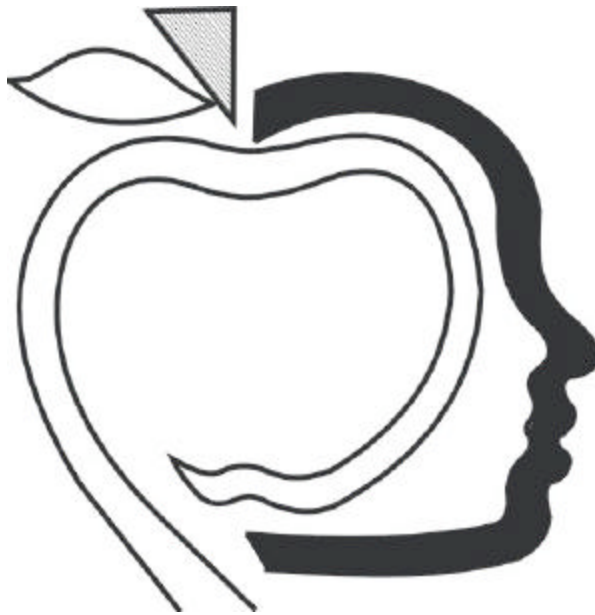


# **The Tampa Scientific Conference on Intellectual Disability, Aging, and Health**

## **Final Report**

**An International Meeting to Develop Recommendations for  
Future Research and Define Salient Areas for  
Medical Concern and Surveillance**



December 7-9, 2002

Tampa, Florida

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## **Logo Design**

Mehmed and Olivera Sisirak

## **Contact Information**

For additional copies contact

The Clearinghouse on Aging and Developmental Disabilities

Rehabilitation and Research Training Center on Aging with Developmental Disabilities

Department of Disability and Human Development

University of Illinois at Chicago

1640 West Roosevelt Road

Chicago, IL 60608-6904

URL: [www.uic.edu/orgs/rrtcamr/](http://www.uic.edu/orgs/rrtcamr/)

Voice: 800-996-8845

TTY: 800-526-0844

Fax: 312-996-6942

Email: [rrtcamr@uic.edu](mailto:rrtcamr@uic.edu)

# The Tampa Scientific Conference on Intellectual Disability, Aging, and Health

## Background

Adults with lifelong intellectual and developmental disabilities are a significant segment of the population of adults with disabilities in the United States. They represent a population that is the focus of significant state legislative activities and mandated services. They also represent a group of individuals with a broad range of impairments, physical conditions, and special health needs.

Over the past decade, the United States government has recognized the need for additional research on aging among adults with intellectual and developmental disabilities. In 1989, a program announcement [NIH Guide, 18 (19), June 2, 1989] was issued calling for applications focused on adults with developmental disabilities, as they grew old. The announcement emphasized the need for research in five areas, including demography and epidemiology, adaptive functioning, social interactions and family support, intervention strategies, and service and care models. The announcement addressed neither health-related studies nor fundamental biological research.

In the intervening years, the urgency for information about older adults with intellectual disabilities has intensified with new hypotheses emerging about the interactions of aging and lifelong disability. A new look at the need for additional

research is in order. This increasing need for new information about the health status of this population was one of the main findings of a report prepared by a working group led by the International Association for the Scientific Study of Intellectual Disability (IASSID) at the behest of the World Health Organization (WHO).<sup>a</sup> That report focused on identifying health issues among adults with intellectual disabilities that should be of concern to policy makers. The report and its findings were published both by the WHO (and posted on its web page) as well as reproduced in a special issue of the *Journal of Applied Research in Intellectual Disabilities*.<sup>b</sup> In addition, the IASSID produced three books resulting from its work for the WHO, published by Blackwell Publishing in 2002 and 2003.<sup>c,d,e</sup> These IASSID-WHO materials summarized the health-related research issues facing this field internationally, but did not propose a specific research agenda for the United States.



<sup>a</sup> World Health Organization. (2000). *Healthy aging – Adults with intellectual disabilities: Summative report* (WHO/MDS/HPS/MDP/00.3). Geneva: Author.

<sup>b</sup> The IASSID papers – Toward a rationale strategy for promoting healthy aging amongst people with intellectual disabilities. (2001). *Journal of Applied Research in Intellectual Disability*, 14, 171-275.

<sup>c</sup> Walsh, P & Heller, T. (Eds). (2002). *Health of Women with Intellectual Disabilities*. Oxford: Blackwell Publishing.

<sup>d</sup> Prasher, V.E. & Janicki, M.P. (Eds). (2002). *Physical Health of Adults with Intellectual Disabilities*. Oxford: Blackwell Publishing.

<sup>e</sup> Davidson, P., Prasher, V.E. & Janicki, M.P. (Eds). (2003). *Mental Health, Intellectual Disabilities, and the Aging Process*. Oxford: Blackwell Publishing.

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In 2001, the United States Public Health Service sponsored two important meetings dealing with physical and mental health issues in persons with intellectual disabilities. The first was a workshop on emotional and behavioral health sponsored by the National Institute of Health (NIH) and cosponsored by the Joseph P. Kennedy, Jr. Foundation.<sup>f</sup> The second was the United States Surgeon General's meeting on health disparities and intellectual disabilities.<sup>g</sup> Both meetings dealt with important research questions, but largely excluded discussion of aging issues.

## Purpose

The Tampa Scientific Conference on Intellectual Disability, Aging and Health was organized to extend the WHO report process and the results of the two 2001 United States Public Health Service meetings, and to convene a team of experts in the area of aging and intellectual disabilities (ID) to develop a research agenda for health and mental health outcomes in older persons with intellectual disabilities. Biomedical, translational, and clinical research issues were discussed by some 75 attendees from the United States and ten other nations, representing universities, government agencies, national organizations, research institutes, health provision centers, families, and adults with ID.

The conference goal was *to identify and encourage studies that enable the prediction, diagnosis, or prevention of emerging secondary age-related physical and mental health impairments in older individuals with intellectual and developmental disabilities (I/DD).*

## Hosts and Sponsors

The meeting, held December 7-9, 2002, was organized by a consortium made up of the Strong Center for Developmental Disabilities and the Geriatric Education Center, University of Rochester School of Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department on Disability and Human Development, University of Illinois at Chicago, the Florida Policy Exchange Center on Aging and the Institute on Aging, University of South Florida, and the Center on Excellence in Aging at the University at Albany (New York). Funding and



<sup>f</sup> N.I.H. (2001). *National Institute of Health workshop on emotional and behavioral health in persons with mental retardation/developmental disabilities: Research challenges and opportunities*. [http://drafty.ninds.nih.gov/news\\_and\\_events/emotional\\_behavioral\\_health\\_2001.htm](http://drafty.ninds.nih.gov/news_and_events/emotional_behavioral_health_2001.htm).

<sup>g</sup> U.S. Public Health Service. (2002) *Closing the Gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation – Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. Washington, DC: Author.

planning support for the meeting was provided by grants from the Centers for Disease Control and Prevention, the National Institute of Aging, the National Institute of Child Health and Human Development, the National Institute of Disability and Rehabilitation Research, the Association of University Centers on Disabilities, and the Upper Pinellas Association for Retarded Citizens, Inc. (UPARC).

Additional supporters and sponsors included the International Association for the Scientific Study of Intellectual Disabilities, the American Association on Mental Retardation, Division 33 (Mental Retardation and Developmental Disabilities) of the American Psychological Association, the Joseph P. Kennedy, Jr. Foundation, The Arc of the United States, the Association of University Centers on Disabilities, the U.S. Office of Disabilities, the U.S. Administration on Aging, the U.S. Administration on Developmental Disabilities, and the Mailman Center at the University of Miami School of Medicine.

## Format

The conference was divided into three topical sessions addressing (1) medical and epidemiological issues (2) syndrome-specific health compromises, and (3) benchmarks for healthy aging. Each session consisted of invited lectures addressing specific core questions. Following each session, delegates divided into small groups of about 25 participants each to explore and discuss gaps in current knowledge related to their topic. Summaries of the small group discussions served as the basis for a consensus discussion during the final plenary

session. The small groups were asked to discuss fundamental, translational, and clinical research needs, to consider biological, behavioral-social, and public policy research issues, to include health and mental health topics, and to preserve an international focus.

## Assumptions

A number of assumptions formed the basis for deliberations and conclusions drawn at the Tampa Conference. These assumptions were based on the relatively large literature on the aging process, and from the much smaller body of knowledge on aging with disabilities.

***Aging Processes.*** There is some evidence to support an assumption that for most adults with lifelong disabilities aging qualitatively follows the same stages and is affected by the same factors as in the general population irrespective of the presence of an intellectual or developmental disability. Variations in the pattern of aging seen in some persons with intellectual disabilities may occur relative to persons without such lifelong disabilities, but these variations seem to be the result of environmental factors and practices, rather than any fundamental difference in biological processes. On the other hand, these data may be an artifact of lack of information on etiology of disabilities and the consequent congregation of people with various unidentified syndromes, as well as biological factors related to successful aging and vulnerability to specific age-associated diseases or impairments.

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Whenever syndrome-specific health problems are examined, different syndromes are found to have a distinct set of co-morbid conditions. These syndrome-specific co-morbidities can present at different ages, and result in different patterns of aging. Intellectual disabilities appear to be etiologically heterogeneous. Many individuals with neurodevelopmental disorders have associated neurological, endocrine and metabolic disorders, and organ system morbidities. Since organ systems age at different rates, it is likely that the spectrum of age-related disease or the age at onset of disease will be different from that in the general population. This is a rationale for (1) determining etiological factors in people with intellectual disabilities and (2) conducting research specifically directed to determining the patterns of aging in people with intellectual or developmental disabilities.

**Reference to Aging.** The scientific fields of geriatrics and gerontology are developing a body of information within which data on aging in persons with intellectual disabilities should be a subset. It would be theoretically counterproductive and fiscally inefficient to establish and expand scientific inquiry on aging and intellectual disabilities independent of this substantial body of scientific information.

**Age Span Approach.** There is a growing body of evidence that all forms of aging, whether *pathological*, *normal*, or *successful* have their foundations in factors and events occurring at younger ages. Studies are needed to determine the specific relationships and correlates between

younger and older age-related conditions, and on the identification of early markers for later outcomes. Prevention and health promotion practices (which are essential at all ages and for all persons) will depend upon knowing risk factors and how they can best be identified in persons with intellectual disabilities.

**Diversity.** As is the case for patterns of growth and development in younger age persons, there is much diversity among older persons and their families. Studying factors that may determine individual differences in the course of the aging process among persons with intellectual disabilities may be more informative than studying the typical indicators of aging derived from studies of older persons without such lifelong disabilities. A comprehensive, inclusive and bio-behavioral theory of aging must account for such variances. Having such a theory will accelerate future research.

**Social Valuation of Research.** As a research agenda is developed, there is a general need to address relevant issues valued by persons with disabilities and their families. Research planned and conducted in an environment of limited resources should meet the test of relevance to the priorities and needs of persons with disabilities. Therefore, persons with disabilities and their families should have clearly defined means of participating in the process of setting the research agenda.

**Multidisciplinary Approach.** Gerontological science is multidisciplinary because the nature of the problem is multi-dimensional. Adding the dimension of lifelong disability to research on aging and health makes the problem only more complex. It is therefore necessary for us to encourage a multidisciplinary approach to hypothesis development and scientific studies.

## Principal Findings

Research on healthy aging among older adults with intellectual disabilities is a relatively new field. Its products have been reaching the scientific literature only since the mid-1980s. In many ways, these products were, and continue to be a reflection of the interests of the handful of scientists who have been working in the field, and tend to cluster around a small number of questions. No comprehensive research agenda has ever been promulgated for the area. In some respects, this situation is no different from what occurred in the early years of research that addressed younger populations of persons with intellectual or developmental disabilities. The application of principles and practices derived from the field of geriatric medicine offers new opportunities to optimize the healthy aging of adults with lifelong disabilities.

Adults with intellectual disabilities constitute a growing population, increasing in numbers proportionate to the general population that is also experiencing enhanced longevity. By the year 2040, about 25% of the general population will be over age 60, compared with about 12% today; a similar trend is expected for persons with intellectual disabilities. Moreover, although the most rapidly growing segment of the general population consists of people over age 80, it is expected that the cohort age 60 to 70 would comprise the largest segment of older persons with intellectual disabilities. With timely research focused on key questions about the biological, behavioral, and social consequences on health and mental health, we may put the next generation of scientists and clinicians into the position of being able to prevent many age-related diseases and functional impairments, and to promote healthy aging for the future increased population of elderly persons with lifelong disabilities.

By the year 2040, about 25% of the general population will be over age 60, compared with about 12% today; a similar trend is expected for persons with intellectual disabilities.

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## ***Basic Research in Health and Aging.***

Research on the social and biological aspects of aging is developing in parallel with major advances in molecular biology and the neurosciences. Human molecular genetics promises to enable new models of aging and the underlying causes of age-related health compromises. Basic research will emphasize the interactions that occur among multiple genetic factors (gene-gene interactions) as well as those that occur between genetic and environmental factors. These scientific opportunities should extend to older adults with a lifelong disability, perhaps affording accelerated advances in the prevention or treatment of specific organ system diseases.

Human molecular genetics promises to enable new models of aging and the underlying causes of age-related health compromises.

Other dramatic advances have been occurring in the neurosciences. Our understanding of brain structure and function has been expanding rapidly in recent years, in part due to the developments in molecular biology just described, but also because of the increasing precision of imaging technologies and the availability of relatively

inexpensive and powerful computers. Comparable advances are also occurring in the cognitive sciences, where detailed aspects of performance and emotion are being related to specific brain mechanisms. All these research developments now provide us with new and emerging opportunities to gain a fundamental understanding of the effects of aging on individuals, both with and without ID.

What are the key issues of concern, issues for which answers would clear the way to more comprehensive health practices and policies for older persons with intellectual and developmental disabilities? Ideally, we should be able to predict emerging conditions, impairments, and disabilities. For instance, we should be able to predict the timing and/or occurrence of specific clinical risk factors for diseases before these diseases occur. We should be able to monitor physical or mental health-related medical problems effectively in individuals with intellectual disabilities. For instance, more effective approaches are needed to identify persons with medical problems who have poor communication and self-assessment skills. We must be in a position to deter the onset of secondary conditions and prevent new disabilities through the early use of non-invasive, cost-effective screening and diagnostic technology. We must learn about ways environmental and behavioral factors experienced by people with intellectual or developmental disabilities influence health outcomes.

We must better understand the family context of developmental disability, including ways in which life-long caregiving may affect family members' health and well-being. Research is needed to improve family members ability to plan for the long term care of persons with developmental disabilities under their care.

The foundation for these developments will come, in large part, from epidemiological studies. A fundamental question relating to healthy aging is to know the extent to which presenting problems are secondary to specific co-morbidities and clinical signs related to the disorder itself or related to environmental factors; including personal-social interactions, dietary factors, living conditions, daily rhythms, and exposures to environmental toxicants. Large-scale case-control studies, prospective cohort studies and database analyses typically useful in addressing such questions are not widely available in the field of aging and intellectual disabilities.

***Health, Medical Care, and Aging.*** Change in efficacy and availability of medical care for older persons with intellectual disabilities over the past 20 to 30 years makes it difficult to predict the aging-related issues of children and young adults with intellectual and developmental disabilities. People who are now 30 years of age will probably not age the same way as people who were 30 years of age 20 or 30 years ago. Also, adults with intellectual disabilities who typically participate in research studies may not be representative of all relevant

lifestyles and settings. Specifically, there has been a lack of participation by persons who have never received services from either the developmental disabilities or mental health systems. Such cohort effects should be studied and their effects on individual differences in aging defined.

There is an acute lack of prospective cohort studies. Most studies of health status in older people with intellectual disabilities are cross-sectional and also tend to focus only on later life conditions. Recognizing that longitudinal studies are expensive, there still are compelling epidemiological reasons to undertake at least some incidence and outcome studies that follow the same cohort over multiple years. Such studies might be multi-site and should include not only assessments of the person with developmental disabilities, but also family members who may be impacted by their condition. Given that many age-related concerns affect a minority of individuals in any sample, large samples of participants should be recruited.

Important answers may be found in careful analyses of specific intellectual disability syndromes, especially in light of recent advances in molecular genetics. For example, the Human Genome Project is likely to generate rapid advances by determining the etiology and genetic loci and specifying the pathogenesis of single gene defects and other polymorphisms that cause select syndromes, ascertaining structure and function of the gene

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products, delineating the effect of these proteins on multiple organ systems during development and aging, and eventually permitting the application of gene therapies. Some major co-morbid conditions, (e.g., epilepsy, sensory impairment, neurodegenerative disorders) require priority research since the frequency of such co-morbidities is clearly different from that in the general population and the impact on healthy aging may be substantial.

Data that may derive from postmortem studies or from studies of adults involved in medical practice and treatment may prove to be important. Therefore, organ donations for research can provide scientists with needed tissue samples. Needless to say, any such gift should be made only with the willing consent of the donor and this consent process must be handled with the utmost sensitivity to all people, including persons with intellectual or developmental disabilities and their families. In general, proscriptions for the participation in human research of persons with intellectual disabilities have bases in historically abusive practices, but with contemporary controls on informed consent, regulations, and policies should be altered to encourage participation in research. At the same time practices of evaluating comprehension of informed consent among adults with intellectual disabilities have been understudied and should be a priority for applied research.

Healthy aging is supported not only by biological factors, but also by a host of cognitive, social, environmental, and behavioral factors, all of which may be poorly understood in older adults with intellectual disabilities. Healthy aging has several components, which include avoiding disease and disability, maintaining high cognitive and physical function, and effectively engaging in rewarding activities. Can the components of healthy aging be readily applied to persons with intellectual disabilities as aptly as they are applied to persons without such disabilities? If so, what are the strategies and interventions needed to optimize their occurrence in persons with intellectual disabilities who are free of physical impediments?

We need to provide for and give greater attention to research addressing a range of health, social and psychological factors related the aging and adult development of persons with intellectual disabilities. However, substantial increases are needed in public and private funding for research in this area if progress is to be made in a timely fashion. At the same time, resources are urgently needed for training of new researchers.

It is important to evaluate the uses of valuable research resources to determine if better outcomes would result from more targeted applications and concentrations on specific problems. In the United States, for example, aging and intellectual disabilities research responsibility

has been funded by numerous governmental and non-governmental agencies; there is no comprehensive or coordinated funding agenda. A more coordinated or unified approach to defining priorities for research funding might focus efforts on the most important problems.

## From Findings to Recommendations

### *Medical and Epidemiological Issues.*

Developing best practices for promoting healthy aging and longevity and preventing avoidable morbidity depends upon:

- (1) defining morbid conditions; and
- (2) establishing accurate and relevant baseline data for older persons with intellectual disabilities. There is also a need to determine risk factors and biomarkers that can predict and modulate disease burden. Research is needed to establish the course and trajectory of healthy aging as well as age-associated problems in people with intellectual disabilities. Variations in these trajectories are most likely due to both genetic and environmental factors but the mechanisms are not well understood. Predictive biomarkers, protective factors and risk factors, including those present early in life, that influence the expression of disease in older age in people with intellectual disabilities should be identified and catalogued. Genetic and environmental interactions that cause behavioral disorders and mental illness must also be

identified. Data from the Human Genome Project should be used to tie genetic determinants of aging profiles to specific impairments associated with intellectual or developmental disabilities. Molecular genetics research should be extended to studies of lifespan physical and mental health. At the same time, emphasis should be placed upon defining the social ecology related to health outcomes.

Research is needed to establish the course and trajectory of healthy aging as well as age-associated problems in people with intellectual disabilities.

Epidemiological data are needed on incidence and prevalence of health and mental health morbidity. There are some serious obstacles to research on aging in people with intellectual disabilities. There is etiological heterogeneity (including unknown etiologies for intellectual disability); it is difficult to assemble etiologically homogeneous samples for study for all but the most common syndromes. Research addressing rare conditions will require multi-site studies. For about

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half of the people with intellectual or developmental disabilities, the cause is unknown. Lumping them together as intellectual disabilities will inevitably make it hard to discover any syndrome specific patterns of aging and risk for specific co-morbid conditions.

There is inconsistency across states within the United States in methods for collecting and reporting diagnosis and prevalence data. There are also concerns about precision of diagnoses in different systems of care, leading to detection bias. Cost effective and well-tolerated sensitive and specific instruments are needed to improve population studies of diagnostic prevalence and evidence-based practice. More data are needed to clarify the association between severity of intellectual or developmental disability and disease burden.

Epidemiological studies should also focus on identification of risk factors and biomarkers for the most frequent health conditions that may appear in older age and that threaten maintenance of independence. Many of these conditions appear to be more prevalent in persons with intellectual or developmental disabilities and may be preventable.

In the broader field of gerontology, aging is often studied in a family context. Life-long developmental disability presents significant challenges for family members who have varying degrees of responsibility for care of aging persons

with developmental disability, ranging from long-term in-home care to support while their relatives receive care in a long-term care facility.

***Syndrome-specific Concerns.*** Ideally, scientific studies should increase our understanding of the biomarkers associated with intellectual and developmental disabilities. In turn, more causes of disabilities will be known and more variation due to specific causes will be identified. Then, our objectives should be to (1) identify syndrome specific patterns of aging and age-related health risks; (2) identify risk factors and biomarkers associated with specific syndromes; (3) determine the underlying pathogenic mechanisms; (4) determine the interactions between the biology of the condition and social and environmental settings; and (5) develop targeted interventions to prevent loss of functions and preserve active life expectancy.

There are two complimentary approaches that are needed regarding research on syndromes associated with intellectual disabilities. First, there is a need for basic scientific studies where the syndrome is associated with increased risk for a specific concern. For example, the relation between Trisomy 21 (leading to Down syndrome) and mid-life emergent dementia of Alzheimer's type (DAT) has been an important focus for basic studies for many years. There are several other promising emergent directions for this type of research, including potential links between a syndrome of

ataxia/dementia in male carriers and pre-mutation of the Fragile X gene. These studies not only inform us about the early and frequent appearance of DAT in adults with Down syndrome; they may also provide important clues to the origins of DAT in persons without lifelong disabilities. Research is also needed regarding the potentially protective characteristics conferred by certain syndromes, such as the lack of solid tumors and possible low rates of arteriosclerosis in persons with Down syndrome.

Second, clinical studies are needed that clarify strategies to treat or prevent downstream morbidity and mortality secondary to particular syndromes. For example, studies of older persons with cerebral palsy have demonstrated later life morbidity and coincidental functional declines that seem to be related to the long-standing effect of the movement disorder on the musculoskeletal system. Some of these declines may be potentially preventable. Recent studies of older persons with autism spectrum disorders, including Asperger and Rett syndromes, reveal preventable late life emergent threats to health maintenance and social isolation. There is an emerging concern for more research on later life consequences of many other more uncommon (or low incidence) syndromes caused by single gene defects, including PKU, Prader-Willi syndrome, and Smith-Lemli-Opitz syndrome. Finally, there may be important interactions between the expression of specific syndromes and environmental factors.

There is evidence that disparities in medical and mental health among persons with syndromes leading to intellectual disability may be associated with exposures to environmental neurotoxicants and lifelong use of medications, and with social and cultural factors, gender, and family history. Little data are available to explain these associations.

**Promoting Healthy Aging.** Systems research is needed to identify effective strategies for promoting healthy aging. We must identify barriers and facilitators for persons with intellectual disabilities to participate in health-promoting activities. For example, more models are needed for encouraging regular exercise, eating healthful diets, attending to regular health care checks, and seeking preventive mental health services (when appropriate). Research projects should focus on defining effective empowerment and self-determination strategies, on roles played by cost factors (e.g., availability of health insurance), on enhancing professional knowledge about risk factors for threats to successful aging, on enhancing environmental access to appropriate care, and on developing valid and reliable assessment tools.



<sup>h</sup> National Institute on Aging. (1987). *Personnel for the health care needs of the elderly*. Bethesda, MD: Author.

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There is evidence that family and health professional attitudes may influence health status through affecting access to and compliance with standard health care practices. This problem should be studied in older persons with intellectual disabilities. Research is also needed to determine methods to balance informed choices about health care against competing attitudes and values about evidence-based health promoting practices. The ethical and practice-based issues raised by these questions involve a lifespan approach. There is evidence that decisions about health practices that ensure healthy and successful aging may have to be made early in life.

The technology revolution may hold promise for improving healthy practices throughout the lifespan and may therefore have a positive impact on aging in persons with intellectual disabilities. There is already a substantial literature on technology assistance for persons with disabilities, but little of this research addresses changing needs of older persons and their carers. Research is needed on technology-driven strategies that improve environmental accessibility and adherence to healthy practices among people with disabilities.

Finally, longitudinal data resulting from studies on changes in physical and mental health across the older age spectrum should be coupled with data on health systems practices to determine models of effective preventive care in people with intellectual disabilities.

**Training Needs.** The serious shortage of qualified or interested research personnel poses a significant barrier to a successful expansion of research and practice in the field of aging and health as applied to people with lifelong disabilities. There is an urgent need to train new professionals who can address the growing health care demands of an aging population of people with lifelong disabilities. Correspondingly, there is an urgent need to train new scientists through existing mechanisms such as the NIH K-award system. Training in this discipline should be an increasing priority for all centers where there is a research capacity in aging or intellectual and developmental disabilities.

Ironically, not much has changed since 1987, when the National Institute on Aging issued its prescient report on the health care needs of elderly persons in the Year 2000.<sup>h</sup> The section on developmental disabilities in the NIA report called for a substantial increase in new professionals and training programs to create a critical mass of workers trained and experienced in aiding people with intellectual and developmental disabilities as they age. However, the need for highly trained professionals has not diminished. Governmental agencies should identify new mechanisms to enhance the availability of professional education and research training funds and provide direction and impetus to the university and service communities to devote more intramural resources to preparing and aiding an aging population. The NIH could establish this area as a priority for fellowship training.

Recognizing the need for new technologies and delivery systems, governmental agencies should encourage the exploration of models for effective community training related to aging, including methods for effectively training persons with disabilities who are aging as well as their carers. Models are also needed for practitioner training and evaluation of the effectiveness of that training. The model for specialized training in aging and intellectual or developmental disabilities introduced by the Administration on Developmental Disabilities within its University Centers of Excellence program in the 1980s if reactivated could begin to meet this need.

## **Perspectives of Persons with Disabilities and their Families**

**Consumer Concerns.** Persons with disabilities and family members at the conference contributed directly to discussions and recommendations for further research. Some of their health care concerns revolved around the doctor-patient communication, as physicians rarely take the time to explain various treatment options, purposes, dosages of medications and their side effects, or other medical procedures. Concerns were raised that physicians often talk to the companion or family members rather than the person with the disability. Another area of concern was relevant to adults having multiple impairments, including co-incident lupus,

asthma, hearing and vision problems, sleep apnea, arthritis, or seizures. Finding physicians who are willing to provide treatment for multiple medical issues is often problematic and it can be difficult for adults with intellectual or developmental disabilities to adhere to complex medication regimens. Finding information about how a condition can be treated is often difficult. For example, the presence of cerebral palsy may affect select internal functions, such as bowel and bladder function and breathing, but most physicians do not know the long term effects of cerebral palsy on organ systems or the concomitant risk for specific diseases. Also, aging often accelerates neurological and musculoskeletal problems among adults with cerebral palsy and most physicians are unaware of this association.

Family members find it difficult to encourage their adult offspring to exercise and eat properly resulting in the likelihood of improper nutrition and low levels of physical activity. Persons with disabilities with limited verbal skills have difficulty communicating medical problems within the family as well as to physicians. Persons with disabilities without supportive families may lack an individual to advocate for appropriate health care. Access to health care specialists with a background in treating older persons with intellectual or developmental disabilities is a major concern.

The cause of sudden death of people with intellectual or developmental disabilities is often not documented or even properly investigated.

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Transition to community living for a person with intellectual or developmental disabilities after the death of a parent is often not accomplished with sensitivity and patience.

## ***Future Research and Training Agenda.***

Suggestions about needed research included studying how medical practitioners, including physicians, nurses, and emergency room personnel, could be better trained regarding communicating with a person with an intellectual or developmental disability, including how to relay information in more easily understood language. Further related to practices, information discussed during the medical appointment should be directly communicated with the person with the disability, and health care professionals should take the time to listen to people and communicate in ways they can understand. Health care professionals also need information on potential medical complications and secondary conditions that can occur with the presence of a lifelong disability. Curricula on these topics should be developed and infused in educational programs for primary care physicians and other allied health care personnel. Family members and carers also need more accessible information about secondary conditions that can occur with the presence of an intellectual disability and what can be done to enhance their prevention and management.

Research should address more effective means of communicating health-related information to people with disabilities and to assist families to

effectively communicate about health problems with their sons or daughters with disabilities.

Study participants often represent samples of convenience and are over-representative of persons living in congregate care settings. More effort needs to be made to include persons with disabilities who reside with families or who live independently, i.e., outside of group homes or institutions given that only a minority of people with intellectual disabilities live in group homes or institutions. Although it is clearly recognized that data on persons with disabilities living with families are much more difficult to collect, this artifact of convenience research needs to be rectified.

## **Summary and Recommendations**

The Tampa Scientific Conference on Intellectual Disability, Aging and Health was held December 7-9, 2002 with the explicit purpose of identifying and encouraging studies that predict, diagnose, or prevent emerging secondary age-related physical and mental health compromises in older individuals with intellectual and developmental disabilities. The participants included 75 attendees from the United States and ten other nations, representing universities, government agencies, national organizations, research institutes, health provision centers, families, and adults with intellectual and developmental disabilities. The meeting was organized by a consortium of several

leading universities with specialty centers in aging and/or intellectual and developmental disabilities and was underwritten by a number of federal research institutes and agencies, as well as private foundations and organizations.

Adults with intellectual and developmental disabilities are a growing population, increasing in numbers proportionate to the general population that is also experiencing enhanced longevity. With timely research focused on key questions about the biological, behavioral, and social consequences on health and mental health, we may put the next generation of scientists and clinicians into the position of being able to prevent unnecessary and preventable age-related diseases, functional declines, and promote healthy aging for a larger number of older persons than now possible, well in advance of the expected changes in population demographics.

**Research Recommendations.** Research on healthy aging and intellectual and developmental disabilities must closely relate and be inextricably interwoven into research in gerontology, geriatric medicine, and eldercare in general. Research on the social and biological aspects of aging with intellectual or developmental disabilities must develop in parallel with major advances in genetics and molecular biology and neurosciences.

Programmatic research should be encouraged in several areas, including:

- Identification of underlying causes of age-related functional decline and disease onset that occur in some genetic syndromes. Clarification of molecular biological contributions to syndrome-specific differences in the aging process may clarify questions about aging in general.
- Determination of potentially protective characteristics against common physical or mental health morbidities related to the aging process that may be conferred by certain syndromes.
- Identification of barriers and facilitators for persons with intellectual and developmental disabilities to participate in health-promoting activities, such as engaging in regular exercise, eating healthful diets, attending to regular health care checks, and seeking preventive mental health services.
- Development of valid and reliable assessment instruments and protocols.
- Determination of the course and trajectory of healthy aging in people with intellectual and developmental disabilities through both longitudinal and cross-sectional tracking studies.
- Clarification of the impact of aging in people with developmental disabilities on their family caregivers, and development of strategies to help family members plan for the long-term care of their loved ones with developmental disabilities.

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- Prevention of secondary conditions and new disabilities before they appear, including the discovery and use of early detection and non-invasive screening and diagnostic methods not now applicable to older persons with lifelong disabilities.
- Development of technology-driven motivational strategies that improve adherence to healthy lifestyles and practices among people with lifelong disabilities.
- Explication of the roles played by cost factors (such as, health insurance), professional knowledge about risk factors for threats to healthy aging, and those that enhance environmental access to appropriate care.

## ***Health Practices and Policy***

***Recommendations.*** Better coordination of research agendas is needed among the several governmental and non-governmental agencies with responsibilities for funding aging and intellectual and developmental disability research. A comprehensive research agenda might lead to a blueprint for sharing responsibility among funders and interested bodies.

- Substantial increases are needed in public and private funding to support research in aging and lifelong disabilities.
- Resources are needed for the training of new researchers to take up the challenge of pursuing questions related to aging and intellectual or developmental disabilities.

- Practices and policies should focus on introducing effective empowerment and self-determination strategies.
- Models are needed for training people to better understand and more effectively use health care services, including more effectively educating persons with disabilities who are aging and their carers in interacting with health care providers.
- Practices need to be put into place that better equip physicians, nurses, emergency room personnel, and other allied health care providers to communicate with persons with intellectual or developmental disabilities, including how to relay information in understandable language.
- Funders should encourage sampling strategies that include persons with disabilities residing with families or who live independently. Such individuals may be more difficult to identify and failure to include them may introduce sampling biases.
- Governmental policies need to be modified to enhance access to specialist practitioners who are skilled in the area of lifelong intellectual and developmental disabilities and to generalist practitioners (both medical and dental) who currently experience disincentives to serve adults with disabilities due to low reimbursement rates or burdensome regulations.

## Conference Attendees

James Acquilano, M.A. (New York State Office of Mental Retardation and Developmental Disabilities and the University of Rochester); Giorgio Albertini, M.D. (Casa di Cura San Raffaele, Rome, Italy and the University of Rome, Tor Vergata); Edward F. Ansello, Ph.D. (Virginia Commonwealth University); Maureen Arcand; DiAnn Baxley, M.A.R. (University at Albany); Kathleen Bishop, Ph.D. (University of Rochester); W. Ted Brown, M.D., Ph.D. (New York State Institute for Basic Research in Developmental Disabilities); Thomas Buckley, Ed.D. (Upper Pinellas Association for Retarded Citizens, Inc); Nancy N. Cain, M.D. (University of Rochester); Margaret Campbell, Ph.D. (National Institute on Disability and Rehabilitation Research); David Coulter, M.D. (Harvard Medical School); Doreen Croser, M.S. (American Association on Mental Retardation); Bill Culhane (Upper Pinellas Association for Retarded Citizens, Inc); Arthur Dalton, Ph.D. (New York State Institute for Basic Research in Developmental Disabilities); Philip Davidson, Ph.D. (University of Rochester); Sharon Davis, Ph.D. (The Arc of the United States); Liz DePoy, Ph.D. (University of Maine); Alan Factor, Ph.D. (University of Illinois at Chicago); Glenn Fujiura, Ph.D. (University of Illinois at Chicago); Margaret Giannini, M.D. (U.S. Office on Disabilities); Stephen F. Gilson, Ph.D. (University of Maine); Randi Hagerman, M.D. (University of California, Davis); Paul Hagerman, M.D., Ph.D. (University of California, Davis); William E. Haley, Ph.D. (University of South Florida); Joy Hamell, Ph.D. (University of Illinois at Chicago); James Hanson, M.D. (National Institute on Child Health and Development); Dennis Harper, Ph.D. (University of Iowa); James Harris, M.D. (Kennedy-Krieger Institute, Johns Hopkins University); Meindert Haveman, Ph.D. (University of Dortmund, Germany); Tamar Heller, Ph.D. (University of Illinois at Chicago); C. Michael Henderson, M.D. (University of Rochester); Anthony Holland, M.D. (University of Cambridge, England); Kuei-Fang (Kelly) Hsieh, Ph.D. (University of Illinois at Chicago); Kathryn Hyer, Ph.D. (University of South Florida); Matthew P. Janicki, Ph.D. (University of Illinois at Chicago); George Jesien, Ph.D. (Association of University Centers on Disabilities);

Thomas F. Kelly, M.D., MPH (Delaware Health and Social Services); Gerard Kerins, M.D. (University of Connecticut); Marty Wyngaarten Krauss, Ph.D. (Brandeis University); Beth Marks, RN, Ph.D. (University of Illinois at Chicago); Philip McCallion, Ph.D. (University at Albany); Mary McCarron, M.Sc., R.N. (University of Dublin, Trinity College); Joav Merrick, M.D., D.M.Sc. (Ministry of Labour and Social Affairs, State of Israel); James Mortimer, Ph.D. (University of South Florida); Marvin Moss; Ray Murphy; Marie Murphy; Wendy M. Nehring, Ph.D., R.N. (Southern Illinois University); Tia Nelis (University of Illinois at Chicago); Joanne B. Oren, M.A., P.T. (University of Florida); Jenny Overeynder, C.S.W. (University of Rochester); Esther Lee Pederson, M.Ed. (Capabilities Unlimited, Inc.); Clifford Poetz; Barbara Polister (University of Minnesota); Huntington Potter, Ph.D. (University of South Florida); Clyde Rapp, M.D. (Philadelphia, Pennsylvania); Sandra Reynolds, Ph.D. (University of South Florida); James Rimmer, Ph.D. (University of Illinois at Chicago); Nicole Schupf, Ph.D. (Columbia University); Marsha M. Seltzer, Ph.D. (University of Wisconsin at Madison); Kathryn Service R.N., M.S.N. (Massachusetts Department of Mental Retardation); Jean Sherman, Ed.D., R.N. (University of Miami); Wayne Silverman, Ph.D. (New York State Institute for Basic Research in Developmental Disabilities); John H. Skinner, Ph.D. (University of South Florida); Philip Stafford, Ph.D. (Indiana University); Noriaki Takada, M.D., D.D.S., Ph.D. (Kawasaki University, Japan); Ryo Takahashi, Ph.D. (Takasaki University of Health and Welfare, Japan); Deborah Turner, M.S. (Upper Pinellas Association for Retarded Citizens, Inc); Carl V. Tyler, M.D. (Case Western Reserve University); Patricia Noonan Walsh, Ph.D. (University College Dublin); Kuo-yu Wang, Ph.D. (National Chung-Cheng University, Taiwan); Sheryl White Scott, M.D. (New York Medical College); Valerie Williams, M.P.A. (Oklahoma Health Sciences Center, University of Oklahoma); Mary Alice Willis (HealthSoft, Inc.); Michael Willis (HealthSoft, Inc.); Anna Zendell, M.S.W. (University at Albany); Warren Zigman, Ph.D. (New York State Institute for Basic Research in Developmental Disabilities).

**UIC** University of Illinois  
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Developmental Disabilities  
(RRTC-ADD)

Department of Disability  
and Human Development  
1640 West Roosevelt Road  
Chicago, IL 60608-6904

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