

# Technical Report – Data Base Analysis: 1994 and 1995 NHIS Phase II Disability Followback Survey, Child Questionnaire (Version 1.0)

Christine S. Moser PhD, OTR

## *Introduction*

The purpose of this technical report is to present preliminary findings regarding the usefulness of the data reported by the National Center for Health Statistics (NCHS) in their 1994 and 1995 Phase II Disability Followback Survey-Child Questionnaire pertaining to the acquisition and use of assistive technology (AT) by children with identified disabilities. This activity fits into the ATOMS Project needs assessment where it examines existing data sets for potential use in assessing AT outcomes.

**Background information about the Disability Followback Survey.** While the passage of The Americans with Disabilities Act (ADA) in July, 1990 prompted reforms in the area of disability, it also helped highlight the very limited existence of any national data on disability-related needs. Subsequently, four Federal offices (Office of the Assistant Secretary for Planning and Evaluation, Health and Human Services; Office of Supplemental Security Income, Social Security Administration (SSA); Office of Disability, SSA; Bureau of Maternal and Child Health, Human Resources Administration) began individual plans for national surveys on various aspects of disability. Acknowledging overlapping interests, efforts were merged into the development of one Disability Survey for inclusion with the annual National Health Interview Survey (NHIS) in two consecutive years (1994, 1995). Twelve additional organizations with interests in disability (i.e. Disability Prevention Program, CDC; Bureau of Transportation Statistics, DOT) joined with the Federal offices as survey plans evolved (National Center for Health Statistics, 1994).

An important goal of this survey (NHIS-D) was to ultimately provide a set of useful measures maintaining a balance between the different considerations in disability management (social, administrative, medical). Not limited to one definition of disability, the NHIS-D allows agency or program analysts to combine data items in ways which meet their specific needs. Establishing such a broad objective when collecting data (for use in understanding disability, developing public health policy, producing simple prevalence estimates of selected health conditions, providing baseline statistics on the effects of disabilities) made it realistically impossible to collect all desired disability data in one interview. A two-phase data collection plan resulted with a series of disability questionnaires. Phase I was administered with the NHIS Core and used as a screen for Phase II eligibility along with responses to other NHIS sections on activity limitation and receipt of disability benefits.

Phase II data of the NHIS-D survey entitled “Disability Followback Survey or DFS” was collected using four targeted questionnaires: one for children, one for adults, one for elderly persons (age 69 and over) without indication of disability, and one for persons with a past history of polio. This technical report highlights data from the DFS Child Questionnaire. The questionnaire respondent was the parent or adult in the household knowing most about the selected child’s health. Information collected included

child's need for and utilization of services, functional assessment of child's emotional and behavioral development, and impact of child's disability on the family (National Center for Health Statistics, 1994).

### *Data collection procedures*

**Sample selection.** The intended interviewees for the NHIS Phase II Disability Followback Survey were the civilian non-institutionalized population living in the United States who had identified at least one household member under the age of 18 with a disability. The technique of over sampling Blacks and Hispanics was utilized to insure more reliable data on these two racial groups. The NCHS survey is a representative sampling of households (U. S. Department of Commerce, 1994).

*Sample set (subjects).* The 1994 and 1995 NHIS Phase II Disability Followback Survey-Child Questionnaire contains records of 6,983 cases (4,296 children from the 1994 cohort, and 2,687 from the 1995 cohort) of children ages birth through 17 years of age. All child participants had reported some type of disability in a previous NCHS survey. Table 1 delineates the similarities in consistency of categorical breakdowns between 1994 and 1995. As a result of the lack of significant differences in the demographic variables between data collected in 1994 versus 1995, the balance of this report will combine the two years of data for each variable.

### *Findings*

**Disability data.** Disability status is queried twice in the Phase II Disability Followback Survey, in the initial screening component, and in section F (educational section). Table 2 delineates the nineteen disability identifiers that were questioned in the preliminary screening portion of the survey. As noted in Table 2, three basic types of identifiers were recognized: interaction with a physician/awareness of the need for medical intervention, awareness of functional limitation, and specific disability categories. Over thirty-five percent of interviewees responded positively when asked if their child's condition necessitated (or was expected to need) regular doctor visits for greater than twelve months. While not identifying a specific disability, the question does substantiate a significant percentage of children who would require consistent medical care. Of the seventeen remaining questions in this section, seven dealt with "difficulties" or "problems" such as difficulty communicating (to family members, 2%, outside family, 4%) and trouble hearing (4%). The 10 remaining questions in this section relate to specific disabilities, with learning disabilities being identified most frequently by survey respondents (25%). In sharp contrast, the remaining disabilities were at or below three percent each (i.e. mental retardation, 3%, cerebral palsy, 2%).

In Section F of the survey, respondents are queried about disability from an educational perspective. Learning disabilities (34%), speech/language problems (22%), and Developmental Delays (10%) comprise over 60 percent of the 14 educationally related disabilities identified. Table 3 provides a complete breakdown of disability rankings in descending order of prevalence.

The Nineteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (U.S. Department of Education, 1997) was

utilized to test both the continuity between, and the robustness of, the 1994 and 1995 NHIS Phase II Disability Followback Survey-Child Questionnaire (concerning educational disabilities) and annual IDEA Child Count data. In both the 1994 and 1995 NHIS Phase II Disability Survey-Child Questionnaire and the Nineteenth Annual Report to Congress, learning disabilities and speech and language problems are noted as the two most prevalent educational disabilities. However, the prevalence of learning disabilities differs by 17% between the two groups (34% NHIS, 51% Annual Report to Congress), demonstrating the under-representation of high incidence disabilities in the NHIS data set. Another difference is the fact that two categories addressed by NHIS (Developmental Delay and Not a Specific Condition) are not included in the Nineteenth Report to Congress, resulting in potentially over 14% of lost data to compare to NHIS statistics. Also of significance is how data for NHIS and the Annual Report were collected. While the NHIS allowed responders to reply positively to as many categories as were pertinent to the condition(s) of their child, the Annual Report permitted only the primary special education need of each individual to be recorded. Refer to Table 4 for detailed comparisons between the two data sources. Finally, the Annual Report to Congress represents children ages 6- 21, while the NHIS included children ages 3-17 (in the Educational Section of Phase II of the survey). Discrepancies in age categories, disability identifiers, and data collection procedures between the two data sources make triangulation of data difficult.

**Technology as identified in the NHIS Phase II Disability Followback Survey.**

Tables 5 (medical AT) and 6 (educational AT) display two areas of assistive technology as identified in the NHIS survey. Specific AT devices are reported in descending frequency of use for each of the two categories identified.

In the area of medically related assistive technology, one general question and fifteen specific AT related queries were addressed. Of those questioned, 41% percent of participants reported using some type of medical supply or device within the past twelve months. Inhalers (27%) and nebulizers (14%) were the two most significantly used pieces of medical assistive technology. The remaining pieces of AT were identified less than four percent of the time. Refer to Table 5 for a complete listing of medically related AT items.

In Section F of the survey (Educational Services), merely four AT related devices were acknowledged. Of the total number of respondents (6,983), just 211 (3%) identified receiving one of these four devices as a benefit through their educational program. Only eyeglasses were identified as being received at least two percent of the time. See Table 6 for complete breakdown of educationally related AT devices.

What is surprising is the lack of educationally based AT survey questions. While it was not until the reauthorization of IDEA'97 that AT had to be considered during the IEP process, technology was being utilized within the educational environment by the early 1990s. As reported by the U. S. Department of Commerce, Bureau of the Census (1998), in 1993, 69.7% of all children in first through sixth grade, and 61.2% of all children in seventh through twelfth grade used a computer at school. Yet, not one question pertaining to the use of computers was asked throughout the entire survey.

Additional references to the use of AT by children with disabilities can be found within the executive summary of the Nineteenth Annual Report to Congress (U.S. Department of Education, 1997). The report acknowledges "remarkable progress" over

the preceding ten year period regarding the use of AT by students with disabilities. The report notes the use of “low tech” (i.e. specially designed pencils) to “high tech” (i.e. voice recognition systems, virtual reality) solutions to enhance the independence of students challenged by cognitive and physical disabilities. To further substantiate the prevalence of AT during 1994 and 1995, the resource directories for Closing the Gap (Hagen, 1994, 1995) were reviewed. Countless assistive devices are highlighted throughout these two publications (from voice output keyboards, vibration switches, and Braille printers to a plethora of software programs) documenting the wide range of educational devices available to the consumer. And yet, only one global question in the entire Educational Services section of the survey is queried regarding AT devices.

*Conclusion*

While the primary purpose of the NHIS Phase II Disability Followback Survey-Child Questionnaire was not the collection of data concerning AT utilization or outcomes, it is none the less disappointing that so little information can be gleaned from the AT data presented from the study. While four specific sections of the survey query a variety of AT, few conclusions can be drawn beyond usage percentages, leaving the researcher with many unanswered questions.

Table 1

Frequency Measures of Participants, 1994 and 1995 Phase II Disability Followback Survey-Child Questionnaire

Item	Frequency		%	
	1994	1995	1994	1995
Participants	4296	2687	100%	100%
Sex				
Male	2558	1604	60%	60%
Female	1738	1083	40%	40%
Age Recode				
0-35 months	335	211	8%	8%
3 -17 years	3961	2476	92%	92%
Race Recode				
White	3350	2146	78%	80%
Black	816	464	19%	17%
Other	130	77	3%	3%

Family Income				
Less Than \$20,000.00	1617	1053	38%	39%
\$20,000.00 or More	2635	1591	61%	59%
Unknown	44	43	1%	2%
NHIS Poverty Index				
At or Above	2979	1790	69%	67%
Below	1096	734	26%	27%
Unknown	221	163	5%	6%
Region				
Northeast	786	513	18%	19%
Midwest	1199	638	28%	24%
South	1436	896	34%	33%
West	875	640	20%	24%
Geographic Distribution				
*MSA Size				
1,000,000 or More	1656	1230	39%	46%
250,000 –999,999	1206	700	28%	26%
100,000-249,999	336	217	8%	8%
Under 100,000	64	36	1%	1%
Non-MSA	1034	504	24%	19%

Note: \*MSA= Metropolitan Statistical Area

Table 2

Frequency of Disability Identifiers as Acknowledged by Survey Respondents,  
Preliminary Screening Process, 1994 and 1995

Item	n	% of Respondents
Interaction with a physician/awareness of the need for medical intervention		
1. Condition necessitating regular doctor visits lasted or expected to last 12 or more months	2159	35%
2. Doctor has mentioned physical problem/delay	394	6%
Awareness of functional limitation		
3. Difficulty learning what others their age can learn	606	10%

4. Difficulty communicating so that people outside family understand	255	4%
5. Trouble hearing normal conversation	248	4%
6. Serious difficulty seeing	174	3%
7. Difficulty communicating so that family members understand	108	2%
8. Use mobility aids to get around	122	2%
9. Uses hearing aid	70	1%
Specific disabilities		
10. Has a learning disability	1514	25%
11. Has mental retardation	167	3%
12. Has cerebral palsy	94	2%
13. Has autism	44	1%
14. Is legally blind	43	1%
15. Has Down syndrome	43	1%
16. Has hydrocephalus	23	<1%
17. Has spina bifida	14	<1%
18. Has muscular dystrophy	11	<1%
19. Has cystic fibrosis	6	<1%
TOTAL	6095	

Table 3

Frequency of Disability Identifiers as Identified by Survey Respondents, Educational Portion of Survey, for Years 1994 and 1995

Item	n	% of Respondents
1. Learning Disabilities	1328	34%
2. Speech or Language Problems	874	22%
3. Developmental Delay	403	10%
4. Emotional Disturbance	350	9%
5. Mental Retardation	178	5%
6. Other Health Problem	163	4%
7. Not a specific Condition	139	4%
8. Multiple Disabilities	103	3%
9. Hearing, Including Deafness or Hard of Hearing	100	3%
10. Visual, Including Blindness	95	2%

11. Orthopedic Problems	87	2%
12. Autism	50	1%
13. Traumatic Brain Injury	26	1%
14. Deaf and Blind	25	1%
<b>TOTAL</b>	<b>3921</b>	

Table 4

Comparison of Educational Disability Identifiers, NHIS 1994/95 and 19<sup>th</sup> Annual Report to Congress

	NHIS		19th Annual Report to Congress	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
1. Learning Disabilities	1328	34%	2,510,224	51%
2. Speech or Language Problems	874	22%	1,020,331	21%
3. Developmental Delay	403	10%		
4. Emotional Disturbance	350	9%	428,049	9%
5. Mental Retardation	178	5%	570,518	12%
6. Other Health Problem	163	4%	107,133	2%
7. Not a specific Condition	139	4%		
8. Multiple Disabilities	103	3%	89,620	2%
9. Hearing, Including Deafness/Hard of Hearing	100	3%	65,204	1%
10. Visual, Including Blindness	95	2%	24,713	<1%
11. Orthopedic Problems	87	2%	60,467	1%
12. Autism	50	1%	22,664	<1%
13. Traumatic Brain Injury	26	1%	7,259	<1%
14. Deaf and Blind	25	1%	1,331	<1%
<b>TOTAL</b>	<b>3,921</b>		<b>4,907,513</b>	

Table 5

Medically Related Assistive Technology as Reported in Survey for Years 1994 and 1995

<u>Item</u>	<u>n</u>	<u>% of Respondents</u>
1. Medical Supply or Device	1500	4%
2. Inhaler	999	27%

3. Nebulizer	497	14%
4. Crutches	119	3%
5. Wheelchair	113	3%
6. Respirator	84	2%
7. Hearing Aid	78	2%
8. Diabetic Equipment	59	2%
9. Catheterization Equipment	52	1%
10. Glucose Monitor	51	1%
11. Walker	42	1%
12. Feeding Tube	22	1%
13. Cane	19	<1%
14. Scooter	10	<1%
15. Tracheotomy Tube	9	<1%
16. Ostomy Bag	8	<1%
<b>TOTAL</b>	<b>3662</b>	

Table 6

Educationally Related Technology as Reported in Survey for Years 1994 and 1995

Item	n	% of 6,983 Respondents
1. Eyeglasses	118	2%
2. Other Assistive Devices	48	1%
3. Wheelchair	24	<1%
4. Hearing Aids	21	<1%
<b>TOTAL</b>	<b>211</b>	

*References*

Hagen, G. (Ed.). (1994, February/March). 1994 closing the gap resource directory

[Special issue]. *Closing the Gap*, 12(6).

Hagen, B. (Ed.). (1995, February/March). 1995 closing the gap resource directory

[Special issue]. *Closing the Gap*, 13(6).



National Center for Health Statistics. (1994). National health interview survey on disability, Phase I and II. Retrieved July 21, 2003, from

[http://www.cdc.gov/nchs/about/major/nhis\\_dis/nhisddes.htm](http://www.cdc.gov/nchs/about/major/nhis_dis/nhisddes.htm).

U. S. Department of Commerce. (1994). *Disability followback survey*. Washington, D.C.: Author.

U. S. Department of Commerce, Bureau of the Census. (1998). *The condition of education 1998*. Retrieved July 14, 2003 from

<http://nces.ed.gov/pubs98/condition98/c9803d01.html>

U.S. Department of Education (1997). *To assure the free appropriate public education of all children with disabilities: Nineteenth annual report to congress on the implementation of the individuals with disabilities education act*. Washington, D.C.: Author.

### *Acknowledgment*

The ATOMS Project and this work are supported in part by the National Institute on Disability and Rehabilitation Research (NIDRR), grant number H133A010403. The opinions contained in this publication are those of the grantee and do not necessarily reflect those of the NIDRR and the U.S. Department of Education.