

# Need for Demographic Data Standardization: Report of the Ad Hoc IASSID Working Group on Aging-Related Demographic Studies Data Standardization<sup>1</sup>

## BACKGROUND

The International Association for the Scientific Study of Intellectual Disabilities (IASSID) recognized that many large-scale population studies are published which fail to report demographic and epidemiological data in a manner that helps specifically identify the characteristics of the study population which can be useful for both replication and comparisons across studies. For example, definitions of study populations are often not reported, age categories may not be consistently used or lack internal coherence, study instruments lack basic demographic questions, and core elements typical of minimum data sets are not reported. Thus, IASSID charged an ad hoc working group to examine such studies and recommend minimal data that should be included. The group was asked to recommend data elements that could be used as the basis for designing and reporting subject information under a variety of study and cultural situations, and which could help with standardizing data collection and reporting across different types of studies.

## ISSUES RELATED TO STANDARDIZATION

### *General Impediments and Recommendation for Standardization*

Problems arise when studies report variations of data which lack consistency or when the ability to evaluate results across studies is impaired because the core data elements lack definition, precision, or objective validation. These result from the following problems.

<sup>1</sup>The Ad Hoc IASSID Working Group on Demographic Studies Data Standardization met for the purpose of developing a set of working guidelines for the reporting of demographic data in studies related to intellectual disabilities and aging – however, these guidelines are applicable to studies involving any age group. The group met twice and also corresponded within the Internet. The first meeting was held at The Forum Conference Center (9 Delgiorgi Street) in Volos, Greece, in conjunction with the 13th annual roundtable of the IASSID Special Interest Research Group on Aging (SIRGAID) and the second meeting was held at the Segedunum (Buddle Street, Wallsend) in Newcastle, England under the sponsorship of the School of Health, Community and Education Studies at the Northumbria University.

*Problems stemming from study designs* Designs that do not include standard age groupings and definitions of disabilities being assessed; inherent difficulties with measuring or defining certain disabilities; the lack of international measures for comparing data or agreement on standard definitions; problems evident from using functional vs. categorical definitions and not defining terms operationally (e.g., learning disability, functional disability, intellectual disability, etc.); and confusion stemming from the use of poorly articulated or defined concepts.

*Problems stemming from publications* Inconsistency among journal requirements with regard to precision in reporting data and defining terms and concepts; authors not using standardized lexicons that can guide work, such as the World Health Organization's International Classification for Diseases-9 (ICD-9), or American Psychiatric Association's Diagnostic and Statistical Manual-IV (DSM-IV); and problems inherent in conducting meta-analyses when terms and data elements in published work are not comparable.

Thus, to minimize difficulties, studies involving populations of adults with intellectual disabilities should endeavor to contain, at minimum, core data elements that provide information on age, sex, disability, functional ability, accommodation, context, culture, and socio-economic levels (SES). Further, as there are often inconsistencies in language and use of concepts, terminology should be harmonized, and authors should include operational definitions of key concepts, terms, and processes.

### *Use of Age Groupings and Defining Disability and Carers*

*Reporting ages* Inconsistencies in reporting ages is a problem, as there are many variations of what is meant by aging people and old age. Definitions of old age are not consistent and biological and social ages are always difficult to define and operationalize. Geriatric issues' researchers often use 60 or 65 and intellectual disability issues' researchers often use younger ages (such as 40, 45, or 50) in defining the beginning of older age. Further, researchers' definitions of older populations may be influenced by political or economic situations. For example, cutoff ages may stem from *public policy* (e.g., national funding schemes for pensioning or legislative factors – as in the United States and the use

of age 60 as the point of eligibility for Older Americans Act services), may reflect *public health realities* (as in some developing economy countries which lack public health services and have low adult survival rates; studies from such developing countries often define older people with intellectual disabilities as those in the 30s and 40s), or result from *political contingencies* (e.g., in countries where war or other turmoil may have adversely affected the survival of certain generational groups or people with atypical attributes).

Standard age groups and reporting of age ranges as well as mean and median ages should be part of any study involving a substantial number of subjects. This would apply to study subjects, irrespective whether they are individuals with disabilities or carers. Grouping by standard 5- or 10-year age groupings would permit others to collapse categories if they wished for comparability. An explanation should be provided for the starting age and the use of the age categories.

*Reporting disability* Studies about people with disabilities often lack definition of the disability or disabilities being studied. This poses a problem when certain disabilities or conditions have vague parameters or are defined differently across countries.

When studying people with disabilities, it is useful to define the disability as clearly and precisely as possible for comparative purposes. The World Health Organization's International Classification of Functioning (ICF) and ICD-10 and the American Psychiatric Association's DSM-IV could be used in defining functional ability (recognizing the ICF's limitations as it applies primarily to physical and not intellectual disabilities).

*Reporting carers* Family research involving "older carers" is another area that provides great variance and confusion. Often researchers fail to define what age groups are included in their category of older carers. Studies also fail to provide standard data such as SES of the participants, their educational levels and relationships, and pertinent cultural or heritage identifiers.

Thus, when reporting data in studies involving carers, it is useful to define relationships of the carers to the people in the study, as not all may be parents. Defining what is meant by "family" is also important as cultural differences may determine who is defined within the family. SES in terms of either "employment/profession" or "income" and educational level of family carers (possible as "years of education") should be included. The structural aspects of "family" should be defined operationally (e.g., one or two parents or others, number of children, people under the same roof, etc.). Family should also be defined in cultural or heritage terms (for example, in some cultures, family is defined quite broadly – e.g., by who is living in the town). Race, when referring to color of skin, should not be used as a substitute for culture, heritage, or country of origin, whenever possible. Although definitions do depend on what the study was designed to accomplish, if appropriate, they should be included for sake of clarity and comparability.

Given the wide disparity in what is meant by older people, disability, and who are carers, reported ages should reflect standard age groupings, disabilities of persons under study should relate to common definitions in use or be operationally defined, and carers should be defined in the context of culture, status, relationships, and the household.

#### *Sex- or Gender-Related Variables*

Confusion may arise when sex or gender of subjects is not reported (sex defines whether the person is male or female; gender defines the social or cultural factors associated with sex). Parsing by sex or gender is helpful in looking for sex-linked differences within the study population. With regard to sex of subjects, studies should always provide a breakdown of males and females (providing both number and percent). Gender factors should be included when relevant to a better understanding of the subjects or their culture.

#### *Accommodation Variables*

Accommodation variables, that is, living arrangements (size, setting, etc.) and locational factors (urban, rural, etc.) are rarely defined and their omission often causes problems in interpretation of data. Confusion arises when local terms for specialty accommodations (e.g., "host homes") are used and not defined. Often idiosyncratic definitions may not apply universally (e.g., "group home" in one culture may denote a residence for three to four people, while in another culture may be a 50-bed residence). Often contextual variables are not presented as to the nature and purpose of the residence, the character of the residents, and factors that may influence function in the home.

Operational definitions of an accommodation should include the number of people living under one roof, the configuration of setting (singular or multiple residences in the site), character of residence (locational and physical building), type of care or support system provided, staffing patterns (live-in or drop in support), staff qualifications or educational level, and characteristics of the other residents. In all instances, reports should use descriptive not labeling language (if labels are used, they need to be defined in operational terms). For example, when studies use the term "nursing home," questions of comparability arise and readers may wish to know whether residences are licensed, whether privately or publicly owned or operated, and whether they fall under some form of government supervision for quality. Also, when parsing data on accommodations, defining the unit of analysis helps in understanding better how the data were derived.

Thus, when reporting residential accommodation variables, information should be provided on number of people living under one roof, the configuration of setting (singular or multiple residences in the site), character of residence (locational and physical building), type of care or support system provided (i.e.,

live-in or drop-in support), and characteristics of the other residents.

#### *Other Factors or Variables*

*Social policies* Confusion often arises when reports use social policy terms (such as social security, pensioning, health scheme waivers, nation-specific social insurance schemes) and do not explain the context of these terms, the citation for the enabling legislation, function of the program, or who are the eligible participants. Such terms and factors should be defined or explained.

*Geography* Often studies fail to define the geography of the catchment area from which their study populations were drawn. When defining study geographic areas, researchers should define the area using such factors as density of the population, population size, location (city, nation, region), and other factors that help identify the characteristics of the environment from which the population has been drawn. This information is important when population prevalence factors are integral to the study.

*Cultural, ethnic, and other contextual factors* When including subject heritage variables, researchers should identify the cultural (customs, institutions, and achievements of a particular nation or people) and ethnic (common national or cultural traditions) features of the study population and clarify the meaning of the factor within that culture. Referring to groups of people by race, residence, and other artificial factors often provides little in terms of placing them in a context of their beliefs, values, and other attributes which may be telling in terms of the study findings.

Similarly, this applies to SES, educational level, and other contextual background information. In family studies, it is help-

ful to operationally define SES and cultural background as such variables help more clearly define the study group. This factor is important in studies where these issues may affect the outcome or interpretation of the study. The definition of SES can be by income, education, or other social status level.

Thus, when including contextual variables (culture, ethnicity, SES, etc.) in a study because these have an ostensible bearing on the outcomes or results, such factors should always be defined as much as possible, so as to advance comparability and replicability.

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