
Developmental Disabilities: Inside Looking Out

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Overview

The National Summit provides an opportunity for the environmental health community and the developmental disabilities community to share ideas about the impact of the environment on individuals with mental retardation (MR). Each group brings to the summit unique experiences and a common mission to improve the quality of life for people with mental retardation and related disabilities.

This paper provides an overview of recent events within the developmental disabilities community and an understanding of current issues facing individuals with MR.

Developmental Disabilities

Developmental Disabilities (DD) is not a specific medical definition. The term DD covers a heterogeneous group of individuals with disabilities. Mental retardation, cerebral palsy, autism, epilepsy, significant learning disabilities and other neurological conditions that begin in childhood fall under the umbrella of developmental disabilities.

The definition of developmental disability has evolved from federal and state laws. The latest federal definition is from Developmental Disabilities Act of 2000 (Public Law 106-402)(4):

A severe, chronic disability that

- A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- B) is manifested before the person attains age twenty-two;
- C) is likely to continue indefinitely;
- D) results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care;
 - receptive and expressive language;

- learning;
 - mobility;
 - self-direction;
 - capacity for independent living/ and
 - economic self-sufficiency; and
- E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services individualized support and other forms of assistance that are lifelong or extended duration and are individually planned and coordinated.

What Is Mental Retardation?

Mental retardation comprises the largest group of individuals with developmental disabilities. AAMR has had responsibility for defining mental retardation since 1921. The latest update of the definition was completed in 2002 (1).

AAMR DEFINITION OF MENTAL RETARDATION

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.

This disability originates before age 18.

Five Assumptions Essential to the Application of the AAMR Definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with MR.

The functional, versus categorical, definitions within the developmental disabilities field remains an ongoing discussion. The newly revised AAMR definition can be used as the basis for identification of individuals with MR for the discussions in these papers. These discussions and future collaborations can provide information that is significant not only for people with MR, but also other related disorders.

Demographics

Developmental disorders, including autism and attention deficit disorder, are widespread and affect 3–8 percent of the four million children born each year in the United States (9,10). Children with developmental disabilities are surviving childhood and adolescence. The improved survival has resulted in a population of individuals with MR and related disorders living into adulthood.

The identification of children and adults with developmental disabilities remains problematic because there is not one specific definition of developmental disabilities. This has to be taken into account when reviewing data and looking at prevalence rates.

The incidence of MR decreases once these children reach adulthood. These individuals once out of the education system are not labeled as “disabled” in society (16). The ability to identify and track adults with mild cognitive disabilities is a challenge. The importance of research needs to evaluate the impact of environmental toxins on individuals with mild mental retardation must be balanced against an individuals right to not be labeled.

Adults with MR Are Living Longer

It is estimated that approximately 526,000 adults, 60 years or older, with developmental disabilities live in the United States. Life expectancy within the United States has increased over the last century. The average life expectancy in the general population for woman is about 79.5 years and men 73 years. The same trend is present in adults with DD with the average age life expectancy for women being 67 years and for men 63 years. Individuals with severe disabilities tend to have shorter life expectancy due to increased medical complications. (2,10) Individuals with Down Syndrome have a shorter life expectancy, with the average life expectancy being 57 years for women and 53 years for men. (6) The increased longevity creates another area for additional evaluation and research.

People with MR Are More Diverse

The population, along with the increased longevity, is becoming more diverse. Racial and ethnic minorities, in the coming years, will be in the majority. The diversity of the population requires awareness of different needs within the developmental disabilities community. This includes a range of cultural, racial, and ethnic groups. The health disparities that have been identified within minority populations are compounded when a person also has a disability (18). Research on the impact of environmental toxins and pollution for this population needs to evaluate race and ethnicity as additional variables.

In addition to race and ethnicity, the association of poverty with disabilities needs to be addressed. The differences in rates of disabilities among different racial and ethnic groups appears directly related to poverty (12). The increased risks of environmental toxins and pollution in lower socioeconomic groups as it relates to developmental disabilities is an area that requires further study.

MRDD Issues: Findings From Recent Conferences and Events

Health Care Disparities

Individuals with developmental disabilities face many barriers in obtaining adequate health care (19). Healthy People 2010 looked at the health status of people with disabilities and addressed the environmental barriers that undermine their health, well-being, and participation in life activities.

The barriers to healthcare access include:

- Lack of information about services
- Shortage of appropriately trained health providers
- Transportation and access problems
- Lack of adequate health insurance coverage
- Cultural and language barriers
- Limited patient education materials
- Lack of health care standards/guidelines

Healthy People 2010

Healthy People 2010 identified certain characteristics of the health status of people with disabilities. People with disabilities would be expected to experience disadvantages in health and well being compared with the general population. People with disabilities may experience lack of access to health services and medical care and may be considered at increased risk for various conditions. Few data systems identify people with disabilities as a subpopulation. Limited information is available but disparities do exist for people with and without disabilities. For example, there are less frequent mammograms for women with disabilities over 55 compared to women without disabilities. Increased awareness of the health needs for people with disabilities and the health disparities for this population led to specific goals in the Healthy People 2010 (17).

The objectives related to this summit are:

- 6-1 Include in the core of all relevant Healthy People 2010 surveillance instruments a standardized set of questions that identify “People with disabilities.”
- 6-10 Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities
- 6-13 Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

The inclusion of people with disabilities into Healthy People 2010 supports increased awareness, activity of self-advocates and the disability community. The results from these objectives will work towards filling the information gap, decrease health disparities and improve the quality of life for individuals with disabilities.

Special Olympics – Promoting Health for Individuals with Mental Retardation-A Critical Journey Barely Begun

Special Olympics has provided activity and health promotion for people with mental retardation. The Special Report on the Health Status and Needs of Individuals with Mental Retardation identified current scientific knowledge and technology, to improve the quality of life for individuals with developmental disabilities. The need to assess and intervene to respond to health needs for this population was the focus of Promoting Health for Individuals with MR (15).

The major findings supported the limited data that does exist. Individuals with MR suffer a wide range of chronic and acute diseases and conditions. Persons with MR experience lower life expectancy and lower quality of life than the population in general.

In situations where persons with MR experience similar levels of disease to persons without MR, access to timely and appropriate health care often is not adequate and generally poorer than for the overall population. This leads to unnecessary suffering, functional compromise, and costs to individuals, families and society.

RECOMMENDATIONS

All public and private programs, initiatives and reports that address the health needs of the general public should explicitly examine the unique needs of persons with MR.

The NIH and other federal agencies with a health research mission should allocate increased levels of funding to issues critical to understanding all dimensions of MR, and where research opportunities exist, to pursue the prevention and rectification of the primary and secondary effects of MR.

Special Olympics has used sports to provide an opportunity to improve the health of people with mental retardation. This is one model to use as an example of health promotion and prevention of secondary conditions.

Closing the Gap: A National Blueprint to Improve the Health of Persons with MR

Dr. Satcher, former Surgeon General, focused on the issue of health disparities for this population and the Surgeon General's Conference on Health Disparities and MR was an outcome. Representatives from the disability community joined together to identify and address health related concerns for people with MR.

Closing the Gap: A National Blueprint to Improve the Health of Persons with MR summarized the proceedings of the conference and provided goals with action steps to improve the quality of health care for people with MR. (18) There were six major goals, all impact on the quality of healthcare for this population, and two are of significance for this summit.

Goal 1: Integrate Health Promotion into Community Environments of People with MR.

“Health Promotion programs should accommodate people with MR. Examples include smoking cessation, weight control, fitness, safe sex, drugs and alcohol.”

Action Steps:

- **Wellness:** Educate and support individuals with MR, their families, and other caregivers in self care and wellness.
- **Workplace:** Protect the health of individuals with MR from occupational hazards.

Goal 2: Increase Knowledge and Understanding of Health and MR, Ensuring that Knowledge is Made Practical and Easy to Use.

We’re invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up.

Action Steps:

- **Participation:** Enable individuals with MR, their families, and their health care providers to partner with professional investigators in identifying health research priorities, and in designing and implementing research related to health and MR.
- **Research Agenda:** Develop a national research agenda that identifies gaps in existing scientific knowledge related to health and MR, including methodological challenges, priorities, feasibility, and timetables for achieving priority research. (Enhance research collaborations across multiple research agendas and disciplines)
- **Data Collection:** Collect data on the health status of persons with MR in relation to the utilization, organization, and financing of their health services.

There is a need to increase awareness and develop a research agenda to fill the gap due to a lack of knowledge in health arena. These goals and action steps can be used as a format to develop an action plan for environmental issues.

Keeping the Promises: National Goals, State of Knowledge, and Research Agenda for Persons with Intellectual and Developmental Disabilities

The Surgeon General’s Report laid the groundwork for further discussion about the quality of health individual’s with intellectual disabilities. Research provides the basis for practice and policy yet there was a gap. Research being done needed to be translated for the general public to be accessible and useful.

Keeping the Promises, an invitational conference held in Washington DC in January 2003, provided a forum for participants to review the nation’s goals for people with intellectual and developmental disabilities and the role of research in helping to achieve them⁷. The conference took a life span approach from early years to aging and across social roles from learning and development to work and community life to address the range of needs within the life of a person with developmental disabilities.

The proceedings from the conference provided national goals, state of current knowledge, review of knowledge that is needed, and emerging issues for each topical area.

Recommendations for collaboration and action steps outlined a plan to continue the work begun at the conference. There are two that relate to the goals of this summit:

NATIONAL GOALS

Self Determination and Self-Advocacy

- People with disabilities are equal partners in research
- People shall make informed decisions about their lives
- People with disabilities shall have the opportunity to build their capacities, such as their knowledge, skill and resources, to control their lives and contribute to their communities.

Biomedical Research

- New scientific techniques emerging from genetics, neurobiology, molecular biology, imaging, toxicology, behavioral/cognitive sciences and related fields will be applied to specific mechanisms that interfere with development throughout the life span to reduce primary and secondary disability.
- Screening and diagnosis of conditions associated with intellectual and developmental disabilities will be employed to maximize opportunities for effective prevention or early intervention.
- Access to screening, diagnosis and treatment approaches will be provided without disparities in access or quality for individuals with developmental disabilities.

Health Services

- People will have the opportunity to participate in the full range of health promotion and wellness activities available to other children and adults.
- Knowledge about the health status of people with intellectual and developmental disabilities will be identified, evaluated and expanded across the life span.
- People with intellectual and developmental disabilities and their families will partner with health care providers to access and use health information to make choices and decisions about their own health care.

The goals, an assessment of the current state of knowledge, the knowledge needed to achieve the goals and emerging issues were developed. The needs identified in research can be used as a basis for discussion at this summit and build collaboration around areas of self-advocacy, health and the environment.

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

The International Association for the Scientific Study of Intellectual Disability (IASSID), in collaboration with the World Health Organization (WHO), prepared a report on the health issues facing adults with intellectual disabilities and the increasing need for research to support health aging for this population²⁰.

The Tampa Scientific Conference on Intellectual Disability, Aging, and Health held in December 2002 proposed a specific research agenda for aging adults with intellectual disabilities within the United States. This conference identified the research agenda for health and mental health outcomes in older persons with intellectual disabilities. Recommendations for research, health practice and policy interventions were reported³.

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.

Statistics are limited in the field of aging but increasing longevity in the general population is mirrored in adults with intellectual disabilities. The impact of environmental toxins and pollution during the early stages of life has been identified. The impact of these changes with aging individuals is still to be researched. The model of collaboration, with the scientific fields of geriatrics and gerontology to include adults with intellectual disabilities in current and future research efforts can be an example for this summit.

These recent conferences helped to improve awareness about current issues within the MRDD field. The process of involving all stakeholders (self advocates, family members, clinicians, policy makers, community leaders) showed an effective strategy to identify and plan for future work. Self advocates and family members have been an integral part of the conferences and in helping to outline the issues facing individuals with MRDD. Building on the work done by self advocates and their presence here at this summit will ensure that everyone is included equally in the decision making for future plans.

Environmental Issues & MR/DD

Environmental issues impact on all segments of the population including individuals with MR. The majority of research and clinical effort has been focused on the early stages of development from pregnancy through early childhood. There is a need for continued attention for prevention and increased awareness of health promotion across the lifespan. Health promotion and the impact of environmental toxins and pollution take on an increased importance with the aging of the general population. This trend is also reflected in the MR/DD community.

There has been little attention paid to the impact of pollution and toxic chemicals on individuals with MR and related disorders. A literature search of multiple databases reflects little or no information on the impact of environmental toxins after early exposure. The environmental pediatric literature includes articles on the impact of toxins on the developing fetus and during early childhood^{5, 11}. The literature review reflects research in the pediatric population and the link of environmental toxins to neurodevelopment (9, 14). The complex interactions of environment, genetics, disabilities in today's constantly changing world reflects the ongoing need for additional

research of the impact, long and short, of environmental toxins on developmental disabilities throughout the lifespan.

The financial impact of environmental exposures and disabilities is an area where there is some data. The study of environmental pollutants and disease in American children provided estimates of morbidity, mortality, and costs for lead poisoning, asthma, cancer, and developmental disabilities. Estimates of the cost for MR, autism and cerebral palsy not attributable to lead generate lifetime costs of \$92 billion dollars per annual cohort. If the attributable costs due to environmental factors is 5 to 20 percent costs can range from 4.6 to 18.4 billion dollars.

The improvements in chronic care for children with neurobehavioral disorders has increased the numbers of children living into adulthood. The costs for caring for these individuals and the impact of aging on the underlying disorders require further investigation (8). An area for discussion and further research is the financial impact of aging and secondary disabilities due to additional exposure to environmental toxins and pollution.

The summit will provide an opportunity for two networks that have a common mission, prevention and health promotion, to work together on recommendations to achieve shared goals.

Summary

Individuals with MR and related disabilities need to have information to make informed decisions and live a healthy life. The barriers to health care and limited research are major deficiencies in making healthy choices. The impact of pollution and environmental toxins across the lifespan is an area for collaboration between the disability and the environmental health network. The environmental pediatrics and public health approach is a model for addressing issues of environmental impact across the lifespan. Involvement of self-advocates, family members, policy makers, clinicians and researchers provide an opportunity for sharing across networks.

The goals of this summit are to foster collaboration between the developmental disabilities network and the environmental health network, to review the latest research findings, identify areas of mutual concern and develop an action plan. The success of this summit can lead to an ongoing process and provide a format for additional collaboration with other areas of concern for individuals with developmental disabilities with nontraditional partners. The ultimate goal is to improve the overall quality of life for all people with developmental disabilities and encourage full healthy participation in all aspects of life in our society.

Recommendations, Questions & Action Steps

The recommendations from the recent conference within the disabilities network give a framework for recommendations in policy, research and practice for environmental issues. It is important to open a dialogue, share ideas and form action steps that will enhance the quality of life for individuals with developmental disabilities.

Policy

RECOMMENDATION

Public policy should reflect the increasing awareness of all individuals with developmental disabilities to live active, healthy lives in our society. Environmental health policy should recognize the full inclusion of individuals with developmental disabilities across the lifespan.

QUESTIONS

How do the public policy issues in the general population relate to the developmental disabilities community? What do policy makers in each network need to know? How will public policy impact on research and policy issues? What do we do to increase awareness in public health networks about developmental disabilities? What are the financial implications that may result with policy decisions?

ACTION STEPS

1. Discuss the common mission and strategies that would create the foundation for collaborative partnerships in developmental disabilities and environmental health.
2. Identify potential partners within the public policy arena and developmental disabilities network to focus on environmental issues across the lifespan.
3. Prioritize top three issues dealing with public policy for this population and develop strategies to address each area.

Research

RECOMMENDATION

Research is needed to identify the impact of environmental toxins and pollution across the lifespan. People with disabilities and family members must be involved in all aspects of research from inception to dissemination. Research findings must go beyond the researchers to help improve the awareness of the impact of environmental toxins and enhance the quality of life.

QUESTIONS

What research is currently being conducted? What are the gaps in current knowledge? What do we need to know? What is the impact of race and ethnicity with exposure to environmental toxins? What research is needed to evaluate occupational exposure, pollution and other environmental toxins on people with MR? What is the impact of environmental toxins on the aging population? How does poverty impact on exposure to environmental toxins?

ACTION STEPS

1. Discuss and draft a process for involvement of self-advocates, family members, clinicians and researchers to identify a research agenda for the impact of environmental toxins and pollution for this population.
2. Analyze the strategies used in environmental pediatrics field to identify models that may be replicated across the lifespan for individuals with developmental disabilities.
3. Identify emerging research issues and current research projects that should include people with developmental disabilities as a subset of ongoing research.

Practice

RECOMMENDATION

Current practice in health promotion and prevention requires increased activities that are targeted to people with developmental disabilities to minimize or eliminate the impact of environmental toxins, pollution and other toxins.

QUESTIONS

What do we need to know about health promotion and prevention? How successful are current efforts in health promotion? How do we track interventions and outcomes? What are barriers to participation in health promotion activities? How do we increase awareness and educate others about developmental disabilities? What type of screening needs to be done on a routine basis? How do we educate health professionals about the health needs that relate to environmental exposures for this population?

ACTION STEPS

1. Gather information on best practices in the area of health promotion and prevention with a process to disseminate information to self-advocates, family members and practitioners.
2. Prioritize current areas of health promotion and prevention in keeping with CDC/NCBDD initiatives and Healthy People 2010 goals for individuals with disabilities.
3. Discuss possible strategies for creating, implementing and evaluating innovative approaches to health promotion and prevention.

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