U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

Design for Survey of Persons with Mental Retardation and Developmental Disabilities:

Summary of Recommendations for Survey Questions and Screening Criteria

November 1989

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This report was prepared under contract #HHS-100-88-0035 between HHS's Office of Social Services Policy (now DALTCP) and Mathematica Policy Research, Inc. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Robert Clark.

DESIGN FOR SURVEY OF PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES:

Summary of Recommendations for Survey Questions and Screening Criteria

Rita Stapulonis
Joy Gianolio
Susan A. Stephens
Craig V.D. Thornton

Mathematica Policy Research, Inc.

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OVERVIEW

This document contains brief summaries of recommendations for survey items to be included in the Survey of Persons with Mental Retardation and Developmental Disabilities. The domains covered by these recommendations are based on the core set identified in consultation with the Technical Advisory Group and the Department (see Attachment A.)

The summaries were developed from a set of more detailed working papers covering each domain. These papers present the rationale behind these preliminary recommendations and were assembled into a separate document. The working papers were circulated for comment to various members of the Technical Advisory Group. Their comments and outstanding issues are noted on the summary sheets.

Each summary sheet presents the following information:

- A brief definition of the domain or subdomain
- A brief description of each proposed question
- A summary of the response categories for each question
- A list of outstanding issues or comments about the proposed questions and/or approach to measurement for the domain.

Attachment B indicates the page number of each summary sheet and also whether each domain is covered in the screener, in the follow-up survey, or in both.

Two things should be noted about the summaries. First, there is considerable overlap among the domains and it is somewhat arbitrary in which domain a particular question appears. For example, questions on limitations in employment are included under Functional Limitations: Economic Self-Sufficiency, while employment status and involvement in supported employment is included in Education/Employment/Training Services. Second, even focusing only on the "core" domains, there are a large number and wide variety of questions that could be included on the survey. It will almost certainly be necessary to reduce the number of questions actually included on the instrument. Please consider what you would recommend in terms of items that must be retained and those that could be deleted.

ATTACHMENT A. COMPARISON OF RFP RESEARCH QUESTIONS WITH CORE/NON-CORE DATA CATEGORIES

Data Category (RFP Research Question)	RFP	Core	Non-Core
RESIDENTIAL ENVIRONMENT (1,3)			
Types of Living Arrangements	X	X	
Attributes/Institutonal Character	X	X	
Quality			X
Residential History		X	
DEMOGRAPHIC CHARACTERISTICS (2)			
Age	X	X	
Sex	X	X	
Race	X	X	
Marital Status	X	X	
Family Structure (household composition)	X	X	
Income (individual and household)	X	X	
Participation in Federal Programs	X	X	
Educational Attainment		X	
Identifiers		X	
FUNCTIONAL LIMITATIONS (4,6)			
Types of Limitations			
Self-care	X	X	
Language	X	X	
Learning	X	X	
Mobility	X	X	
Self-direction	X	X	
Independent Living	X	X	
Economic Self-sufficiency	X	X	
Adaptive/Maladaptive Behavior		X	
Severity of Limitations	X	X	
Age of Onset	X	X	
FORMAL SERVICE USE (5,7,9,10)			
Types of Services			
Health and Medical	X	X	
Other Formal Services	X	X	
Equipment/Aides	X	X	
Quantity of Services	X	X	
Need for Services			X
Satisfaction with Services		X	
Payment for Services			
Insurance Coverage	X	X	
Source of Payment	X	X	
Expenditures by Source Out-of-Pocket Other sources	 X	 X X	
PROVISION OF INFORMAL SUPPORT (5)			
Types of Support/Assistance (including financial contributions)	X	X	

Data Category (RFP Research Question)	RFP	Core	Non-Core
Quantity of Support/Assistance	X	X	
Caregivers' Experiences and Attitudes			X
CATEGORICAL CONDITIONS (6,7)			
Conditions			
Primary diagnosis	X	X	
Other diagnoses	X	X	
Health Status	X	X	
EMPLOYMENT STATUS (8)			
Type/Level of Support	X	X	
Hours/Earnings		X	
PARTICIPATION IN OTHER REGULAR DAILY ACTIVITIES			X
SOCIAL INTERACTION/INTEGRATION		X	
SUBJECTIVE WELL-BEING			X

ATTACHMENT B. OVERVIEW OF RECOMMENDED QUESTIONS

	Screening Instrument	Follow-Up Instrument
CATEGORICAL CONDITIONS (pp.14)	X	X
LIMITATIONS IN FUNCTIONING		
Self-care (pp.16)	X (subset)	X
Independent living (pp.18)	X (subset)	X
Self-direction (pp.20)	X (subset)	X
Mobility (pp.23)	X (subset)	X
Communication (pp.22)	X (subset)	X
Learning (pp.26)	X (subset)	X
Economic self-sufficiency (pp.25)	X (subset)	X
FORMAL SERVICE USE (quantity, payment, satisfaction)		
Medical services (pp.36)		X
In-home services (pp.42)		X
Social/psychological services (pp.39)	X (subset)	X
Adaptive equipment/assistance devices (pp.34)	X (subset)	X
Education/employment/training services (pp.29)	X (subset)	X
Transportation services (pp.44)		X
Income support services (see Demographics, pp.52)	X (subset)	X
RESIDENTIAL ENVIRONMENT (pp.45)	X (including past use)	X
INFORMAL SUPPORT (pp.50)		X
SOCIAL INTERACTION AND BEHAVIOR (pp.48)		X
DEMOGRAPHICS (see also Income Support Services (pp.52) and EDUCATION/EMPLOYMENT/TRAINING SERVICES (pp.29)	X (subset included on NHIS core)	X

OVERVIEW OF SCREENING MODULE

Background

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 provides a definition of developmental disabilities (see Attachment A) that is the basis of the screen for the Survey of Persons with Mental Retardation and Developmental Disabilities.

The definition requires that a developmental disability be attributed to mental and/or physical impairments, manifested prior to age twenty-two, chronic (likely to continue indefinitely), result in substantial limitations in functioning in three or more of seven major life activities, and require individually planned, coordinated, and extended services.

This definition primarily revolves around functional limitations and requires development of measures of the severity of limitations in seven life activities and standards for judging the substantiality of limitations in functioning across life activities. States and specific programs have adopted many alternative means for judging limitations and substantiality. Also, some service programs use definitions of developmental disabilities that rely more on categorical conditions than limits in functioning as key defining factors.

The variation and inherent imprecision in definitions supports the decision to adopt a broad screening approach for the Survey of Persons with Mental Retardation and Developmental Disabilities. Analysts using the survey data will then be able to use more restrictive definitions of developmental disabilities to specify subgroups from the survey sample.

Purpose

To establish a valid, reliable, and efficient approach for identifying the sample of individuals to whom the full set of survey questions should be administered.

These individuals should include all persons from the national sample who are likely to be considered developmentally disabled under any of a number of policy-relevant definitions.

Inclusivity Versus Exclusivity

The screener must balance the two competing goals of inclusivity and exclusivity. Policy interest in the implications of alternative definitions of developmental disabilities argues to include in the survey a broad group of persons who might be developmentally disabled and from which specific groups of interest can be defined analytically. At the same time, cost considerations require that the survey be focused as accurately as

possible and that it exclude persons who would not be considered developmentally disabled.

Inclusivity is important so that the survey will support analysis of the groups of persons classified as developmentally disabled by various state and federal programs. Inclusivity is also important because of the inherent imprecision in survey methods. Inclusive screening criteria help to ensure that the survey include developmentally disabled individuals whose limitations may not be captured in an interview either because of misreporting or because available formal or informal services enable a person to perform specific activities they would unable to perform without assistance.

Exclusivity is important in order to contain the costs of the survey. The survey should minimize inclusion of persons who would not be considered developmentally disabled by any likely definition: for example, persons who have become disabled in adulthood. The need to constrain the size of the sample screened eligible for the survey may mean that some "at risk" persons will not be identified and thus not included in the survey.

A comprehensive profile of the national population requires that children be included in the survey. However, it is important to note that the functional definition was primarily designed to identify adults. Screening criteria for children must therefore rely heavily on identification through the school system for special education services and on progress toward developmental milestones for pre-school age children.

A comprehensive national profile also requires data on persons with developmental disabilities living in various group settings and institutional arrangements. Screening questions will be asked of persons in these types of living arrangements in order to obtain data comparable to the data collected from persons living in community settings. However, the screening function of these question will be less important for persons in facilities who can be identified as having developmental disabilities from information collected in the sample development process.

Finally, although persons whose functional limitations are associated with mental illness rather than other mental or physical impairments are sometimes excluded from the developmentally disabled population, the survey will include all persons who meet the functional limitations and age of onset criteria, regardless of the categorical condition associated with the limitations.

Categories of Screening Questions

In order to ensure inclusion in the survey of all persons who may be developmentally disabled, three categories of questions will be asked during the screening process.

The three categories of screening questions include:

- Categorical Conditions
- Functional Limitations (with onset prior to age 22)
- Use of Selected Services Targeted toward Persons with Developmental Disabilities

Persons identified as potentially developmentally disabled on any one of the three categories would be considered eligible for the survey. Persons excluded from the survey would be those who reported no conditions generally associated with developmental disabilities, no functional limitations starting prior to adulthood, and no use of services often used by persons with developmental disabilities.

Use of questions in any one category as the single screening device would potentially underrepresent certain persons with developmental disabilities; taken together no person with developmental disabilities should be inappropriately screened out of the survey.

Number of Screening Questions

We recommend that the screening questions be administered to a nationally representative sample of households through a supplement to the National Health Interview Survey. Thus, a large number of individuals (about 100,000) would be screened for later administration of the Survey of Persons with Mental Retardation and Developmental Disabilities.

Supplements to the NHIS are expensive (about $100,000 per minute). Therefore, there is good reason to try to limit the questions on the NHIS supplement to the smallest number of items that efficiently screen the sample--that is, to use the fewest number of questions needed to identify persons with developmental disabilities. This would reduce the cost of the screening effort and the burden on respondents.

Even if a small set of items for the screen could be identified, the number of questions and type of questions on the proposed NHIS supplement should not be restricted unduly. Detailed information on functioning is needed to operationalize many policy relevant definitions of developmental disabilities. Other information is required to identify subgroups of interest, such as degree of formal support provided in the residential setting. If a relatively broad set of functioning and service use items were collected from the large national sample screened by the NHIS supplement, this would permit (1) more accurate and complete descriptions of the developmentally disabled population from the screening data alone, even before the full survey was administered, (2) comparison of the developmentally disabled population with the nondisabled population and with the population of persons with other disabilities, and (3) evaluation of the sample size and efficiency associated with various criteria for selecting the sample of persons for the full survey (i.e., various combinations of characteristics, for example, combinations of categorical conditions and functional limitations).

Recommendation for a Pilot Test of Screening Questions and Criteria

There does not appear to be good evidence at the present time as to what set of questions' would be both accurate and efficient. For this reason, we believe that a relatively large pilot test of the screening instrument is warranted. Such a test would ensure that the screening questions accurately identify persons known to be developmentally disabled while not including an undue number of persons known not to be developmentally disabled. The pilot test would also help determine if there is a small set of items that are accurate and efficient discriminators between these two groups so that the NHIS screening supplement can be as efficient as possible.

Recommended Screening Questions and Criteria

The attached charts (see Attachment B) present in diagrammatic form the process by which individuals in the NHIS sample would be screened for the Survey of Persons with Mental Retardation and Developmental Disabilities. The charts indicate the specific questions in each of the three categories (conditions, functional limitations, and service use) that would be used in screening. The charts also indicate our preliminary recommendations about criteria for screening decisions (who to include in the full survey and who to exclude).

All individuals in the NHIS sample would be asked the full set of screening items on the supplement; that is, even if an individual was deemed to be eligible for the full survey on the basis of responses to a particular item on the screening supplement, information on the other screening items would also be obtained. This would provide a complete set of screening and descriptive data on all individuals in the NHIS sample for preliminary analysis. In addition, the screening questions would be repeated in the full survey to verify and update the screening information and to set the context for other questions.

Please refer to the Summary of Recommended Questions for more details on the selection of items, question wording, and response categories. Also note that additional questions related to a screening item (such as the adequacy of the performance of a functional activity) are recommended for the full survey.

ATTACHMENT A. DEFINITION OF DEVELOPMENTAL DISABILITY IN DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT AMENDMENTS OF 1987

A severe, chronic condition which:

A. is attributable to a mental or physical impairment or a combination of mental or physical impairments;

B. is manifested before the person attains age twenty-two;

C. is likely to continue indefinitely;

D. results in substantial functional limitations in three or more of the following areas of major life activity:
   - self care
   - receptive and expressive language
   - learning
   - mobility
   - self-direction
   - capacity for independent living and
   - economic self-sufficiency; and

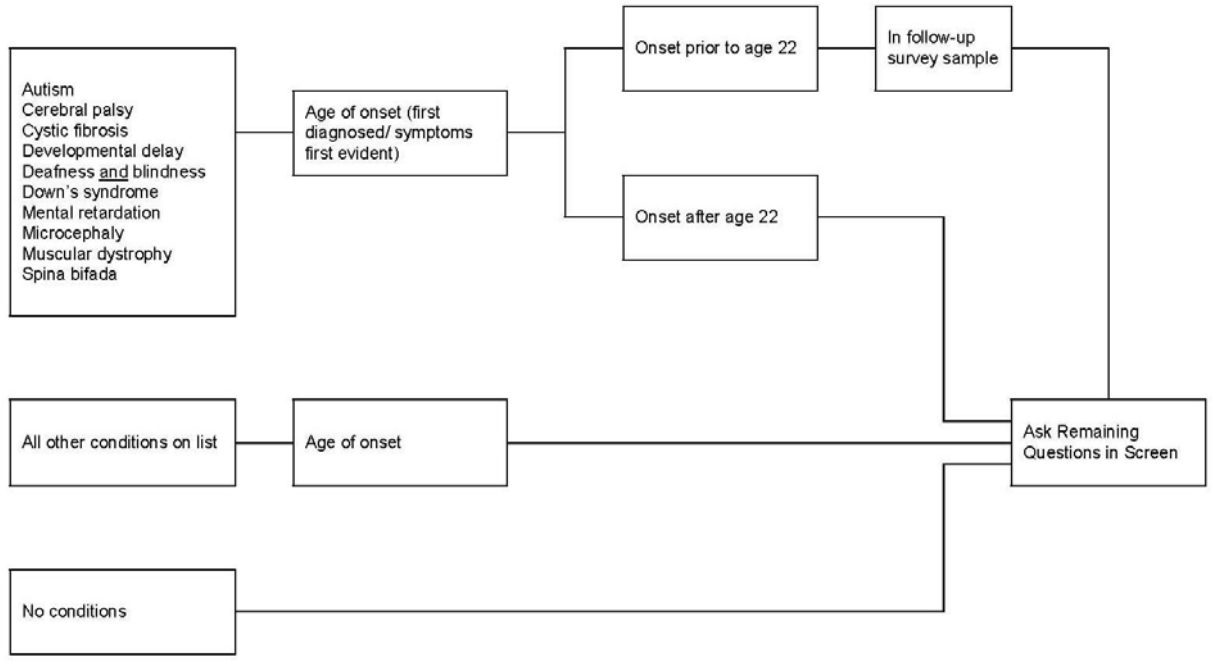
E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned or coordinated.

ATTACHMENT B. RECOMMENDED LIST OF CATEGORICAL CONDITIONS TO BE ASKED AS PART OF SCREENER

Autism
Blindness*
Cerebral Palsy
Childhood schizophrenia
Cystic Fibrosis
Deafness*
Deafness and blindness*
Development Delay
Down's Syndrome
Epilepsy
Genetic syndrome affecting development (other than Down's Syndrome)
Head injury or trauma*/Brain damage*
Hearing impairments*
Infantile Paralysis (Polio)
Mental retardation
Microcephaly
Missing or malformed limbs*
Multiple Sclerosis (M.S.)*
Muscular Dystrophy (M.D.)
Osteogenesis Imperfecta
Paralysis (other than those due to Cerebrel Palsy or Polio)*
Severe emotional disturbance or mental illness*
Sickle-Cell Anemia
Spina Bifida
Spinal Cord injury*
Tourette's disease
Visual impairment*
Any other serious condition beginning before age 22

* Conditions which require a follow-up question regarding when condition first occurred or was first diagnosed.

FIGURE B-1. Screening on Categorical Conditions List

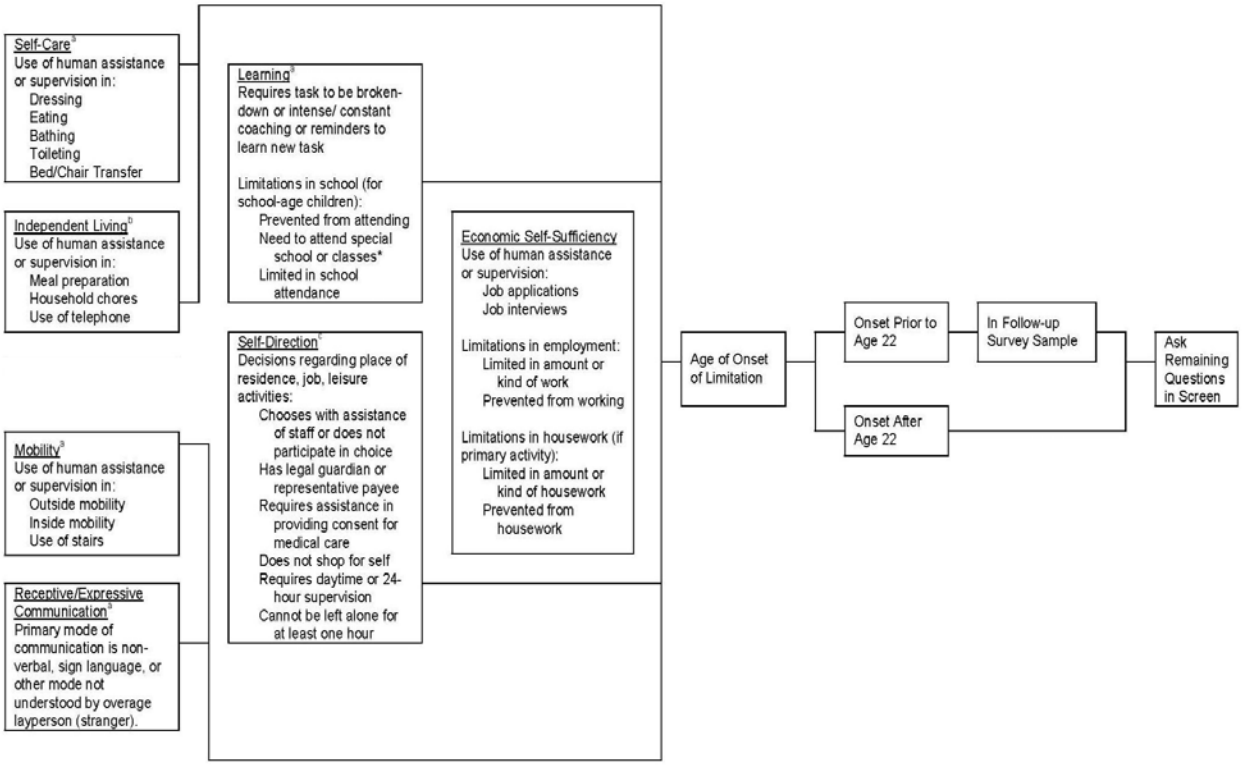


NOTE: Recommended Categorical Conditions List Appended.

Outstanding Issues:

Conditions included on list
Conditions used to identify follow-up sample
Age of onset cutoff to identify follow-up sample

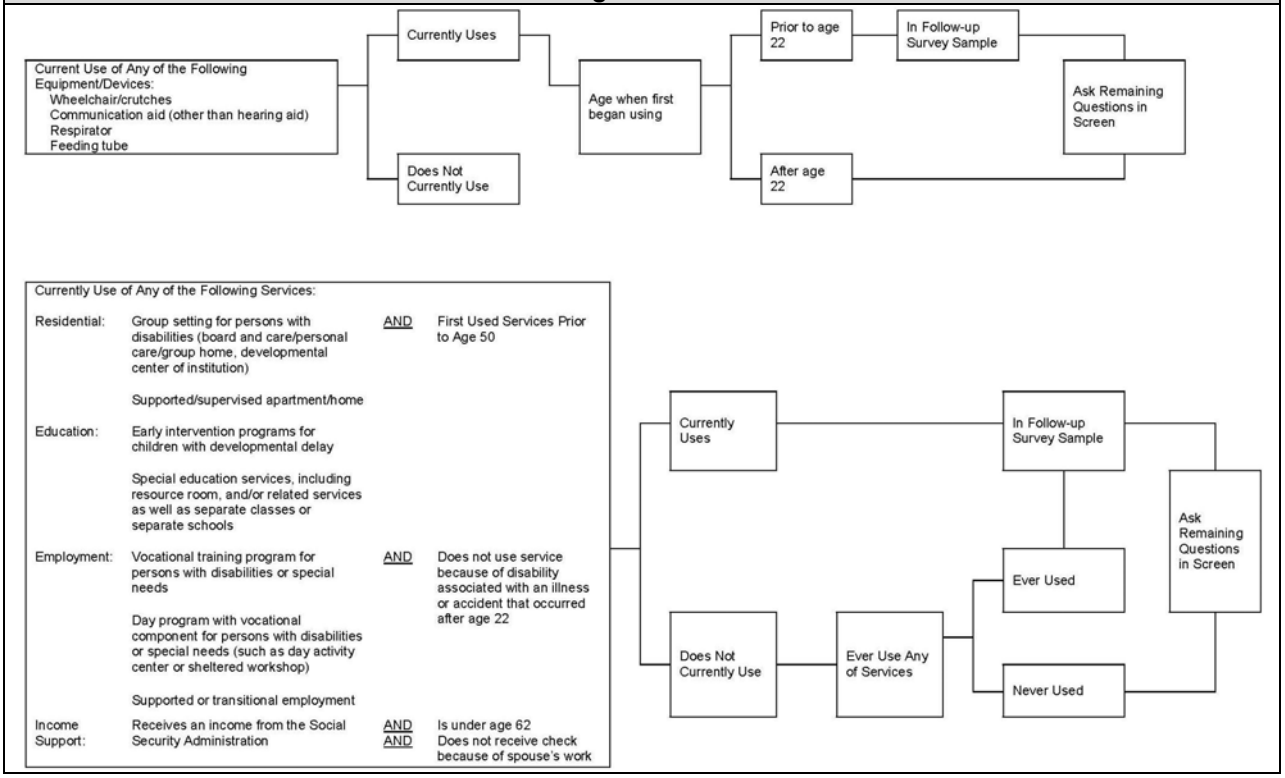
FIGURE B-2. Screening on Functional Limitations



a. Appropriate for all but very young children.
b. Appropriate for older children and adults.
c. Primarily appropriate for adults.

* Attending special school/classes is covered under services.

FIGURE B-3. Screening on Use of Selected Services



Categorical Conditions[1]

Defined

The underlying mental or physical health conditions) associated with the sample member's impairment(s)/functional limitations/disability.

Instrumentation

NHIS Core	• Asked with respect to limitations) of activities – condition which causes limitation – other condition which causes limitation – limitation caused by any (other) specific condition – Main cause of limitation (condition) Limitations from surgery and/or pregnancy are excluded
Conditions to Screen	• See "Screening Section"

Issues/Questions

- The value of the NHIS core information is limited by the condition coding procedures used by NCHS.
- Should rare conditions be added to the conditions list?

[1] Items recommended as screening criteria. See Overview of Screen, Figure 1.

Overriding Issues: Functional Status

- **Performance versus capacity**. In measuring functional limitations in the seven key life areas it is recommended that the study measure the individual's current performance as opposed to their assumed or judged capacity. Measuring capacity would result in severe reliability problems since respondents and proxies would be rating behavior based on standards that would doubtless vary from case to case, especially since proxies will include both relatives, informal care providers, and staff. While measuring performance also raises measurement issues--such as the person who can (capacity) do housework but doesn't (performance)--the performance measure is much more concrete and leaves less room for subjective interpretation.

- **Age**. Limitations in seven key life areas are highly variable upon age. An individual's "limitation" in a certain area may be a function of age and not a developmental disability. In the MR/DD survey, questions that are inappropriate to an individual because of age will not be asked (i.e. self-medicating for children, and economic self-sufficiency for non-working aged individuals). Other variables have recommended age limits (for example, self-direction questions are asked of age 12+, mobility questions of age 3+, self-care questions (except medicating) asked of age 5+).

- **Residence**. As with age, an individual's residential setting affects the opportunities that individual has to perform in key life areas. For example, in more "institutional" settings some self-care activities (such as administration of medications and independent living activities) may be routinely performed by staff and in fact not permitted for residents. However, we recommend that all age-appropriate questions in the key functioning areas be asked of institutionalized individuals and that the settings be taken into account during analysis.

Functional Status: Limitations in Self-Care[2]

Defined

Primarily the traditional activities of daily living:

dressing
continence
eating
bed/chair transfer
bathing
self-medicating
toileting

Instrumentation

Dressing	• Use of human assistance, supervision, special equipment[2] • Adequacy: pain/discomfort, mistakes, no problems
Eating	• How accomplished: standard utensils, special utensils, tube feeding • Use of human assistance, supervision, special equipment[2] • Adequacy: time-consuming, tiring, trouble chewing/swallowing, keeping food down
Bathing	• How accomplished: bed bath, sponge bath, shower, bath • Use of human assistance, supervision, special equipment[2] • Adequacy: pain/discomfort, forgetting to bathe, trouble bathing as often as would like, no problems
Toileting	• Method (urinary): catheter, bedpan, absorbent pads, standard/modified toilet Method (bowel): colostomy bag, bedpan, absorbent pads, standard/modified toilet • Use of human assistance, supervision, special equipment[2] • Adequacy: forgetting to go or attend to equipment, pain/discomfort/takes longer, emptying thoroughly/going as often as would like, no problems
Continence (urinary and bowel)	• Number of accidents: never, 1-2/week, 3+ a week

[2] Items recommended as screening criteria.

Bed/Chair Transfer	• Use of human assistance, supervision, special equipment[3] • Adequacy: pain/discomfort/takes longer, don't do as often as would like, no problems
Self-Medicating (first aid and prescription medication)	• Level of assistance: none, with supervision, family/staff completes task, medical staff completes task

Issues/Questions

- Is, for example, "getting dressed" too general? Should it be broken down into: puts on pants, ties shoes, can button/use zipper, etc.

- Should pain/discomfort be included in the response categories -- people with DD have generally grown up with pain and/or discomfort (comment is applicable to all functional variables).

- Are the response categories applicable to various types of living arrangements i.e., minimally supervised living arrangements. Or, are the response categories geared to extremes living independently and institutional life.

[3] Items recommended as screening criteria.

Functional Status: Limitations in Independent Living[4]

Defined

Primarily the traditional instrumental activities of daily living:

meal preparation
household chores
using the telephone
doing laundry
household repairs/yardwork
purchasing personal items

Instrumentation

Meal Preparation	• General method: prepared at home (with/without assistance), eat in dining hall, meals are delivered, someone else prepares meal, generally eat out • If prepared at home: use of human assistance, supervision, special equipment[4] • Adequacy: forgets to cook, pain/discomfort/time consuming, makes mistakes/trouble finishing, no problems
Household Chores	• General method: does it oneself (with/without assistance), a service of the residence, friend/family cleans, paid service • If does it oneself: use of human assistance, supervision, special equipment[4] • Adequacy: forgets a chore, pain/discomfort/time consuming, mistakes/trouble finishing, no problems
Using the Telephone	• Use of human assistance, supervision, special equipment[4] • Adequacy: forgets how to use, pain/discomfort/time consuming, makes mistakes/trouble completing call, no problems
Doing Laundry	• General method: does it oneself (with/without assistance), a service of the residence, friend/family launders, sends laundry out • If does it oneself: use of human assistance, supervision, special equipment[4] • Adequacy: forgets to launder, pain/discomfort/time consuming, makes mistakes/trouble finishing laundry, no problems

[4] Items recommended as screening criteria.

Household Repairs/Yardwork	• General method: does it oneself (with/without assistance), a service of the residence, family/friend does repairs/yardwork, pay for services • If does it oneself: use of human assistance, supervision, special equipment[5] • Adequacy: forgets a chore, pain/discomfort/time consuming, makes mistakes/trouble finishing, no problems
Securing/Purchasing Personal Items	• See Money Handling in Self-Direction Section

Issues/Questions

- Does the food preparation item preclude life in a group home where residents assist in food preparation and may or may not be served by staff?

- Should a different measure of assistance be used:

  human assistance

  - occasionally, 2-3 times/week
  - frequently, short time each day
  - continuously during waking hours/24 hrs.
    and/or need for special equipment
    and/or person can function only in barrier-free environment

[5] Items recommended as screening criteria.

Functional Status: Limitations in Self-Direction[6]

Defined

Independence in selecting/arranging services and activities
Ability to manage finances
Ability to defind and/or advocate for oneself
Need for supervision

Instrumentation

Independence in Selecting/Arranging Services and Activities:	
personal care attendant	• Chooses unassisted, chooses with assistance from personal unpaid friend, chooses with assistance of family member, chooses with assistance of legal guardian, chooses with assistance of agency/school staff, does not choose/choice made by unpaid friend/family member/legal guardian/agency or school staff
residence	• Chooses unassisted, chooses with assistance from personal unpaid friend, chooses with assistance of family member, chooses with assistance of legal guardian, chooses with assistance of agency/school staff, does not choose/choice made by unpaid friend/family member/legal guardian/agency or school staff[4]
current job	• Chooses unassisted, chooses with assistance from personal unpaid friend, chooses with assistance of family member, chooses with assistance of legal guardian, chooses with assistance of agency/school staff, does not choose/choice made by unpaid friend/family member/legal guardian/agency or school staff[4]
leisure activities	• Chooses unassisted, chooses with assistance from personal unpaid friend, chooses with assistance of family member, chooses with assistance of legal guardian, chooses with assistance of agency/school staff, does not choose/choice made by unpaid friend/family member/legal guardian/agency or school staff[4]

[6] Items recommended as screening criteria.

Defend/Advocate for Oneself	• Have legal guardian: yes/no[7] • Have representative payee: yes/no[7] • Give consent for medical care: unassisted, with assistance from personal unpaid friend, with assistance of family member, with assistance of legal guardian, with assistance of agency/school staff, does not give consent/consent given by unpaid friend/family member/legal guardian/agency or school staff[7]
Financial Management	• Shop for yourself: yes/no[7] • Pay money to clerk: by self, someone helps • Who helps: _____ • Person receives bills (i.e. telephone bill: yes/no • Take care of bills: by self, someone helps • Who helps: _____ • Have bank account: yes/no • Make deposits/withdrawals: by self, someone helps • Who helps: _____
Need for Supervision	• Feel comfortable being alone for 1+ hours at a time: yes/no[7] • Level of supervision in past week: minimal (every now and then), during daytime hours only, constant/round-the-clock[7] • Length of time (months/years) this level has been required

Issues/Questions

- Should response categories for "choice" be revised as follows:

  Choices are made . . .:

  - unassisted (by self)
  - primarily by self with help or advice from _____
  - by concensus between self and _____
  - by _____ with input from individual

[7] Items recommended as screening criteria.

Functional Status: Limitations in Receptive/Expressive Communication[8]

Defined

Ability to engage in the communication of needs, attitudes, and ideas with others and to receive and provide imput in social interchange:

mode
adequacy

Instrumentation

Mode	• Expressive (primary mode): speaks, non-verbal gestures/grunts, sign language, communication board/other device, does not communicate[8] Expressive (secondary mode): non-verbal gestures/grunts, speaks, sign language, communication/board/other device • Receptive (primary mode): speech, non-verbal gestures, sign language, communication board/other device, does not understand any communication[8] Receptive (secondary mode): non-verbal gestures, speech, sign language, communication board/other device
Adequacy	• Expressive: understood easily by strangers and intimates, understood partially/with difficulty by strangers, understood only by intimates, little can be understood by strangers or intimates, does not attempt communication[8] Receptive: understands strangers and intimates easily, understands strangers partially/with difficulty, understands only intimates, understands little by strangers or intimates, does not attempt to communicate

Issues/Questions

- Two main types of impairments in receptive/expressive communication--physical (sensory, mechanical) and cognitive. Should this be more fully addressed?

[8] Items recommended as screening criteria.

Functional Status: Limitations in Mobility[9]

Defined

Primarily the traditional activities of daily living:

walking/wheelchair use
use of stairs
ability to lift/carry
use of automobile
outside mobility
use of public
inside/in-home mobility
transportation

Instrumentation

Walking/Wheelchair Use (ambulation)	• Determined through use of assistive devices and other mobility variables
Lifting and Carrying	• Ability to lift and carry 10 lbs. (bag of groceries): use of human assistance, supervision, special equipment
	• Adequacy: pain/discomfort/time consuming, cannot do as often as would like, no problems
Outside Mobility	• Use of human assistance, supervision, or special equipment[9]
	• Adequacy: pain/uneasiness/time consuming, can't go out as often or as many places as would like, no problems
Inside Mobility	• Use of human assistance, supervision, or special equipment[9]
	• Adequacy: pain/discomfort/time consuming, can't go as far or as often as would like, no problems
Use of Stairs	• Use of human assistance, supervision, or special equipment[9]
	• Adequacy: pain/discomfort/time consuming, can't climb as many as would like or stairs prevent person from going places, no problems
Use of Automobile	• With vehicular modifications, without modifications, unable to drive
	• Adequacy: pain/discomfort, can't drive as far or as often as would like, no problems

[9] Items recommended as screening criteria.

Use of Public Transportation	• Types used in past 4 weeks: bus (specially equipped or not), train, subways taxicab, van • Use of human assistance, supervision, or special equipment • Adequacy: pain/discomfort, can't travel as often or as far as would like, no problems

Issues/Questions

- Should mobility for people who are blind be explicitly addressed?

Functional Status: Limitations in Economic Self-Sufficiency[10]

Defined

The ability to work and maintain employment:

vocational skills
work habits
job finding
earning capacity/income adequacy

Instrumentation

NHIS Core	• Is person limited in kind/amount of work he/she can do -- based upon major life activity: – work – housework – school – play
Vocational Skills	• Covered under cognition/retention/reasoning in learning section (i.e. the ability to learn and apply job skills)
Job Finding	• Completes job applications: use of human assistance or supervision[10] • Job interviews: with human assistance or support/supervision[10]
Earning Capacity/Income Adequacy	• Steady source of income for basic needs: yes/no • Enough money for "extras" or special items: yes/no (See also Demographics and Employment Services Sections)

Issues/Questions

- How do we want to differentiate or classify productivity (i.e. volunteer work) from economic self-sufficiency. We should also consider the gender bias of economic self-sufficiency and determine how to measure the value of contributing to an economic unit (i.e. homemaker).

[10] Items recommended as screening criteria.

Functional Status: Limitations in Learning[11]

Defined

The ability to acquire new knowledge and skills and to apply one's experiences in new situations:

cognition
retention
reasoning
academic skills

Instrumentation

Cognition/Retention/ Reasoning	• For learning (cognition) a series of tasks, each task more complex (reasoning) and requiring greater cognitive skills than the former, the individual will be asked:[11] – Level of assistance needed to learn (the task): written instructions only, 1-2 demonstrations, tasks broken into smaller segments, intense/constant coaching – Ability to remember how to accomplish (task): cannot remember/must be continuously reminded, can remember after several repetitions, can remember most without reminding
Retention	• Basic facts (Mental Status Questionnaire): – date – year – day of week – age – name of president, etc.
Reasoning	• Application of previously learned knowledge/skills in new situation: can do without new instruction/help, need written instruction only, 1-2 demonstrations, task broken into smaller segments, intense/constant coaching or prompting

[11] Items recommended as screening criteria.

Limitations in School

NHIS Core Items (school-aged children)

- impairment keeps child from attending school: yes/no[12]
- Because of impairment, child attends special school or classes: yes/no[12]
- Because of impairment, child needs to attend special school or classes: yes/no[12]
- Because of health child is limited in school attendance: yes/no[12]

Additional Items (school-aged children and adults)

- Writing ability:
  - Writes
  - Letters/lists
  - Short sentences
  - Prints words
  - Traces or copies name/words
  - Cannot write/print/trace/copy
- Reading ability:
  - Reads newspapers/magazines/most books
  - Reads books for children/adolescents
  - Reads simple stories/comics
  - Reads street signs etc.
  - Recognizes no words/signs
- Mathematical ability:
  - Does addition/subtraction
  - Can count items (up to 10)
  - Counts aloud from 1 to 10
  - Counts up to 2 items
  - Understands one versus many
  - No understanding of numbers

Issues/Questions

- Is the Mental Status Questionnaire, usually asked of the elderly, appropriate for the MR/DD population?
- Is the recommended measure of reasoning too complex to measure? Is there a better way to operationalize this variable?
- Since most DD children are in regular classes, are the items on reading/writing/mathematical ability sufficient to measure limitations in academic skills or should an item be added on the need for "special help or assistance" in school?

[12] Items recommended as screening criteria.

- Distinguish primary and secondary obstacles to learning. For example, sensory or physical disabilities may interfere with accessing what is to be learned. While this is a limitation, it is secondary in nature to cognitive disabilities.

Employment and Educational Services[13]

Defined

Jobs and job-support services as well as education and training:

Employment	Education
Employment/labor force status	Service use
Type of work/integration	Satisfaction with services
Use/satisfaction with services	Connection with employment status
Support network	
Wages	
Hours	
Earnings	
Access/Transportation	

Instrumentation

Labor Force Status

- Currently have job: yes/no
  - If no, currently looking: yes/no
- Occupation (covered in NHIS core)

Integration

- Setting: regular job, sheltered workshop, work/day activities center, volunteer, work/study[13]

Training Program

- Is job part of training program: yes/no[13]

Supported Employment

- Presence of someone at work who helps person learn the job: yes/no[13]
- Presence of someone at work who person can ask questions: yes/no
- Who is person: _____ (write-in)
  - parent
  - friend/co-worker (also, is it person's ob to train?)
  - job coach (training program) -- (name of program
  - supervisor (also, does supervisor work for employer versus training program?)
- Do you pay the person who is helping you?

[13] Items recommended as screening criteria.

Hours/Wages

- Days of week usually at work: Monday-Friday
- Hours worked most days: ___ ___ . ___ hours
  - per day
  - per week
  - variable
- Is person paid: yes/no
- Amount of pay: $___, ___ ___ ___ . ___ ___
  - per piece
  - per hour
  - per day
  - per week
  - per two weeks/semi-monthly
  - per month
  - combination of rates
- Frequency of pay: everyday, every week, every two weeks/semi-monthly, every month

Transportation to Work

- How person usually gets to work and back:
  - driven by parents/friends/houseparents
  - picked up in van/car/schoolbus/special bus
  - taxi
  - public bus/other public transportation
  - walk/bicyle
  - drive oneself
  - works at residence no transportation needed
  - other _____ (specify)

If driven:

- Who drives person to work: _____ (write-in)
  - relative
  - friend
  - staff member

If picked up by van/bus/car, etc.:

- Whose vehicle picks person up: _____ (write-in)
  - friend/relative
  - staff member
  - employer

- Is it friend's job to pick person up: yes/no

- Where is staff member from: _____ (write-in)

If person takes taxi:

- Who calls taxi: person does by self, someone else does at least sometimes/it is prearranged

- Who is the person who calls taxi: _____ (write-in)
  - relative
  - friend
  - staff member
  - employer

- Is it friend's job to call taxi: yes/no

- Where is staff member from: _____ (write-in)

Satisfaction with Services	• For each service: very satisfied, satisfied, Services neither satisfied/dissastisfied, dissatisfied, very dissatisfied • Why dissatisfied: – Receives too little/too much of service – Service is not appropriate to needs – Not reliable – Not timely, too expensive – Problem with provider's attitude – Problem with transportation – Other _____ (specify)
Educational Services Ever Received	• Special school (residential - during academic year only), special school (day), special class in regular school, resource room in regular school, regular class in regular school, regular class in regular school, homebound education, special residential school (out of state), residential facility for persons with disabilities, residential facility for persons with mental illness, challenging behavior, not applicable (no formal education)[14]
Early Intervention (Service is Defined in Memo)	• Received services: yes/no (also covered in the In-Home Services Section)[14]
Current Educational Status	• Now in school: yes/no – Name of school: _____ (write-in) • Is person learning about job and work in school: yes/no – How is person learning about work/jobs: classes only, job only, both classes and job – Is this same job as previously mentioned: yes/no (if no, ask job questions)
Other Vocational Programs	• Aside from previously mentioned job/school programs are there any others which teaches person about jobs/work: yes/no – Name of program: _____ (write-in)
Satisfaction With Services	• For each service: very satisfied, satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied • Why dissatisfied: – Receives too little/too much of service – Service is not appropriate to needs – Not reliable – Not timely – Too expensive – Problem with provider's attitude – Problem with transportation – Other _____ (specify)

[14] Items recommended as screening criteria.

Reasons for Not Working	• If determined person is not working (or looking for work) through job, school, or training program: – Health reasons – Attending school – Retired, homemaker – Caring for children – Caring for adults – Lack of transportation – Lack of job skills – Discrimination – Fear of losing SSI or other benefits – Other _____ (specify)

Issues/Questions

- Enclaves may not be distinguished from supported employment or regular employment.

- Job tenure is not measured.

Adaptive Equipment/Assistive Devices[15]

Defined

The medical equipment/special aids used or the physical/structural modifications made to one's residence as a result of his/her impairment:

Types of equipment/aids
Types of modifications
Payment mode
Satisfaction

Instrumentation

Types of Equipment/Aids

- Current use:
  - Manual wheelchair[15]
  - Motorized wheelchair[15]
  - Crutches[15]
  - Cane
  - Walker
  - Leg, back, or other type of brace
  - Special shoes
  - Artificial arm or leg
  - Hearing aid
  - Communication board[15]
  - Glasses or contact lenses
  - Guide dog
  - Respirator[15]
  - Kidney dialysis machine
  - Feeding tube/machine[15]
  - Colostomy bag
  - Urinary catheter
  - Velcro fasteners or snaps
  - Special dishes, cups, or utensils
  - Other _____ (specify)
  - None

[15] Items recommended as screening criteria.

Types of Residential Modifications	• Currently have in residence: – Grab bars, and/or railings – Shower seat or tub stool – Hand held shower – Raised toilet – Portable toilet – Specially equipped telephone (TTY, TTD, or amplified) – Widened doorway – Ramp – Removed door sills/raised threshold – Repositioned light switches, electrical outlets, and/or heating and cooling controls – Adjusted height of cabinets/storage areas, counter tops, sinks – Changed or repositioned sink or shower controls – Faucets on side or front of sinks – Lever-style door handles – Emergency alarm – Visual signals for telephone or door – Braille or raised markings – Accessible parking space or garage – Sidewalks with curb cuts – Other _____ (specify)
Payment Mode	• Who paid/is expected to pay for costs of services: sample member/family, Medicare/medicare HMO, Medicaid, Veteran's benefits, CHAMPUS/CHAMPVA, private insurance/non-Medicare HMO, other, no cost of sample member/family/third party • Any costs incurred by sample member/family: yes/no • Total paid by sample member/family excluding insurance paybacks
Satisfaction With Equipment/ Modifications	• For each service: satisfaction with availability of equipment, cost, way equipment works, adequacy of home modifications: – Very satisfied – Satisfied – Neither satisfied or dissatisfied – Dissatisfied – Very dissatisfied

Issues/Questions

- Is "communication board" too specific? Should a more general term be used such as "assistive communication device"?
- Addition of fire safety residence modifications: fire doors, wall to roof compartmentalization, alarm systems, etc.

Medical and Health Services

Defined

Services received which are related to one's physical health -- either direct results of one's impairment or of other current or chronic condition:

Types of services (doctor visits, hospital stays, nursing home stays, dental visits, emergency health, medication/supplies, physical/occupational/speech/hearing therapy)

Frequency of use
Payment mode
Satisfaction

Instrumentation

NHIS Core

- Overnight hospital stays (13-month period)
  - Date of admission
  - Number of nights spent
  - Reason for hospitalization
  - Whether surgery was performed
  - Name/address of hospital
- Doctor visits (2-week period)
  - Date of visit
  - Setting
  - Physician specialty
  - Whether surgery was performed
  - Location (city, county, state)

  Also collected: number of times family member received health care/medical advice/prescription/test results over telephone
- Number of medical doctor/assistant visits in past 12 months

Additional Questions on Frequency	• Number of times in nursing home/convalescent home/similar place • Total number of nights in nursing home/convalescent home/similar place • Number of dental visits • Number of emergency room/emergency treatment center visits • Frequency of purchases: – Prescription drugs – OTC medications – Incontinence supplies – Other • Frequency of therapy: – Physical – Occupational – Speech/hearing
Payment Mode	• Who paid/is expected to pay for costs of services: – Sample member/family – Medicare/medicare HMO – Medicaid – Veteran's benefits – CHAMPUS/CHAMPVA – Private insurance/non-Medicare HM – Other – No cost to sample member/family/third party • Any costs incurred by sample member/family: yes/no • Total paid by sample member/family excluding insurance paybacks

Satisfaction with Services	• For each service: very satisfied, satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied Reason for dissatisfaction: • For each service: very satisfied, satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied • Why dissatisfied: – Receives too little/too much of service – Service is not appropriate to needs – Not reliable – Not timely – Too expensive – Problem with provider's attitude – Problem with transportation – Other _____ (specify)

Issues/Questions

- Reference period for receipt of each service must be determined
- Is satisfaction with services a relevant and/or useful question for this survey effort, especially since most respondents are expected to be proxies.

Social and Psychological Services

Defined

Services received which are related to one's social needs and mental health needs -- either direct results of one's impairment or of other life circumstances

Types of services
Frequency of use
Payment mode
Satisfaction
Provider (residential setting, other agency)

Instrumentation

Case Management

- Ever received (several examples of case management are given in the instrument): yes/no[16]
- Provided as part of residential environment: yes/no
- Provided by one agency or more than one
- Does agency mostly serve MR/DD/mental health
- Name of agency: _____ (write-in)
- Number of visits from agency in past 12 months

[16] Items recommended as screening criteria.

Mental Health Services

- Received in past month any mental health program/day treatment program, or partial hospitalization for all/part of the day
  - Number of days received
  - Were services part of residential arrangement
- Visits in past month with mental health professional (i.e. psychologist, social worker, psychiatric nurse) or attended group sessions
  - Number of visits/sessions
  - Were services part of residential arrangement
- Hospitalized overnight in past year for mental health reasons: yes/no
  - Number of times hospitalized

  (This information can be obtained in the NHIS core under "reasons for hospitalization" but may be added in this more specific format)
- Attend in past month adult day care program
  - Number of days attended
  - Were services part of residential arrangement

Payment Mode

- Who paid/is expected to pay for costs of services:
  - Sample member/family
  - Medicare/medicare HMO
  - Medicaid
  - Veteran's benefits
  - CHAMPUS/CHAMPVA
  - Private insurance/non-Medicare HMO
  - Other
  - No cost of sample member/family/third party
- Any costs incurred by sample member/family: yes/no
- Total paid by sample member/family excluding insurance paybacks

Satisfaction with Services	• For each service: very satisfied. satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied Reason of dissatisfaction: • For each service: very satisfied, satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied • Why dissatisfied: – Receives too little/too much of service – Service is not appropriate to needs – Not reliable – Not timely – Too expensive – Problem with provider's attitude – Problem with transportation – Other _____ (specify)

Issues/Questions

- Since most of the MR/DD population receives assistance for "maladaptive behavior" through behavioral intervention serivces provided by specialized MR/DD agencies, the distinction should be made between these specialized services and the generic mental health services

- Terminology: use adult development services or adult habilitation services in place of adult day care -- should avoid confusion with day programs for frail elderly. Furthermore, are these programs purely for adults?

- In the "Adult Day Care" section, should information be collected on the reasons for enrollment -- acquire job skills, learn activities of daily living.

In-Home Services

Defined

Services provided by formal caregivers in the residential setting that are not part of the residential arrangement:

Types of services

Personal attendants (self-care/personal needs)
Household chores/home-delivered meals
Home health aide and visiting nurse/occupation and physical therapy
Respite care
Early intervention

Instrumentation

Personal Attendants	If one or more of the self-care, mobility, communication, use of assistive devices activities require help/supervision: • Who is person that helps: _____ (write-in) • Is person paid to help with these things is it part of their job: yes/no • Frequency of services in past month
Household Chores/ Home-Delivered Meals	If these activities are required (limitations in independent living): • Who is the person who (helps with cleaning/brings in your meals)? _____ (write-in) • Is person paid to help with these things is it part of their job: yes/no • Frequency of services in past month
Home Health Aide/ Visiting Nurse/ Occupation and Physical Therapy	• Has home health aide/visiting nurse come to person's residence in past month to change dressing, take blood pressure, etc.? yes/no • Frequency in past month • Has physical/occupational therapist come to person's residence to provide therapy in past month? yes/no • Frequency in past month

Respite Care	• Has someone other than friends/family members cared for person in past 6 months in order to provide primary informal caregiver a break: yes/no • Frequency in past 6 months • Usual length of breaks • Location: sample member's residence, day care facility, other facility, other _____ (specify)
Early Intervention (For Children 0-3 Years)	• Received service: yes/no • Frequency
Payment Mode	• Who paid/is expected to pay for costs of services: – Sample member/family – Medicare/medicare HMO – Medicaid – Veteran's benefits – CHAMPUS/CHAMPVA – Private insurance/non-Medicare HMO – Other – No cost of sample member/family/third party • Any costs incurred by sample member/family: yes/no • Total paid by sample member/family excluding insurance paybacks
Satisfaction with Services	• For each service: very satisfied, satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied • Reasons for dissatisfaction: – Receives too little/too much – Not appropriate to needs – Not reliable – Not timely – Too expensive – Problem with provider's attitude – Other _____ (specify)

Issues/Questions

- The same information should be collected even if the services are part of the residential arrangement.

Transportation Services

Defined

Types of services used to go to:

Employment/day activity
Leisure/social events
Shopping/chores/errands
Health care/doctor visits
Frequency of use
Payment mode

Instrumentation

Transportation to Work	• Covered under Employment Services
Transportation to: – leisure/social – shopping/chores/ errands – health care/ doctor visits – other day activity	• How person usually gets to activity: – Driven by parents/friends/houseparents – Picked up in van/car/special bus – Taxi – Public bus/other public transportation – Walk/bicycle – Drive oneself – All activities are at residence or Transportation is part of residence program – Other _____ (specify)
	• Most frequent mode of transportation
	• If person is driven or picked up, a series of questions determine who (formal informal) provides transportation. If person takes a taxi, it is determined who calls.
Payment Mode	• Who paid/is expected to pay for costs of services: sample member/family, no cost
	• Any costs incurred by sample member/family: yes/no
	• Total paid by sample member/family excluding insurance paybacks

Residential Environment[17]

Defined

Residential environment in the Survey of Persons with Mental Retardation and Developmental Disabilities will be defined as follows:

Dimensions:

Size
Relationship to others in H.H.
Services provided
- Type
- Level of supervision (constant vs. protective oversight)

Instrumentation

NHIS Core	• Number of persons in household (H.H.) • Relationship of people to each other
Added Questions for NHIS "Special Places"[17]	• Any persons paid to live in H.H. as staff: yes/no • Any persons who live in H.H. and rent rooms to others (roomers/boarders): yes/no • For facilities with ≤15 people, characteristics of residents: – Gender – Age – Disability status • Facilities with >15 people: – Demographic averages
Services Provided in Residence	• Services: – Counseling/supervision (round-the-clock part-time) – Meals – Laundry/housecleaning – Personal care assistance – Medical/nursing assistance – Day activity (See Social/Psychological Services Section)

[17] Items recommended as screening criteria.

Public/Private Operation

- Individual/family/partnership, public agency, private agency
- If public: state, local, county

  Name of agency _____
- If private: religious, not-for-profit, for-profit
- Licensed/certified by state, county, local agency

  Name of agency _____

Group Home Staff--Asked of Staff (Questions for Large Institutions May Be Based On NMES)

- Number of staff living here during the week
- Number living here on any given day
- Number working here during the week
  - Number involved with supervision of residents
  - Specific duties
  - Average hours worked per week
  - Average hours worked per week in each of the following:
    Administration
    Maintenance/housekeeping
    Education/day programming
    Medical/nursing services
    Other therapeutic services

Payment for Services

- Who is expected to pay:
  - Sample member/family
  - Medicare
  - Medicaid
  - Veteran's benefits
  - Private insurance
  - State/local agency
  - Other
  - No cost to sample member/family/third party payor
- Any costs paid by sample member/family
- Amount paid last month (nonreimbursable) by sample member/family

Satisfaction with Services	• Very satisfied, satisfied, neither satisfied or dissatisfied, dissatisfied, very dissatisfied • Reasons for dissatisfaction: – Not appropriate to needs – Cost – Roommate conflicts – Staff conflicts – Not convenient (transportation/other places) – Not attractive/sanitary/safe – Neighborhood not safe
Interviewer Observation of Environment	• Number of bedrooms (separate or not), number of public rooms, nature of neighborhood, external signs of "group home", evidence of health/safety problems
Choices in Residential Services	• Covered in Self-Direction

Issues/Questions

- Are the recommended questions sensitive enough to identify individuals living with people who are not disabled in a "homelike" way -- not a mini-facility/institution/group home?

- Will service questions measure help/caregiving which is provided but not paid for such as people who live together and help each other in various ways but not paid for it? Also, roommate could be added to the list of payors for services.

- The NHIS definition of a household may cause problems for this survey if a group home is categorized as "separate households" since we will need to know the overall composition and organization of the group home.

- Validity issues surrounding questions about characteristics of other non-family residents. Can people report this and will people report this?

Social Interaction and Behavior

Defined

Frequency of social interaction
Extent of interaction with nonhandicapped persons
Use of community facilities
Maladaptive/problem behaviors

Instrumentation

Frequency of Interaction/Past Week (Telephone or In-Person 5+ Minutes)	• With family members not living with sample member, friends not living with sample member (excluding staff/counselors) – More than twice a week – Twice a week – Once a week
Location of Interaction	• Location: – Sample member's residence – Other person's residence – public place
Interaction With Nondisabled People	• Number of different friends sample member interacted with in past week (excluding family and paid staff) who were not disabled
Community Activities/ Past Month	• Store/mall, restaurant, movies/play/concert, church/synagogue, participated in sporting event, attended sporting event, party/dance/social, museum/library • Was activity group event: yes/no • Was activity only/primarily people with handicaps: yes/no
In Mainstream School	• See Employment/Educational Services Section
In Regular Job	• See Employment/Educational Services Section
Problem Behaviors/ Past Month (Age 6+)	• Self injury, violence, threats, property damage, disruptive, screams/yells/cries, temper trantrum, undressing, unacceptable sexual behavior, lying/stealing, repetitive movements, repetitive speech, withdrawn, uncooperative, restless, runs away – never – not past month – 1-3 times/month – 1-2 times/week – 3-6 times/week – 1-2 times/day – 3-10 times/day – 1+ times/hour

Problem Behavior (Prior to 6 Years)	• National Maternal and Infant Health Survey questions: – Independent to clinging – Not demanding to demanding of attention – Easy to difficult to manage – Easy to difficult to discipline – Not too frequent/long temper tantrums – Usually happy to frequently miserable or irritable – Not a worrier to very anxious about things – Rarely to very fearful – Few problems with siblings to serious difficulties with siblings – Gets along well with other children to very difficult jto play with other children

Issues/Questions

- Avoid use of the term "disturbance of mood"
- Should the quality of the interaction be measured as well as the quantity of interactions? If so, how?
- There may be multiple causes or reasons why an individual displays behaviors which are socially defined as problem behaviors, i.e. do others cause the behavior?
- Should activities/interactions at work or school be included in the list of "Community Activities/Use of Community Facilities"?

Informal Support

Defined

Emotional, financial, self-care, or general assistance provided by family or friends:

number of informal providers
primary informal provider
relationship of provider to individual
types of services/assistance provided
amount of assistance provided

Instrumentation

Number of Informal Providers	• List all names (specify primary provider)
Relationship/ Description of Provider to Individual	• Relationship to individual: parent, brother/sister (in-laws), spouse, child, other relative, non-relative • Gender: male/female • Lives with sample member: yes/no
Non-Monetary Types of Service/Assistance	• Personal care, housekeeping/house maintenance, meals, medication/medical treatment, managing finances or legal matters, grocery/other shopping, transportation, supervision
Amount of Assistance Provided	• When: weekday days, evenings, during the nights, weekend days • Hours per week (Monday-Friday), _____ (write-in) • Hours per weekend, _____ (write-in)
Monetary Types of Services/Assistance Including Purchasing Clothes/Groceries, etc.	• Groceries, clothing, housing (rent, mortgage, utilities, payments for personal care/housekeeping/other assistance, medicine/supplies, treatment, cash, other
Amount of Expenses	• Average for week or month $_____ (write-in)

Issues/Questions

- Instead of just questioning "tasks" which must be "accomplished" should we also look at "activities" which one "does" such as recreation, leisure, or hobbies?

- Is it better to measure the "pay" questions by asking about "shared expenses" or "reimbursement for expenses"?

- Questions on informal support will be integrated into general functioning/activity questions.

Demographic Characteristics

Defined

Age
Gender
Race/ethnicity
Marital status
Family income
Participation in public income/insurance programs

Instrumentation

NHIS Core

- Age: date of birth
- Gender: interviewer observation
- Race/ethnicity

  Race: Aleut/Eskimo/American Indian, Asian/Pacific Islander, Black, White, Other _____ (specify)

  National origin/ancestry: Puerto Rican, Cuban, Mexican/Mecicano, Mexican American, Chicano, Other Latin American, Other Spanish
- Marital status: now married, widowed, divorced, separated, never married
- Family income:
  - More/less than $20,000
  - More specific categories are determined through an exhibit card
- Educational attainment: highest year completed
  - Elementary (1-8)
  - High School (9-12)
  - College (1-6+)

Additional Questions on Program Participation (Based Upon SIPP)

Social Security

- Currently receiving[18]
- Reason for receiving: retired, disabled, widowed/surviving child, spouse/dependent child, other, don't know
- Other reason
- If disabled: age began receiving benefit

[18] Items recommended as screening criteria.

Supplemental Security Income	• Currently receiving[19]
	• Received SEPARATE SSI payment from state/local welfare office as well
Medicare	• Covered by Medicare (shown sample card)
	• Claim number and coverage recorded from card
	• Covered by optional feature for doctor bills
Medicaid	• Currently receiving
	• Record claim number
Food Stamps	• Person or spouse in H.H. authorized to receive
	• Covered under other person's allotment
Other Public Assistance	• Received welfare such as AFDC, WIC, foster child care, or general assistance
	• Covered under other person's payment
	• _____ (specify type of welfare)

Issues/Questions

- Poverty status will be determined from family composition and income information.

[19] Items recommended as screening criteria.

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Office of Disability, Aging and Long-Term Care Policy
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200 Independence Avenue, S.W.
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FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

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