moon-Biedl
16. Marfan
17. Marshall
18. Morquio
19. Norrie Disease
20. Neurofibromatosis
21. Prader-Willi
22. Progressive Quadriparesis and RP
23. Rubella
24. Syphilis
25. Septo Optic Dysplasia
26. Smith-Lemli-Opitz
27. Treacher-Collins
28. Usher I (born deaf, retinitis pigmentosa, balance problems)
29. Usher II (born hard-of-hearing with retinitis pigmentosa)
30. Usher III (born hard-of-hearing with progressive hearing loss and retinitis pigmentosa)
31. Vogt-Koyanagi-Harada
32. Waardenburg
33. Wolf-Parkinson-White
34. Unknown
35. Other (specify):

12-05-2000 3:01AM FROM HELEN KELLER 5169447302

P. 2

National Registry of Persons Who are Deaf-Blind

Helen Keller National Center for Deaf-Blind Youths and Adults
111 Middle Neck Road
Sands Point, NY 11050
516-844-8000

Please return this form to:

The purpose of the Registry is to provide basic information about persons with deaf-blindness in the United States. This information is to be used as a census, to identify the needs of persons with deaf-blindness, as a planning tool and for research purposes. All identifying information is confidential and written consent of the individual or guardian is required before it will be shared outside HKNC.

INFORMATION ABOUT INDIVIDUAL WHO IS DEAF-BLIND

Status 1. New
 2. Update Record # _____ ID # (office use only) _____

Last Name _____ First Name _____ Middle Name _____ Maiden Name _____ Date Completed _____

Mailing Address _____ City _____ County _____ State _____ Zip _____ Gender 1. Male 2. Female

Phone with area code voice TTY _____ e-mail _____ Social Security Number _____ Date of Birth _____

Marital Status 1. Single 2. Married 3. Divorced 4. Widowed 5. Separated 6. Unknown
 Ethnicity 1. African-American/Black 2. Alaskan Native 3. Asian 4. Caucasian/White 5. Hispanic 6. Native American 7. Pacific Islander 8. Unknown 9. Other _____

Relationship to Individual Listed Above _____

Last Name _____ First Name _____ Address _____
 City _____ County _____ State _____ Zip _____ Phone _____ Voice TTY

<p>Onset of Hearing Loss</p> <p><input type="radio"/> 1. Congenital (present at birth) <input type="radio"/> 2. Prelingual (hearing lost before language was present) <input type="radio"/> 3. Adventitious (after language acquisition) at age: _____ <input type="radio"/> 4. Unknown</p> <p>Degree of Hearing Loss (Better Ear Corrected)</p> <p><input type="radio"/> 1. Mild (26-45 dB) <input type="radio"/> 2. Moderate (46-70dB) <input type="radio"/> 3. Severe (71-90 dB) <input type="radio"/> 4. Profound (91-110 dB) <input type="radio"/> 5. Unable to Test - Uses Hearing <input type="radio"/> 6. Unable to Test - Does Not Use Hearing <input type="radio"/> 7. Unknown</p> <p>Prognosis of Hearing Loss</p> <p><input type="radio"/> 1. Stable <input type="radio"/> 2. Progressive <input type="radio"/> 3. Fluctuates <input type="radio"/> 4. Unknown</p>	<p>Onset of Vision Loss</p> <p><input type="radio"/> 1. Congenital - present at birth <input type="radio"/> 2. Adventitious - vision lost later in life at age: _____ <input type="radio"/> 3. Unknown</p> <p>Degree of Vision Loss (Better Eye Corrected)</p> <p><input type="radio"/> 1. Severely Visually Impaired (20/70 to 20/200, severe field restriction) <input type="radio"/> 2. Legally Blind (20/200 or less or field restriction of 20 degrees or less) <input type="radio"/> 3. Light Perception Only <input type="radio"/> 4. Totally Blind <input type="radio"/> 5. Unable to Test - Uses Vision <input type="radio"/> 6. Unable to Test - Does Not Use Vision <input type="radio"/> 7. Unknown</p> <p>Prognosis of Vision Loss</p> <p><input type="radio"/> 1. Stable <input type="radio"/> 2. Progressive <input type="radio"/> 3. Fluctuates <input type="radio"/> 4. Unknown</p>
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