

Manual for the Rochester Health Status Survey-IV (RHSS-IV)

The RHSS-IV was designed to collect information about the health and physical condition of an adult with an intellectual or developmental disability. The RHSS was validated for use by a licensed medical professional. All items should be completed based on information available from qualified informants and reliable records. The reliability of the information entered should be ascertained by interviewing the person or his or her carers, examining his or her medical record, or from discussion with his or her health care providers. The confidentiality of the information should be maintained according to the rules and practices of your jurisdiction or organization.

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The development of the RHSS was supported in part by:

- Grant# H133B031134 to the University of Illinois at Chicago from the US Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research, and
- Grant# 90DD0590 to the University of Rochester from the US Department of Health and Human Services, Administration on Children and Families, Administration on Developmental Disabilities.

MANUAL FOR THE ROCHESTER HEALTH STATUS SURVEY-IV (RHSS-IV)

Background

The Rochester Health Status Survey-IV is a survey instrument that can be used to identify incidence, lifetime prevalence, and point prevalence of diseases and conditions common in adults with intellectual disabilities, as well as functional abilities, medication usage, and health care services usage. The survey was designed to be completed from chart/medical record review and informant information. The RHSS-IV can be completed in about 45 minutes, but may take longer for some people.

Note: In a validation study (see Davidson et al., 2008), data were collected on each subject by three different respondents (a service coordinator, and a nurse, and, when available, a family member). Their responses were compared item by item with the responses of a geriatrician who also completed the survey on each subject. Correlations and Kappa statistics confirmed that the highest agreement scores resulted between nurses and the geriatrician. Given these findings, we recommend that the survey be completed by a health professional, preferably one who is also familiar with the individual. In uses outside of medical settings we recommend that multiple informants (e.g., family members, agency personnel, primary physicians, health care workers) be interviewed.

As part of the development of the RHSS-II, user focus groups advised that the quality of responses to survey questions could be improved by guidance provided prior to use. This Manual is intended for that purpose.

The Manual provides detailed item-by-item instructions that are linked to the World Health Organization's International Classification of Diseases, Ninth Revision, Clinical Modification ([ICD-9-CM](#)), which is a classification system for organ system diseases and disorders (sourced via: <http://www.cdc.gov/nchs/datawh.htm#International%20Classification>). Please direct any questions about this manual or the RHSS-IV to the Aging and Neurodevelopmental Conditions Project at the University of Rochester (Rochester, New York USA), email contact: LauraM_Robinson@urmc.rochester.edu.

Note on Maintenance of Confidentiality

Persons completing the RHSS-II are advised to treat all information provided as confidential and protected. All applications of restrictions on collection and use of confidential information in force in the data collection should be observed.

Specific Guidance

1. **Age (yrs.) and Birth Year** – Indicate the person’s age in years (use this style: Birth-first year = 0, first to second year = 1, etc.) and all four digits of the birth year.
2. **Sex** – Place a check mark in one box, “male” or “female”. For transgendered or transsexual individuals, place the mark in the box that corresponds to the individual’s self-identification AND note this also in Q 11 -- “other syndrome (specify)” as a condition.
3. **Height** – Place the person’s height either in centimeters (cm) OR feet and inches in the appropriate boxes. It is not necessary to convert from one unit of measurement to the other.
4. **Weight** – Place the person’s weight either in kilograms (“kg”) OR pounds (“lbs”). It is not necessary to convert from one unit of measurement to the other.
5. **Waist circumference** – Place the person’s waist circumference either in centimeters (cm) or inches (in). It is not necessary to convert from one unit of measurement to the other.
6. **What does the individual do during the day** – Check any and all that apply.
7. **Where does the person currently live** -- Please check only the one where he or she lives and sleeps (residence) more than 50% of the time during the year. If "supervised setting" is checked, please add the number of other persons who typically live at that setting on the line below the check. Otherwise leave the line blank.
8. **Where is the person’s residence** -- Check the type of community that applies. “City (large urban area)” is an entity with over fifty thousand (50,000) persons. “Town (small urban area)” is between ten thousand and forty-nine thousand nine hundred ninety nine (10,000-49,999) persons. “Rural area” is less than ten thousand persons.
9. **IQ measurement or level of disability** – Check the box with the appropriate level of intellectual disability [“retardation”] as diagnosed with ICD-CM or DSM. In cases where there is no level of “retardation”, check the box marked “None”.
 - ▶ If there is no formal diagnosis and the IQ testing has shown a lower than average IQ score, then check the box that corresponds to the highest IQ score the person achieved as measured by a psychologist, pedagogue, or other appropriate professional.
 - ▶ If no testing is documented, please indicate level by clinical judgment.
 - ▶ Do NOT check Q11 -- “Other intellectual or developmental disabilities –Learning disabilities” if the person’s IQ score and

adaptive functioning meet the ICD-CM or DSM criteria for “mental retardation” [intellectual disability].

10. **Exact IQ Score (if known)** – Use the most recent full-scale IQ score that was determined by a comprehensive test of intellectual functioning, as described above in Q 9.

10. **Other intellectual or developmental disabilities** – Check the appropriate box for any developmental or intellectual disabilities noted as diagnosed with ICD-CM or DSM. For the box labeled “Autism spectrum disorder,” check if the person meets the ICD-CM or DSM criteria for either Autism, Pervasive developmental disorder, Not otherwise specified, or Asperger’s syndrome.
▶ If the person meets the criterion for “Obsessive compulsive disorder”, do not check in this question, but note at Q 41 (g).
▶ For the box labeled “Childhood-onset epilepsy” do not note “Adult-onset epilepsy” here, but note at Q 39 (b).
▶ For the box labeled “Learning disability” (LD) do NOT check if the person meets the criteria for intellectual disability (“mental retardation”) as outlined in the ICD-CM or DSM and does not have a comorbid LD. Check instead the appropriate ‘mental retardation’ diagnosis in Q 9. *“Learning disability”, in this case,*

refers to a group of disorders that affect a broad range of academic and functional skills including the ability to speak, listen, read, write, spell, reason and organize information. For UK applications of LD, please use Q 9.

▶ For the box labeled “Tourette’s syndrome (motor or vocal tics)”, check only if Tourette’s syndrome is diagnosed. Motor or Vocal tics not diagnosed as Tourette’s syndrome can be noted in Q 37 (o).

12. **Person’s overall health** – The respondent should be a person who has had knowledge or access to the person’s health records for at least 24 months prior to filling out this form. If the person does not have the knowledge or access either choose another adult or give the form to a licensed professional who has this knowledge or access. Indicate the person’s overall health status both at the time of the survey and 24 months previously.

13. **Fallen recently** – Check only one.

14. **(a) Smokes cigarettes** – If “Yes” please answer Q14 (b). If “No” please skip to Q 15. Include smoking tobacco in pipes and cigars under this item.

(b) Number of cigarettes smoked per day – One pack is equal to twenty (20) cigarettes.

15. **Adverse drug reaction in last 24 months** – If the person has had an adverse reaction to a medication or a medical error that resulted in either an assessment by a physician or more than an observation check this box and fill

out Q 16. If no adverse drug reaction, skip to Q 17.

16. **If adverse drug reaction, specify symptoms** – Check all that apply, include medical error in “Other (specify).”

Medical History Section – Questions 17 through 41 refer to the person’s past and current medical issues. The diagnostic criteria to follow correspond to ICD-9-CM and DSM conventions. The codes below are provided as guidelines and are not intended to be comprehensive as to the diagnostic categories. When a documented diagnosis conflicts with the code, please use the written description of the procedure or diagnosis.

In general, for each section, if the person’s organ system in question has a history of *bacteriological infection*, that history should be documented in the appropriate place in Q 29 – *History of infectious diseases*. As examples: (1) for Q 27 – skin diseases, ‘cellulitis of the skin’ would be documented in Q 29 (e), (2) for Q 28 genito-urinary and kidney diseases, ‘urinary track infection’ would be documented in Q 29 (b), (3) for Q 32 – History of eye diseases, ‘conjunctivitis’ would be documented in Q 29 (m).

17. **Surgical history** – If no record of any surgeries, check *None*.

ICD-9-CM Codes for surgical procedures

Procedure	Code
Hysterectomy	68.3x-68.9x
Appendectomy	47.xx
Gastronomy tube	96.xx
Bowel resection	46.xx
Cholecystectomy	51.2x
Fracture repair	multiple codes
Joint replacement	00.7x or 00.8x
Mastectomy	85.4x
Prostate resection	60.29
Colostomy	46.1x
Ileostomy	46.2x
Cataract extraction	13.1x
Spinal surgery, e.g. scoliosis	03.x

18. **If female ever pregnant** – Check if there is a history of pregnancy, regardless of the outcome (live birth, stillbirth, or abortion). If male, skip to Q 19.
19. **Herbal remedies** – Self-explanatory.
20. **Vitamins** – Self-explanatory.
21. **Supplements** – Self-explanatory.
22. **Accident or Injury in the last 24 months** – Check all that apply per documentation or knowledge.
23. **Prescribed medications** – Please check all that apply. If the person does not take any medications please check “None” in the first column only. If the person does not take medications for the specific condition please do not check any column in that row.
24. **Oral health problems** – Please see note under Medical History Section heading, If none check *None*.

ICD-9-CM Codes for oral health problems

Diagnosis Code

Debris in mouth	No codes specified
Dental caries/cavities	521.0x
Inflamed, swollen, or bleeding gum	multiple codes
Oral abscess/infection	522.5
Oral ulcers/canker sores	528.2
Toothache, oral pain	No codes specified
Broken or loose teeth	521.81 or 873.73
Chewing problems	No codes specified
Ill-fitting dentures	No codes specified
Restricted diet due to teeth lost	No codes specified
Too much drooling/saliva	No codes specified
Dry mouth/too little saliva	No codes specified

25. **Nutritional conditions** – (b) For ‘overweight’ or ‘obesity’ use the current U.S. Department of Health and Human Services [Dietary Guidelines for Americans](#) or ICD-CM diagnostic criteria for these conditions. (d & e) Weight loss/gain of more than 10% of body weight in less than 6 months time should be noted. If none check *None*.

► **NOTE:** For adults, ‘overweight’ and ‘obesity’ ranges are determined by using weight and height to calculate a number called the “body mass index” (BMI). BMI is used because, for most people, it correlates with their amount of body fat. An adult who has a BMI between 25 and 29.9 is considered *overweight*. An adult who has a BMI of 30 or higher is considered *obese*. To calculate BMI, use one of these formulas: $BMI = \text{[weight in kilograms/ (height in meters)}^2 \text{] or$

$$\text{BMI} = [(\text{weight in pounds})/(\text{height in inches})^2] * 703.$$

26. History of heart and circulatory diseases –If none check *None*.

ICD-9-CM Codes for heart and circulatory diseases

Diagnosis Code

Ischemic heart disease (angina)	413.x
Congestive heart failure	428.x
Myocardial Infarction (heart attack)	410.x-412.x
Acquired valvular heart disease	424.9x
Congenital heart disease	746.x-747.x (except 747.6)
Peripheral artery disease	747.6
Hypertension	multiple 4xx.x codes
Syncope (e.g. postural hypotension)	multiple codes (except 992)
Cardiac rhythm disease	427.89

27. History of blood diseases -- Please see note under Medical History Section heading. If none check *None*.

ICD-9-CM Codes for blood diseases

Diagnosis Code

Iron deficiency anemia	280.x
Anemia not due to iron deficiency	mostly 281.x-285.x
Thrombotic disease	444.x

28. (For Females) History of gynecological conditions or infections -- Please see note under Medical History Section heading. If none check *None*.
 ► If Male, skip to Q 29.

ICD-9-CM Codes for blood diseases

Diagnosis Code

Dysmenorrhea	625.3 (exclude 306.52)*
Endometriosis or chronic pelvic pain	617.x
Vaginitis	multiple codes
Peri- or post-menopausal status	not applicable
Benign breast disease	217 or 610.0
Non-menopausal irregular menses	626.x

* 306.52 should be placed in Q 41 row L (I).

29. History of pulmonary disease -- If none check *None*.

ICD-9-CM Codes for pulmonary diseases

Diagnosis	Code
Allergic rhinitis	477.x
Asthma	493.x
COPD	496.x *
Obstructive sleep apnea	327.2x or 780.57
Restrictive lung disease 2 ^o	multiple codes
Pulmonary fibrosis	multiple 5xx.x codes

* or conjoint with diagnoses 491.x-493.

30. History of endocrine/metabolic disease – Please see note under Medical History Section heading. Childhood-onset Type II diabetes should be noted at (h), other endocrine/metabolic disease, and specified. Childhood Type I diabetes should be noted at (b). Adult onset Type II diabetes should be noted at (c). If none check *None*.

ICD-9-CM Codes for endocrine/metabolic diseases

Diagnosis	Code
Diabetes type 1 (childhood onset)	249.x-250.x (see above)
Diabetes type 2 (adult onset)	249.x-250.x (see above)
Hypothyroidism	244.x
Hyperthyroidism	242.x
Dislipidemias (e.g. high cholesterol)	272.x
Increased insulin resistance	Not applicable

31. History of cancer -- If none check *None*.

ICD-9-CM Codes for cancer

Diagnosis	Code
Bladder	188.x
Breast	174.xx or 175.xx
Colon	153.x
Leukemia	204.x-208.x

Lung	162.x
Lymphoma	200.x-202.x
Oral	149.x
Prostate	185
Skin (non-melanoma)	multiple codes *
Melanoma	172.x

* exclude 172.x and place this under row k (melanoma)

32. History of infectious diseases -- Please see note under Medical History Section heading. If none check *None*.

ICD-9-CM Codes for infectious diseases

Diagnosis	Code
Urinary tract infections	599
Pneumonia/bronchitis	466.x & Multiple 48x.x codes
Sinusitis or middle ear infection	473.x & 461.x codes
Cellulitis	Multiple codes
Herpes simplex	054.xx
Sexually transmitted disease	090.xx-099.xx
Hepatitis B	070.2x-070.3x
Other infectious hepatitis	070.0x-.1x; 070.4x-.9x & 072.71
Positive PPD	795.5
Tuberculosis (active infection)	010-018
Parasitic infestation	Multiple codes
Helicobacter pylori gastritis	041.86
Conjunctivitis (pink eye)	372.x
Human immunodeficiency virus	Multiple codes
Acquired immunodeficiency	Multiple codes

33. History of skin diseases -- Please see note under Medical History Section heading. If none check *None*

ICD-9-CM Codes for skin diseases

Diagnosis	Code
Fungal nail or skin disease	117.8 or 118
Decubitis (pressure) ulcer	707.2x
Dry skin	690-691
Eczema or allergic skin rash	692.xx
Leg/foot edema (e.g. venous stasis)	757.0 & other codes
Shingles (herpes zoster)	053.xx

- 34. History of gastrointestinal disease** – Please see note under Medical History Section heading. (c) Ulcers secondary to confirmed *h. pylori* should also be noted in Q 32 (m). If none check *None*.

ICD-9-CM Codes for gastrointestinal diseases

Diagnosis	Code
Gastroesophageal reflux	530.81
Gastric or peptic ulcer	531.x-532.x & other codes
Constipation	564.0x
Bowel obstruction	Multiple codes
Inflammatory bowel disease	564.1
Celiac sprue	579.x
Non-infectious hepatitis	571.x
Gallbladder disease (e.g. gallstones)	574.xx

- 35. History of genito-urinary and kidney diseases or infections--** Please see note under Medical History Section heading. If none check *None*.

ICD-9-CM Codes for genito-urinary and kidney diseases

Diagnosis	Code
Benign prostatic hyperplasia	600.2x
Neurogenic bladder	596.54 & 344.61
Flaccid bladder	specific 596 codes
Spastic bladder	specific 596 codes
Urinary incontinence	788.3x & other codes
Chronic kidney disease	specific 403 & 404 codes
End-stage renal disease (dialysis)	585.6
Kidney stone	592.0

36. History of musculoskeletal disease -- Please see note under Medical History Section heading. If none check *None*.

ICD-9-CM Codes for musculoskeletal diseases

Diagnosis	Code
Scoliosis	737.3x
Inflammatory arthritis	714.xx
Osteoarthritis	715.xx
Osteoporosis (diagnosed)	733.0x
Gout	274.xx *
Chronic low back pain	724.2
Bunions or other acquired foot	727.1
Acquired limb or joint deformities	736.xx
Acquired hip dislocation	835.xx
Cervical spine disease	737.x or 738.5
Tendonitis, bursitis or myofascial	727.2-727.3x

* Gout due to toxic metals should be documented in row m ("Other ...").

37. History of eye diseases or conditions -- Please see note under Medical History Section heading. If none check *None*.

ICD-9-CM Codes for eye diseases

Diagnosis	Code
Refractive error or astigmatism	367.2x
Strabismus	378.xx
Amblyopia	368.xx
Cataract	366.xx
Glaucoma	365.xx
Retinal disease	361.xx-362.xx
Corneal disease (ulcer, abrasion)	371.xx
Eyelid disease (blepharitis)	373.xx-374.xx
Severe acuity impairment (not correctable)	369.xx

38. History of audiologic conditions -- Please see note under Medical History Section heading. If none check *None*.

ICD-9-CM Codes for audiologic conditions

Diagnosis	Code
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Conductive hearing loss	389.0x
Sensorineural hearing loss	389.1x
Cerumen (wax) impaction	380.4
Severe hearing loss (mixed cause)	389.2x-389.9x

39. **History of neurological disorders or conditions** – Please see Q 11 to document childhood-onset epilepsy. If none check *None*.

ICD-9-CM Codes for neurological disorders

Diagnosis Code

Adult onset epilepsy	Multiple codes
Chronic severe headache (migraine)	346.xx
Stroke	434.xx
Dysphagia (swallowing disorder)	787.2x
Parkinson's disease	332.x; 331.82
Alzheimer's disease	331.0
Fronto-temporal dementia	331.1x
Lewy body dementia	331.82
Vascular dementia	290.4x
Undifferentiated dementia	294.8
Neuropathy	Multiple codes
Chronic vertigo/dizziness	386.xx & 780.4
Chronic drug-induced movement dx	333.9x

If any column in row b (“Adult onset epilepsy”) is checked please answer Q 40, otherwise please skip to Q 41.

40. **How many seizures** – If no seizures, please skip to Q 41. If the person has seizures choose only one period of time that would be most convenient to describe the frequency of seizures, check that box and place the number of seizures the person typically has during that period of time on the line to the left of that time.

41. **History of psychiatric disorders or conditions** – Please document only if a formal DSM or ICD-CM psychiatric diagnosis has been made. Diagnosis of ‘pica behavior’ should be documented in (k) and specified. Document ‘autism spectrum disorders’ or ‘learning/attention disorders’ only at Q 11

ICD-9-CM Codes for psychiatric conditions

Diagnosis

Code

Schizophrenia	295.xx
Other psychosis	295.xx; 297.xx-299.xx
Bipolar disorder	296.0x-296.1x; 296.4x-296.9x
Depression	296.2x-296.3x
Anxiety disorder	300.0x-300.2x; 300.4x-300.9x
Obsessive-compulsive disorder	300.3x
Post-traumatic stress disorder	309.81
Personality disorder	301.xx
Alcohol or substance abuse	303.xx-305.xx
Eating disorder (e.g. anorexia,,bulimia)	307.1; 307.5x; 783.6; V69.1

42. ADL (Activities of Daily Living)

– Check only one box per row. The rating for each activity should correspond with documentation based on a scale of adaptive functioning, if available, or on most informed impressions.

43. Walking – Check only one box.

44. Assistive aids – Check only one box per row. If (a) “None” (no aids are used), check (a) “None” only and skip to Q 45.

45. Medical Equipment -- Check only one box per row. If (a) “None” (no aids are used), check (a) “None” only and skip to Q 46.

46. Number of primary health care office visits for acute illness in the last 24 months – Self-explanatory. Includes appointment visits to physician or clinic.

47. Number of emergency room visits in the last 24 months –

Self-explanatory. “Emergency room” refers that part of a hospital that takes care of sick or injured people who need immediate attention.

48. Number of acute hospitalizations in the last 24 months -- Self-explanatory. ‘Acute’ refers to short-term stay in a hospital.

49. Number of rehabilitation or nursing home placements in the last 24 months -- Self-explanatory.

50. Number of primary preventive dental visits in the last 24 months – Self-explanatory. Includes routine appointments for dental care.

51. Number of acute or emergency dental care visits in the last 24 months – Self-explanatory.

52. Types of dental procedures in the last 24 months – Check all

that apply. If none leave blank and go to Q 53.

53. Specialist care visits at least once in the past 24 months –

Check all that apply. If None check “None” and skip to Q 54.

54. Diet prescription – Check all that apply, if none check “None”.

55. Exercise prescription – Check all that apply. If none check None.

56. Routine health screening and prevention procedures – Check all that apply.

57. Please comment on your ability to access health care for the person – Specifically please comment on ease or difficulty in finding an appropriate health care provider, ease in making appointments, ease in transporting the individual to the appointment, quality of service at the appointments.

58. Any comments concerning health status that you feel would add to the understanding of the person’s general health status – Specifically please comment on any health status areas either incompletely covered or omitted from this survey.

FOR U.S. PARTICIPANTS ONLY

What is the person’s cultural/ethnic/racial background –The determination of these cultural/ethnic/racial backgrounds should **not** be based on the individual’s self-report, but on the clinical documentation.

The following definitions are from the *NIH POLICY ON REPORTING RACE AND ETHNICITY DATA: SUBJECTS IN CLINICAL RESEARCH*, (released 8-08-2001, updated 11-06-2006) reproduced below (with specific definitions of cultural/ethnic/racial categories highlighted in **bold** by the RHSS research team:

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NOTICE: NOT-OD-01-053

National Institutes of Health

POLICY: The NIH has adopted the 1997 Office of Management and Budget (OMB) revised minimum standards for maintaining, collecting, and presenting data on race and ethnicity for all grant applications, contract and intramural proposals and for all active research grants, cooperative agreements, contract and intramural projects. The minimum standards are described in the 1997 OMB Directive 15, http://www.whitehouse.gov/omb/fedreg/directive_15.html.

SUMMARY: This document provides additional guidance and instruction for using the revised minimum standards for maintaining, collecting, and presenting data on race and ethnicity found in the PHS 398 (rev. 5/01) and PHS 2590 (rev.5/01) instructions and forms <http://grants.nih.gov/grants/forms.htm>. Comparable information will be provided in research and development contract solicitations and awards for intramural projects. This document should be used in conjunction with the instructions in the PHS 398 and PHS 2590 instructions and forms.

The 1997 OMB revised minimum standards include two ethnic categories (Hispanic or Latino, and Not Hispanic or Latino) and five racial categories (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White). The categories in this classification are social-political constructs and should not be interpreted as being anthropological in nature

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Collection of this information and use of these categories is required for research that meets the NIH definition of clinical research.

EFFECTIVE DATE: This policy applies to all new applications and proposals, annual progress reports, competing continuation applications, competing supplement applications for research grants, contracts, and intramural projects as of January 10, 2002.

I. Revised Minimum Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

The following are the ethnic and racial definitions for the minimum standard categories (1997 OMB Directive 15).

Ethnic Categories:

Hispanic or Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can also be used in addition to "Hispanic or Latino."

Not Hispanic or Latino

Racial Categories:

American Indian or Alaska Native: A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliations or community attachment.

Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan,

Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. (Note: Individuals from the Philippine Islands have been recorded as Pacific Islanders in previous data collection strategies.)

Black or African American: A person having origins in any of the black racial groups of Africa. Terms such as “Haitian” or “Negro” can be used in addition to “Black or African American.”

Native Hawaiian or Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

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References

1. Janicki MP, Davidson PW, Henderson CM, McCallion P, Taets JD, Force LT, Sulkes SB, Frangenberg E, Ladriagan PM. (2002). Health characteristics and health services utilization in older adults with intellectual disabilities living in community residences. *J Intellect Disabil Res*, 46, 287-298.
2. Davidson PW, Henderson CM, Janicki MP, Robinson LM, Bishop KM, Wells A, Garroway J, Wexler O. (2008). Ascertaining health-related information on adults with intellectual disabilities: Development and field testing of the Rochester Health Status Survey. *J. Policy Pract Intellect Disabil.*, 5(1), 12-23.