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The Identification of Individuals with Disabilities in National Databases: Creating a Failure to Communicate

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Abstract

The purpose of this study was to analyze similarities and differences in how students with disabilities are identified in national databases. National data collection programs in the U.S. Departments of Education, Commerce, Labor, Justice, and Health and Human Services, as well as databases from the National Science Foundation, the American Council of Education, and the College Board, were examined. Nineteen national data collection programs were selected as being potentially useful in the extraction of policy-relevant information on the educational status and performance of students with disabilities. Among these 19 programs there was significant variability in the disability categories used. These programs were targeted for two reasons: (a) their potential usefulness in providing indicators of domains in key models of educational outcomes for children and youth with disabilities, and (b) their prominence in current efforts to monitor progress toward the attainment of national education goals. Discussed are issues related to improving disability identification in large-scale data collection programs and the effects of these issues on reporting policy-relevant information.

Calls for reform in American education during the past decade have resulted in raised expectations; attempts to develop uniform, "world-class" standards; increased emphasis on school accountability; and heightened interest in the measurement of school outcomes.

Reform initiatives at national, state, and local levels are focused more frequently on the products as well as the processes of schooling. As professionals seek to produce policy-relevant information on the educational performance and status of children in our nation's schools, the search for indicators of success is playing a central role in reform activities. National and state databases are being used as a basis for monitoring and evaluating the effects of these reform initiatives (McGrew, Spiegel, et al., 1992).

Efforts to assess educational progress flourish in eras of reform and innovation. Probably no single factor has pushed current accountability efforts more than the reform activities surrounding the six national education goals and the National Education Goals Panel that assumed responsibility for monitoring them. Since 1990, when the goals were endorsed by President George Bush and the nation's governors, a flurry of state and federal activity has been focused on identifying indicators of progress toward these goals. Developing indicator systems has become big business in the United States (Odden, 1990), with nearly all national and state education agencies becoming more involved in making decisions related to monitoring of, accountability for, and measuring of educational progress than ever before in the nation's history (McGrew, Thurlow, Shriner, & Spiegel, 1992). Even a cursory review of the educational reform literature leads to the conclusion that there exists a hunger for policy-relevant information on the educational performance of students.

The United States has a developing and rich tradition of assessing student progress as a measure of the overall quality of its education system (McGrew, Thurlow, et al., 1992). Scores on cumulative (and generally standardized) tests administered at selected school transition points (e.g., graduation, promotion to third grade) serve as data for making decisions and documenting the need for improvements and programs. National data collection programs such as the National Assessment of Educational Progress (NAEP), often called the Nation's Report Card; the National Longitudinal Study (NLS); High School and Beyond (HSB); and the National Education Longitudinal Study (NELS) are a few examples of recent and continuing efforts to provide periodic data on the educational status of U.S. school children.

In an era of significant rhetoric and action characterized as "education reform," the terms *full-inclusion*, *inclusionary practices*, and *equity* have become commonly used phrases for highlighting the need not to exclude students with disabilities and students from disadvantaged backgrounds and different cultures when producing educationally relevant policy reports (Ysseldyke, Algozzine, & Thurlow, 1995). More than ever before, a "one system for all" mentality has become the driving force in bringing special and general education together (Lipsky & Gartner, 1989; Stainback, Stainback, & Forest, 1989; Ysseldyke, Algozzine, & Thurlow, 1992). Although not a new idea, the practice of including *all* students in educational experiences available to *any* students has recently had an impact on personnel concerned with assessment and educational outcomes. Findings that significant numbers of students with limited English proficiency and students with disabilities are not included in state reports of pupil performance and national databases have added to the urgency of these concerns (Ingels, 1991; McGrew, Thurlow, et al., 1992; Spencer, 1991).

Not including specific subgroups of people in any national, state, or local sources of data causes concerns when compiling, reporting, and interpreting scores; including students but using different definitions or methods for grouping and describing them also causes problems (Algozzine, 1992). For example, if one state excludes all students with learning disabilities and another excludes only some, reporting and comparing outcomes across the states becomes meaningless. Considering the combinations of student types that may or may not be included in assessment-related practices illustrates the complexity of problems created by selective inclusionary practices in outcomes assessment. Under conditions of national importance, policy decisions should be made on the basis of consistent information with known characteristics.

The purpose of this study was to describe similarities and differences that exist in how subpopulations of students with disabilities are identified in national educational databases. Students with a wide array of disabilities fit within this population, including those with learning disabilities, emotional disabilities, and speech and language impairments; with sensory disabilities such as hearing and/or visual impairments; and with multiple and more severe disabilities, typically involving significant mental impairments. Given that almost 5 million school-age youngsters with disabilities receive some form of special education services—services that are provided at significant expense to our educational system—it is imperative that the performance of these students be examined. A recent report (McGrew, Thurlow, et al., 1992) suggested that large numbers of students with disabilities are excluded from many prominent national data collection programs. In addition to the issue of exclusion, there is also an issue of inclusion of appropriate descriptor variables in national data collection programs.

Method

Twenty-eight national data collection programs were identified by the National Center on Educational Outcomes as available for analysis. These data collection programs were identified as being potentially useful in the extraction of policy-relevant information on the educational status and performance of students with disabilities (McGrew, Spiegel, et al., 1992). They were targeted based on: (a) their potential usefulness in providing indicators of outcome domains in the center's conceptual model of educational outcomes for children and youth with disabilities (Ysseldyke, Thurlow, et al., 1992), and (b) their prominence in current efforts to monitor progress toward the attainment of national education goals. A list of these programs is presented in table 1.

Table 1. Preliminary List of National Data Collection Program Targeted by NCEO

Department of Education
- Transcript Studies
- National Adult Literacy Survey
- National Assessment of Educational Progress
- National Assessment of Educational Progress: Trial State Assessment Program
- National Longitudinal Transition Study of Special Education Students
- National Education Longitudinal Study
- National Household Education Survey
- Young Adult Literacy Survey
- Beginning Postsecondary Student Longitudinal Study
- Baccalaureate and Beyond Longitudinal Study
- Early Childhood Longitudinal Study

Department of Commerce
- Current Population Survey
- Survey of Income and Program Participation

Department of Labor
- Workforce Participation Survey
- Workplace Literacy Assessment

Department of Justice
- National Crime Survey

Department of Health and Human Services
- National Health Interview Survey
- National Health and Nutrition Examination Survey, Epidemiologic Follow-up Study
- National Survey of Personal Health Practices and Consequences
- National Survey of Family Growth
- National Adolescent School Health Survey
- Youth Risk Behavior Surveillance Survey
- National Household Survey of Drug Abuse
- Monitoring the Future

National Science Foundation
- Survey of Graduate Students and Post-Doctorates
- Longitudinal Study of American Youth

American Council of Education
- General Education Development Testing

The College Board
- Advanced Placement Tests

Note: NCEO = National Center on Educational Outcomes

In this study, a subset of data collection programs was analyzed. This selection was not done on a random basis to represent all national data collection programs that provide potentially useful, policy-relevant information for students with disabilities. Instead, we selected programs based on inclusion of important indicators of outcome domains related to individuals with disabilities or high visibility and prominence in recent education reform initiatives. Given the prominence of the Department of Education's data collection activities in reform activities, a decision was made to include programs sponsored by this agency. Finally, several data collection programs were not selected either because they were too new and had limited documentation available for review (e.g., Baccalaureate and Beyond) or because they were not recurring programs or were relatively dated (e.g., HSB) and had been replaced with newer programs (e.g., NELS). Eighteen of these programs included in the current investigation are briefly described in table 2 (the child and adult versions of the National Household Education Survey are counted as separate programs due to different samples and instrumentation). Programs sponsored by the Department of Education and conducted or monitored by the National Center for Education Statistics comprise the largest number of databases (*n* = 11). Five programs were sponsored by the Department of Health and Human Services; the others were sponsored by the National Science Foundation, Department of Commerce, or Department of Justice.

Table 2. Descriptions of National Data Collection Programs Included in Investigation

National Adult Literacy Survey (Department of Education)—NALS:92

A nationally representative cross-sectional study designed to collect information on the types and levels of literacy skills of adults and how these skills are distributed across major subgroups. This study assessed the prose, document, and quantitative literacy of young adults in 1992.

National Assessment of Educational Progress (Department of Education)—NAEP:88

NAEP is a nationally representative cross-sectional study designed to monitor the knowledge, skills, understanding, and attitudes of the nation's children and youth. This data collection program began in 1969 and currently assesses different curriculum areas (e.g., reading, writing, mathematics, science, citizenship, U.S. history, geography, social studies, art, music, literature, career and occupational development) in Grades 4, 8, and 12 every 2 years. The 1988 NAEP and the voluntary state program started in 1990 were reviewed for this report.

National Assessment of Educational Progress: Trial State Assessment Program (Department of Education)—TSAP:90

The Trial State Assessment Program provided state-level mathematics data for eighth graders for 40 participating jurisdictions.

National Education Longitudinal Study (Department of Education)—NELS:88

A nationally representative longitudinal study designed to assess the baseline experiences of eighth-grade students and to relate these experiences to current academic achievement and to later achievement in school and life. The 1988 base year data collection program gathered data in a variety of areas such as work status, opinion values, school characteristics, school atmosphere, school work, school performance, guidance, special programs, after-school supervision, involvement with community, after-school activities, educational and occupational life goals, and financial assistance. Follow-up assessments will be completed every 2 years from 1990 to 1996.

National Longitudinal Transition Study of Special Education Students (Department of Education)—NLTS:87

A nationally representative longitudinal study of special education students who were in Grades 7 through 12 during the 1987 base year sample. By collecting a wide array of information from parents/guardians, school records, and school administrators, this data collection program provides descriptive information regarding the transition of youth with disabilities from secondary school to early adulthood, and seeks to identify factors that contribute to effective transition of youth with disabilities. The first follow-up was completed in 1990.

National Household Education Survey-Adults (Department of Education)—NHESA:91

A nationally representative cross-sectional sample of households was surveyed in 1991 to provide national data regarding adult education issues.

National Household Education Survey-Children (Department of Education)—NHESC:91

A nationally representative cross-sectional sample of households were surveyed in 1991 to provide national data regarding early education issues. The 1991 base year survey targets information on the care and education of 3- to 8-year-old children in education activities.

Young Adult Literacy Survey (Department of Education)—YALS:85

A nationally representative cross-sectional sample of young adults from ages 21 to 25 who were surveyed together with the 1985 NAEP survey. The survey assessed literacy skills in order to better understand the nature and extent of literacy problems facing young adults.

1987 Transcript Study (Department of Education)—TS:87

A nationally representative cross-sectional sample of 11th-grade or 17-year-old students selected from the 1986 NAEP survey. The study provided information on course-taking and its relationship to the knowledge, skills, concepts, understandings, and attitudes of 11th-grade students.

Beginning Postsecondary Student Longitudinal Study (Department of Education)—BPS:90

A nationally representative longitudinal sample of students who entered postsecondary education in public and private institutions in 1989–1990. The base year sample was drawn from the 1990 National Postsecondary Student Aid Study (NPSAS). The study gathers information on the persistence, progress,

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curriculum, attainment, and outcomes from initial time of entry into postsecondary education through leaving and entering the work force. Follow-up surveys to be completed every 2 years until 1998.

Baccalaureate and Beyond Longitudinal Study (Department of Education)—B&B:93

A nationally representative longitudinal sample of students in private and public postsecondary education institutions drawn from the 1993 National Postsecondary Student Aid Study (NPSAS). The study addressed the issues of access and entry into graduate education and the workforce, the relationship between undergraduate and graduate experiences, and the return on investment in postsecondary education.

Current Population Survey, March Supplement (Department of Commerce)—CPS

A nationally representative cross-sectional study designed to collect information on the employment situation and demographic status of the complete U.S. population (birth through adulthood). The March Supplement is specifically designed to gather data on work experience, income, noncash benefits, and population migration. Data collection in this program has been occurring annually since the 1940s.

National Health Interview Survey (Department of Health and Human Services)—NHIS:89

A nationally representative cross-sectional study designed to provide information on the health of the civilian noninstitutionalized U.S. population (birth through adulthood). This survey has been completed annually since 1957. Although the same basic demographic and health-related information is collected each year, additional information on special health topics (e.g., AIDS, aging, etc.) may be covered in any one survey.

National Health and Nutrition Examination Survey Epidemiologic Follow-up Study (Department of Health and Human Services)—NHEFS:86

A nationally representative longitudinal study designed to: (a) provide information on the prevalence of health conditions and risk factors; (b) monitor changes over time in health, functional status, and utilization of hospitals; and (c) track the incidence of various medical conditions in the U.S. population (birth through adulthood). The base year data are drawn from the National Health and Nutrition Examination Survey 1 (NHANES 1), with follow-ups in 1982–1984, 1986, 1987, and 1991.

National Survey of Family Growth (Department of Health and Human Services)—NSFG:88

A nationally representative cross-sectional sample drawn from households involved in the National Health Interview Survey (NHIS). The 1988 cycle included women from 15 to 44 years of age who were included in the 1986 NHIS. The study provides national data on the demographic and social factors associated with childbearing, contraception, adoptions, and maternal and child health.

National Adolescent Student Health Survey (Department of Health and Human Services)—NASHS:88

A nationally representative cross-sectional sample of 8th- and 10th-grade students. The study examined the health-related knowledge, practices, and attitudes of youth in the areas of AIDS, nutrition, consumer health, sexually transmitted disease, drug and alcohol use, suicide, injury prevention, and violence.

Youth Risk Behavior Survey (Department of Health and Human Services)—YRBS:90-91

A nationally representative cross-sectional sample of students in Grades 9 to 12. As part of the Youth Risk Behavior Surveillance System (YRBSS), this study is designed to periodically (every 2 years) measure the prevalence of priority health-risk behaviors among the nation's youth and to assess whether these behaviors change over time.

National Crime Survey (Department of Justice)—NCS:86-89

A nationally representative cross-sectional sample (collected on a 3-year cycle) of household members ages 12 and above. The study is designed to collect data on personal and household crime victimization.

Longitudinal Study of American Youth (National Science Foundation)—LSAY

A nationally representative longitudinal study of 7th and 10th graders designed to assess student attitudes toward science and mathematics as areas of study and possible career choices. Base-year data collection started in 1987, with annual follow-ups.

Information regarding the disability definitions and categories used in each of the 19 programs was abstracted from disability sensitivity review summaries (McGrew, Spiegel, et al., 1992). This information served as the primary data for the current investigation. The process and procedures used to obtain this information for each data set were described by McGrew, Spiegel, et al. and are summarized below:

1. Contacts were made with the sponsoring agencies to request all relevant methodology information, technical reports, and manuals.
2. Descriptive information (e.g., title, collection cycle, design), source and method of data collection (e.g., who provides information, how it is collected), and general domains contained in the data set were tabulated and analyzed.
3. Sampling design was tabulated and analyzed, with particular attention to the use of disability-related exclusionary procedures, the definitions of disability categories or terms, and the disability characteristics o f the final sample.

The correspondence between the disability categories or terms used in each data collection program and those used by the U.S. Department of Education (1992) in the *Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act* was examined. Only the correspondence between the categorical labels or terms was evaluated. No attempt was made to compare the correspondence between specific operational definitions or criteria.

Results

The correspondence between the 10 federal special education categories included in this analysis (autism and traumatic head injury categories, added in 1991, were not included) and similar or related disability categories used in the 19 national educational data collection programs is summarized in table 3. The results are organized into two categories: programs sponsored by educational agencies (i.e., U.S. Department of Education), and programs sponsored by other types of agencies (i.e., other federal agencies). Tables listing the different disability-related category variables used to identify individuals in the different programs are available from the National Center on Educational Outcomes (see McGrew, Algozzine, Ysseldyke, Thurlow, & Spiegel, 1993).

Table 3. Correspondence between Federal Special Education Category and Disability Category Terms Used in Selected Programs

National data source[a]	Federal special education category[b]									
	SI	LD	MR	SED	HHD	VI	DB	OI	OHI	MH	Rating
Dept. of Education											
NLTS:87	*	*	*	*	*	*	*	*	*	*	+
NAEP:88	*	*	*	*	*	**	*	*	*	*	+
TSAP:90	*	*	*	*	*	**	*	*	*	*	+
NHESC:91	*	*	*	*	*	**	*	*	*	*	*
YALS:85	*	*	0	0	*	*	0	*	*	0	+/–
NALS:92	*	*	*	*	**	*	0	*	***	0	+
TS:87	*	*	*	*	**	*	*	*	*	*	+
BPS:90	*	*	0	0	*	*	0	*	*	0	+/–
B&B:93	*	*	0	0	*	*	0	*	*	0	+/–
NELS:88	0	**	0	0	**	0	0	*	0	0	–
NHESA:91	0	0	0	0	0	0	0	0	0	0	–
Other agencies											
NHIS:89	**	0	*	***	**	**	0	***	0	0	+/–
NSFG:88	0	0	0	0	0	0	0	0	0	0	–
NASHS:88	0	0	0	0	0	0	0	0	0	0	–
YRBS:90–91	0	0	0	0	0	0	0	0	0	0	–
LSAY	0	0	0	0	0	0	0	0	0	0	–
CPS	0	0	0	0	0	0	0	0	0	0	–
NCS:86–89	0	0	0	0	0	0	0	0	0	0	–
NHEFS:86	0	0	0	0	0	0	0	0	0	0	–

Note: Table entries represent the number of category terms used in the national data source that correspond to the federal special education category (e.g., for NHIS under SI indicates that NHIS has two categories of speech impairment—in this case, stammering/stuttering, and other speech impairment). The entry *** indicates that three *or more* categories are used for the one federal category. Cells with a zero (0) indicate that no categories correspond to the federal special education category. In the rating column, + reflects 80% to 100% correspondence, +/– reflects 31% to 79% correspondence, and – reflects 0% to 30% correspondence. Additional details on the information in this table are available from the National Center on Educational Outcomes.

a. Sources of data are listed in table 2.

b. Federal categories are as follows: SI = speech impairment; LD = learning disability; MR = mental retardation; SED = serious emotional disorder; HHD = hard of hearing/deaf; VI = visual impairment; DB = deaf/blind; OI = orthopedic impairment; OHI = other health impairment; MH = multiple handicaps.

Analysis of this information revealed significant variability in the disability-related terminology used by educational and noneducational federal agencies, as well as within these agencies. The federal disability category for which there was the greatest similarity of terms across the largest number of data collection programs was *speech impaired.* Ten of the 19 (52.6%) programs made use of a single speech-related variable. Most of these programs (i.e., nine) were sponsored by the Department of Education. However, even within the programs sponsored by that department, there was variability. For example, no speech impairment variable was included in the NELS:88 program. A somewhat different approach was taken by the National Health Interview Survey (NHIS:89), which used two different speech-related categories (i.e., stammering/stuttering and other speech impairment). Only one of the eight (12.5%) noneducational agencies included some form of speech-related category in its data collection program.

Given the educational nature of the *learning disability* category, it was not surprising to find a clear distinction concerning this category between programs sponsored by the educational and noneducational agencies. None of the noneducational programs used the term. Nine of the 11 (81.8%) educational programs included a single label indicating a learning disability. One educational program (NELS:88) used a combined category (i.e., in a program for individuals with orthopedic *or* learning disabilities) that would make disaggregation of the results for only individuals with learning disabilities impossible. Across both types of agencies, only about half of the programs (10 of 19; 52.6%) included a learning disability–related variable.

For three federal special education disability categories (i.e., *mentally retarded*, *deaf-blind*, and *multihandicapped*), either the federal category was used or the disability was not categorized at all. Seven of the 19 (36.8%) programs used a term for individuals with mental retardation, and only 5 (26.3%) included the deafblind and multiple handicaps categories. In all but one instance (i.e., use of the mentally retarded category in NHIS:89), all of the data sets that used these three federal categories were under the direction of the Department of Education.

Together with the previously presented results, the remaining analyses revealed that across data collection programs there was significant variability in the use of terms that corresponded to the federal categories of *seriously emotionally disturbed*, *hard of hearing*, *deaf visually handicapped*, *orthopedically impaired*, and *other health impaired*. In each of these analyses, single and multiple category variables were found. When multiple categories would be appropriate, such as in the case of the separate federal special education categories of hard of hearing and deaf, only six data collection programs provided this option. Five of the six were under the direction of the Department of Education. However, sponsorship by the Department of Education did not ensure the appropriate use of two categories in six of their other data collection programs. With the exception of NALS:92 in the case of other health impaired, all instances where multiple categories were available that appeared to correspond to a single federal special education category occurred in the NHIS:89 survey directed by the National Center for Health Statistics.

The only noneducational programs that included any variables that could be matched with the federal special education categories were the Longitudinal Study of American Youth (LSAY), NHIS:89, and the National Health and Nutrition Examination Survey, Epidemiologic Follow-up Study (NHEFS:86). Such a finding is not surprising, given that the noneducational programs were designed to address predominately noneducational issues (e.g., health, crime, family growth). Although some of these programs do not gather any disability-related information (National Survey of Family Growth—NSFG:88, National Adolescent Student Health Survey—NASHS:88, National Crime Survey—NCS:86–89, Youth Risk Behavior Survey—YRBS:90–91), others (e.g., NHIS:89, NHEFS:86) do, but use a different conceptual framework such as the International Classification of Impairments, Disabilities, and Handicaps or the "functional limitation" or Nagi framework (Pope & Tarlov, 1991). Although there is some correspondence between terms used in these other disability conceptual frameworks and the federal special education categories, the correspondence is limited. Given that many of these noneducational programs are some of the most inclusive national programs in terms of individuals with disabilities (McGrew, Thurlow, et al., 1992), the lack of any disability-related category variables or the limited correspondence with the federal special education disability category variables results in a significant "lost opportunity" for the production of important policy-relevant information on this portion of the population.

Finally, it is important to note that the listing of a data collection program as including a term related to a federal special education category does not mean that disaggregation of the results by that category is possible. For example, the national and state NAEP programs (i.e., NAEP:88, Trial State Assessment Program—TSAP:90) are listed as including many o f the special education categories. However, this disability-related information was collected only for students who were *excluded* from the NAEP data collection activities. Disaggregation of the NAEP results for any students with disabilities who were not excluded is not possible. Thus, the summary percentages reported for those programs that include variables similar to the federal special education disability category variables paint a rosier picture than the reality.

Discussion

Significant variability was evident in the manner in which individuals with disabilities are identified in national educational and noneducational data collection programs. Notable differences were observed between programs sponsored by educational agencies and those sponsored by noneducational agencies. As would be expected when the federal special education categorical system was used as the basis for the analytical framework, programs sponsored by the Department of Education contained the largest number of data elements displaying some correspondence to the federal special education categories. However, even within these programs, there was variability. The conclusions reached in this investigation echo recent conclusions of the Committee on a National Agenda for the Prevention of Disabilities (Pope & Tarlov, 1991) that:

> Despite its significance as a public health and social issue, disability has received little attention from epidemiologists and statisticians; consequently, surveillance of disabling conditions is inadequate in many ways. (p. 96).
>
> Much of the available information on people with disabling conditions has been collected piece meal by many agencies, each with the aim of its own particular needs. (p. 97)

The variability evident in this study was not unexpected. Many of the programs reviewed here were not originally designed to provide answers to educational questions or questions about disability groups (e.g., programs of the National Center for Health Statistics). These programs admittedly are burdened with many competing goals and objectives, the least of which may be concern for consistency across agencies.

In an environment of limited resources for new and expensive large-scale nationally representative data collection programs, it would be most practical and cost-effective to modify and use existing programs to answer new and emerging questions. How individuals with disabilities perform during and after their educational careers is an important public policy and research question that needs to be addressed now and in the future (Ysseldyke, Thurlow, et al., 1992). Although specially designed national studies focused exclusively on the population of students with disabilities (i.e., National Longitudinal Transition Study of Special Education Students) provide valuable information, such special surveys are expensive, offer limited coverage of outcome domains, provide no comparable data on students without disabilities, and are typically fixed-duration studies that do not give routine information as part of a recurring national information system.

The need for improving the system of data collection for individuals with disabilities is evident; however, the means for meeting this need cannot be achieved easily. Even with a singular definitional system, problems remain. For example, gathering information from adults about disabilities during childhood may yield data of suspect validity. Similarly, variability in accuracy and depth of information provided in data from different sources (e.g., schools versus courts, employers versus parents) also may render large-scale information gathering results incomparable, regardless of the specificity of the disability definition.

Under conditions of national importance, policy decisions should be made on the basis of information reflecting all students (Algozzine, 1992; Bruininks, Thurlow, & Ysseldyke, 1992; Ysseldyke, Algozzine, & Thurlow, 1992). Problems arise when different federal agencies or different programs within the same federal agency do different things. Variation in information about people with disabilities in national data sources creates variation in estimates of performance, prevalence, incidence, and contributions. Estimates from surveys and programs using different categories for classifying subgroups of individuals with disabilities create confusion for users of this information, including policy analysts and decision makers. Also, the lack of consistent disability-related category variables across national databases makes it all but impossible to produce useful policy-relevant information from a secondary analysis of national databases. This does not mean that a system of singular categorical designations will solve the problems inherent in identifying and comparing people in large-scale data analysis efforts. In fact, we believe it reinforces the need to periodically evaluate what is being done to include people with disabilities in national policy-making actions.

A Step in the Right Direction

Toward the goal of improving the system for collecting and reporting information in national databases by including students with disabilities, we offer the following suggestions:

1. A more uniform and standard disability variable system that parallels the federal special education categories should be used for educationally oriented national data collection programs, particularly those sponsored by the U.S. Department of Education. Such a sys-

tem should be used to identify not only those individuals with disabilities who are excluded from these data collection programs but also those individuals who do participate. Although the use of a standard system in no way eliminates problems inherent in accuracy of reported data, such a system should increase the feasibility of disaggregating and reporting important outcome information, especially when coupled with efforts directed at decreasing the exclusion of individuals with disabilities and increasing their participation through testing accommodations (McGrew, Thurlow, et al., 1992).

2. Many noneducational data collection programs include numerous indicators that represent important domains in the National Center on Educational Outcomes' conceptual model of outcomes for students with disabilities. For example, many of the data collection programs conducted by the National Center for Health Statistics include important indicators in the National Center on Educational Outcomes' domains of physical health and social adjustment. More importantly, through the use of proxies (informed individuals who can answer questions) in many of the surveys sponsored by the National Center for Health Statistics, individuals with disabilities are excluded very infrequently (McGrew, Thurlow, et al., 1992). Thus, many of these data collection programs are potentially rich sources of information on important outcomes for students with disabilities. However, as currently designed, it is impossible to extract this rich source of information in a manner useful to the development of policy related to such students.

It is recommended that a dialogue be initiated between representatives from the appropriate federal groups and agencies, both educational (e.g., National Center for Education Statistics, Office of Special Education Programs) and noneducational (e.g., National Center for Health Statistics, Census Bureau). The purpose of this dialogue would be to identify possible means by which uniform disability-related variables could be collected across agencies, particularly for the school-age population surveyed by each data collection program. The feasibility of using the same special education categorical variable system recommended for the Department of Education (i.e., Recommendation No. 1) should be examined. Alternatively, the feasibility of developing "cross-walk" procedures that would allow the different disability information collected by different agencies to be converted to the federal special education categories should be explored. This dialogue is necessary because it is important that educational and quality-of-life information be available for *all* of the population, as well as for students with disabilities. For example, the extent to which individuals who are using family planning also are engaging in high-risk health behaviors, are victims of crime, and are healthy is vital information.

3. Although the recommendation for a standard terminology system that parallels the federal special education categories would make policy research based on extant national databases much easier, such an approach is not without problems. For example, local school records would be the most likely source for identifying students with disabilities; however, although most states use either the federal categories or modified versions of them, a number of states do not (Ysseldyke, 1987; Ysseldyke, Algozzine, & Thurlow, 1992). Procedures would need to be developed that would allow different state terms to be converted into

the standard federal categorical framework. Research and discussion is needed to identify the possible problems in and solutions for this issue.

In addition, much has been written within the special education literature about the problems of using a categorical system to organize the field of special education, with frequent calls for a noncategorical approach (cf. Heller, Holtzman, & Messick, 1982; Hobbs, 1975; Ysseldyke, Algozzine, & Thurlow, 1992). The use of a standard categorical system for reporting national-level policy reports may tend to contribute to many of these problems (e.g., a "hardening of the categories") mentioned by advocates of the noncategorical approach. Research and discussion is needed to determine what steps can be taken to minimize the potential negative effects of national categorically based reports.

Finally, much has been written about the significant variability among states in the operationalizations of definitions of the same federal disability categories, and about the variability among professionals when implementing the same operational criteria (Ysseldyke, 1987; Ysseldyke, Algozzine, & Thurlow, 1992). These variabilities can introduce unknown sources of error into any national statistical estimates that might be reported by different disability categories. Although these categories accurately describe the disability population identified by current practice, research is needed to determine whether this classification system, as applied to the samples of national data collection programs, can be made more uniform. Research and development needs to be done to explore the advantages and disadvantages of developing a small set of standard personal competency variables (e.g., academic, cognitive, adaptive, social, emotional, physical) that could be used in all data collection programs. The results could be used to describe and operationally classify the sample respondents according to the federal special education categories.

4. In addition to the development of survey procedures to collect standard personal competence information for describing national samples, it is also recommended that those individuals charged with the design of such instruments include additional variables that would help to better describe both included and excluded individuals in such programs. A list of possible new variables for standardizing data collection procedures is presented in table 4.

Generalizing from this study to all national data collection programs must be done with some caution because a nonexclusive, nonrandom sample of programs was analyzed. Still, the preliminary results raise a number of important issues. Widespread exclusion of students with disabilities from national data collection programs, and extreme variability in the classifications that these programs assign to students with disabilities when they are included, creates a real failure to communicate. This lack of communication among national data collection programs on disability-related issues continues to have a significant impact on our ability to extract important information from existing data and move in the right direction when trying to improve services to people with disabilities.

Table 4. Variables to Be Considered in Standardized Data Collection Procedures

Information of Intellectual Functioning (possible items)

1. Of the following choices, which best describes this student's level of intellectual functioning?
   - A. Well above average (IQ above 115)
   - B. Average (IQ 85 to 115)
   - C. Below average (IQ 70 to 84)
   - D. Mild retardation (IQ 52 to 69)
   - E. Moderate retardation (IQ 36 to 51)
   - F. Severe or profound retardation (IQ 35 or below)
   - G. Don't know, unable to provide estimate
2. When providing the information on this student's level of intellectual functioning, which of the following was the basis for your response?
   - A. Most recent standardized intelligence test score
   - B. Professional estimate, not based on standardized intelligence test scores
   - C. Combination of standardized intelligence test score and professional judgment
   - D. Unable to provide an estimate

Information on Personal Functioning (possible items)[a]

1. Of the following choices, which best describes this student's primary means of communication or expression? (circle one)
   - 1) None
   - 2) Gestures
   - 3) Speaks
   - 4) Sign language or finger spelling
   - 5) Communication board or device
   - 6) Don't know
2. Of the following choices, which best describes this student's vision? (circle one)
   - 1) Sees well (may wear glasses)
   - 2) Vision problems limit reading or travel (may wear glasses)
   - 3) Little or no useful vision (even with glasses)
   - 4) Don't know
3. Of the following choices, which best describes this student's hearing? (circle one)
   - 1) Hears normal voices (may use hearing aid)
   - 2) Hears only loud voices (may use hearing aid)
   - 3) Little or no useful hearing (even with hearing aid)
   - 4) Don't know
4. Of the following choices, which best describes this student's general health? (circle one)
   - 1) Health results in no limitation in daily activities
   - 2) Health results in few or slight limitations in daily activities
   - 3) Health results in many or significant limitations in daily activities
   - 4) Don't know
5. Of the following choices, which best describes this student's use of his or her arms and hands? (circle one)
   - 1) Normal or no limitations in daily activities
   - 2) Some daily activities limited
   - 3) Most daily activities limited
   - 4) Don't know
6. Of the following choices, which best describes this student's mobility or movement throughout the school building? (circle one)
   - 1) Walks by self with no assistive devices (cane, walker, crutches, etc.)
   - 2) Walks by self with assistive devices (cane, walker, crutches, etc.)

3) Usually in a wheelchair
4) Limited or confined to specially designed chair or bed most of the day
5) Limited or confined to specially designed chair or bed for entire day
6) Don't know

7. Of the following choices, which best describes this student's behavior in typical educational and social settings? (circle one)
   1) Normal behavior, with no limitations in daily activities
   2) Minor behavior problems, with no limitations in daily activities
   3) Moderate behavior problems, with some limitations in daily activities
   4) Severe behavior problems, with many limitations in daily activities
   5) Don't know

a. Items 1 to 6 are from *Inventory for Client and Agency Planning,* by R. Bruininks, B. Hill, R. Weatherman, and R. Woodcock, 1986, Chicago: Riverside. Copyright © 1986 by Riverside Publishing Co. Adapted with permission.

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References

Algozzine, B. (1992). *Including students with disabilities in systemic efforts to measure outcomes: Why ask why?* Minneapolis: National Center for Educational Outcomes.

Bruininks, R., Hill, B., Weatherman, R., & Woodcock, R. (1986). *Inventory for client and agency planning.* Chicago: Riverside.

Bruininks, R., Thurlow, M. L., & Ysseldyke, J. E. (1992) Assessing the right outcomes: Prospects for improving education for youth with disabilities. *Education and Training in Mental Retardation, 27*(2), 93–100.

Heller, K. A., Holtzman, W., & Messick, S. (1982). *Placing children in special education: A strategy for equity.* Washington, DC: National Academy Press.

Hobbs, N. (1975). *Issues in the classification of children.* San Francisco: Jossey-Bass.

Ingels, S. J. (1991, April). *The problem of excluded baseline students in a school-based longitudinal study: Correcting national dropout estimates and accommodating eligibility change over time.* Paper presented at the annual meeting of the American Educational Research Association, Chicago.

Lipsky, D. K., & Gartner, A. (1989). *Beyond separate education: Quality education for all.* Baltimore: Brookes.

McGrew, K. S., Algozzine, B., Ysseldyke, J. E., Thurlow, M. L., & Spiegel, A. N. (1993). *The identification of people with disabilities in national data bases: A failure to communicate* (Technical Report 6). Minneapolis: University of Minnesota, National Center on Educational Outcomes.

McGrew, K. S., Spiegel, A. N., Thurlow, M. L., Ysseldyke, J. E., Bruininks, R. H., & Shriner, J. G. (1992). *Outcomes for children and youth with disabilities: Secondary analysis of national data collection programs* (Working Paper 3). Minneapolis: University of Minnesota, National Center on Educational Outcomes.

McGrew, K. S., Thurlow, M. L., Shriner, J. G., & Spiegel, A. N. (1992). *Inclusion of students with disabilities in national and state data collection programs* (Technical Report 2). Minneapolis: University of Minnesota, National Center on Educational Outcomes.

Odden, A. (1990). Educational indicators in the United States: The need for analysis. *Educational Researcher, 29*(5), 24–28.

Pope, A. M., & Tarlov, A. R. (Eds). (1991). *Disability in America: Toward a national agenda for prevention.* Washington, DC: National Academy Press.

Spencer, B. D. (1991). *Eligibility/exclusion issues in the 1990 Trial State Assessment.* Evanston, IL: Northwestern University, Methodology Research Center, NORC.

Stainback, S., Stainback, W., & Forest, M. (1989). *Educating all students in the mainstream of regular education.* Baltimore: Brookes.

U.S. Department of Education. (1992). *Fourteenth annual report to Congress on the implementation of the Individuals with Disabilities Education Act.* Washington, DC: Author.

Ysseldyke, J. (1987). Classification of handicapped students. In M. C. Wang, M. C. Reynolds, & H. J. Walberg (Eds.), *Handbook of special education: Research and practice* (Volume 1, pp. 253–271). Elmsford, NY: Pergamon.

Ysseldyke, J. E., Algozzine, B., & Thurlow, M. L. (1992). *Critical issues in special education.* Boston: Houghton Mifflin.

Ysseldyke, J., Thurlow, M., Bruininks, R., Gilman, C., Deno, S., McGrew, K., & Shriner, J. (1992). *A conceptual model of educational outcomes for children and youth with disabilities* (Working Paper 1). Minneapolis: University of Minnesota, National Center on Educational Outcomes.