



A WISCONSIN BLUEPRINT TO IMPROVE THE HEALTH OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

**Invitational Conference Report:
Health Disparities and Developmental
Disabilities in Wisconsin**




The Waisman Center is the largest interdisciplinary research and training center within the University of Wisconsin System. The Center is dedicated to the advancement of knowledge about human development, developmental disabilities and neurodegenerative diseases. It is one of 9 national centers that encompass both a Mental Retardation/Developmental Disabilities Research Center designated by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) designated by the Administration on Developmental Disabilities (UCEDD). The objectives of the Waisman Center are to promote:

- Research in behavioral and biomedical sciences relevant to human development and developmental disabilities
- Scientific training in fields related to the study of human development and developmental disabilities
- Clinical training in the delivery of clinical, educational, and support services to people with developmental disabilities
- A broad range of services for people with developmental disabilities and their families
- Outreach, continuing education, and technical assistance programs

The specific mission of the UCEDD is to support the full inclusion and self-determination of people with developmental disabilities and their families. That mission is accomplished through the Center's efforts in preservice training, clinical and intervention service, continuing education, technical assistance and consultation. The UCEDD is one of a national network of University Centers for Excellence that is coordinated by the Association of University Centers on Disabilities.

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Health Disparities and Developmental Disabilities in Wisconsin, October 8-9, 2002

Fluno Center, University of Wisconsin–Madison

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Arc Wisconsin	• Professional Development & Applied Studies
Center on Disability and Health	• School of Nursing
Community Living, Inc.	• Waisman Center
Dungarvin – Wisconsin Inc.	Waukesha Department of Health and Human Services
Wisconsin FACETS	Wisconsin Department of Health & Family Services
Family Voices - Wisconsin	• Division of Supportive Living
Independent Care	• Division of Public Health
Max Pohle Dental Clinic/Meriter Health Services	• Division of Care and Treatment Facilities
Medical College of Wisconsin	• Division of Health Care Financing
Milwaukee County Human Services	• Office of Strategic Finance
National Association of State Directors of Developmental Disability Services	Wisconsin Coalition for Advocacy
Office of the Commissioner of Insurance	Wisconsin Council on Developmental Disabilities
People First – Wisconsin	Wisconsin State Legislature
Regional Centers for Children with Special Health Care Needs	Wisconsin Technical College System
REM Wisconsin	
Special Olympics, Wisconsin	

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Definitions

Health Disparity refers to differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific populations groups in the United States.

*National Institutes of Health
Working Group on Health Disparities*

Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.

*World Health Organization
April 7, 1948*

Developmental Disability by the Wisconsin definition means a disability attributable to brain injury, cerebral palsy, epilepsy, autism, Prader-Willi syndrome, mental retardation, or another neurological condition closely related to mental retardation or requiring treatment similar to that required for mental retardation, which has continued or can be expected to continue indefinitely and constitutes a substantial hardship to the afflicted individual. *Wisconsin Statute: Chapter 51.01(5)(a)*.

Developmental Disability by the federal definition means a severe, chronic disability of an individual that (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. *Public Law 106-402, 114 STAT. 1684*



EXECUTIVE SUMMARY

The purpose of this report is to summarize recommendations that were developed during an Invitational Conference on Health Disparities and Developmental Disabilities in Wisconsin that was held October 8-9, 2002 at the Fluno Center on the campus of the University of Wisconsin-Madison. This conference was held in response to a series of events that had taken place over previous year to bring attention to the fact that individuals with developmental disabilities were experiencing less access to routine and specialized health care, and consequently higher incidences of illness and disease. Most notably these events included a special hearing of the U.S. Senate Committee on Appropriations, a national listening session on health disparities and mental retardation, and a Surgeon General conference on the same topic.

The Wisconsin conference was attended by over 70 individuals who included individuals with developmental disabilities, family members, physicians, nurses, dentists, social workers, nutritionists, health care administrators, policymakers, insurance representatives, managed care organizations, professional societies, medical and nursing schools, research institutions, technical college training programs, state planning agencies, community service providers, and advocacy organizations.

The recommendations that were developed address the following areas:

- Promoting greater awareness of health related needs of individuals with developmental disabilities, and resources to address those needs.
- Modifications to existing health and social service systems to increase understanding of and responsiveness to the health needs of individuals with developmental disabilities.
- Creation of a wide range of preservice and continuing education programs.
- Development of clinical guidelines and other resources to improve quality of health care to individuals with developmental disabilities.
- Creation of a collaborative health services network that offers primary care providers specialized expertise, consultation and technical assistance to serve those with developmental disabilities.
- Processes for continuous quality improvement.



INTRODUCTION


Health disparities for individuals with developmental disabilities began to receive national attention in the spring of 2001 when the U.S. Senate Committee on Appropriations convened a *Special Hearing on Promoting Health for People with Mental Retardation*¹. That hearing was prompted by an appeal from Special Olympics, which had made alarming observations about vision and oral health problems of athletes who were being screened in the Special Olympics Healthy Athletes² program. Of those athletes.

- 85% had refractive errors in vision
- 28% astigmatism
- 25% strabismus
- 68% gingivitis
- 33% had a least one dental decay
- 15% were referred to emergency room for acute pain

In response to their concerns, Special Olympics commissioned the Yale University School of Medicine to conduct a thorough review of the literature on the health status of individuals with mental retardation (MR) and to prepare a summary report for presentation to the Senate Committee. The study was completed in December 2000³. Despite noting significant limitations in our nation's capacity to capture sound epidemiological data on the health status of individuals with MR and other developmental disabilities, the study reported that when compared to the general population, individuals with MR have:

- Four times more preventable mortality.
- Less access to primary and specialty health care providers, including physicians and dentists.
- Higher rates of obesity, otitis media, asthma, cardiovascular disease, depression and other mental health conditions.

Surgeon General David Satcher, MD., Ph.D., attended the Senate Hearing and announced that in response to the issues that had been raised, he would convene a national conference on Health Disparities and Mental Retardation. The purpose of that conference would be to identify the underlying issues that contribute to the health disparities, and to develop a national blueprint of action steps to address those issues. In preparation for that conference the Surgeon General held a national Listening Session on October 10, 2001 and received testimony from over 800 individuals with developmental disabilities, family members and other advocates. The Waisman Center at the University of Wisconsin-Madison served as one of the four national listening session sites. Other sites were Bethesda Maryland, Birmingham Alabama, Worcester Massachusetts, and Portland Oregon. A summary of primary concerns that were raised by Wisconsin participants during that listening session is included on the next page. More detailed individual comments are included in the Appendix.



The information from the national listening session was then used to plan the Surgeon General Conference on Health Disparities that was held in Washington DC on December 6-7, 2001. At that conference participants discussed a range of topics that included provider attitudes, health care financing, and appropriateness and quality of services across the lifespan. At the conclusion of the conference, Dr. Satcher explained that a summary report would be prepared.⁴ He then urged federal agencies, individual states, and advocacy and professional groups to do what was necessary to keep the issues that had been raised on the table for discussion, and to work with one another to address those issues.

Health Issues for Individuals With Developmental Disabilities In Wisconsin

Cluster Areas of Primary Concern Reported During Wisconsin Listening Session*

Attitudes and Assumptions

- ✓ About disabilities and people with disabilities – inaccurate, negative views, low expectations.
- ✓ About care and service providers - what constitutes good care, role of providers.
- ✓ About the way the system should work - be open to doing things in different ways.
- ✓ Ethics and risks – What is ethical? Who is at risk?

Specific Health Issues for People With Developmental Disabilities

- ✓ Health Promotion, Wellness and Safety – apply this to individuals with DD.
- ✓ Recognize and address specific health issues that are more challenging for individuals with developmental disabilities. (*e.g. dental, mental health, aging, etc.*)

Care and Service Coordination

- ✓ Integrate health with other supports.
- ✓ Partnerships – between disciplines and across programs.
- ✓ Transitions – across programs, systems.

Financing: Insurance and Access

- ✓ Insurance, including special issues with Managed Care.
 - Preauthorization – simplify.
 - Access to specialists – assure access, especially in managed care.
 - School and Health System Responsibility – clarify how to work together

Training – of Everyone

- ✓ Training to advance best practice.
 - Assure cultural competency
- ✓ Understanding consumer choice, preferences, needs.
- ✓ Specialty training.
- ✓ Parent training.
- ✓ Self-advocacy.
- ✓ Integration of health care, behavioral and other community supports.

*See Appendix for summary of individual participant comments.



"I am very impressed with the thoughtful manner in which Wisconsin has followed up on the Surgeon General Initiative on Health Disparities and Mental Retardation. Your work here can serve as an example for other states in the nation."

*David Satcher, M.D., PhD
16th Surgeon General
October 9, 2002
Madison, Wisconsin*

Wisconsin Follow Up to Surgeon General Initiative

In an effort to build on the momentum that had been generated by the national discussions on health disparities, and to continue the discussions in Wisconsin, an ad hoc workgroup was organized in December, 2001 with representatives of the Wisconsin Department of Health and Family Services, Waisman Center, Wisconsin Council on Developmental Disabilities, Wisconsin Coalition for Advocacy, and Arc-Wisconsin. This workgroup concluded that the next step in the process should be to convene an Invitational Conference on Health Disparities and Developmental Disabilities in Wisconsin in order to develop specific recommendations that should be implemented in Wisconsin. That conference was held on October 8-9, 2002 at the Fluno Center at the University of Wisconsin-Madison.

As a special feature of this conference, then former Surgeon General Satcher attended the second day and received and commented on the recommendations that were developed. As he stated at that time, "I am very impressed with the thoughtful manner in which Wisconsin has followed up on the Surgeon General Initiative on Health Disparities and Mental Retardation. Your work here can serve as an example for other states in the nation."

Purpose and Organization of This Report

The purpose of this report is to serve as a resource document that summarizes the recommendations that were developed by the participants of the October 8-9, 2002 Invitational Conference on Health Disparities and Developmental Disabilities in Wisconsin. The sections that follow correspond to the major topics that conference participants addressed during their deliberations. Within each section background information is presented. This is followed by a listing of related issues and recommended action steps. The sections also include information and references that may be useful to individuals and organizations as they continue to address the concerns that have been raised and to encourage others to become involved with advancing solutions to those concerns.

ATTITUDES AND ASSUMPTIONS ABOUT DISABILITY AND HEALTH

Our concern in this section is with the more fundamental issue of societal and professional attitudes and assumptions about disability and health. How do these attitudes and assumptions shape the structure of health related programs and services? How do they influence the nature of the relationships and interactions. . . ?

For the past several years our nation has been struggling to determine the directions it should take to improve its health and human service systems.⁵ Attention has been drawn to these systems because of increasing concerns with service costs, quality, and accessibility. While it is very important to address these issues in order to make a meaningful impact on reducing health disparities, they are issues that will be discussed in later sections of this report. Our concern in this section is with the more fundamental issue of societal and professional attitudes and assumptions about disability and health. How do these attitudes and assumptions shape the structure of health related programs and services? How do they influence the nature of the relationships and interactions between the persons being served and the persons providing those services? These are questions that have been raised most directly by people with disabilities and those who partner with them. As a result of their dialog, they have grown more confident in themselves and their ability to advocate for and promote new types of partnerships with the professionals in their lives.

Several issues come into play in this discussion, but the following three have received special attention in recent years; (1) The shifting paradigm of disability, (2) Health care quality improvement processes, and (3) Self-determination and consumer driven service models.



A “new paradigm” of disability has emerged that considers disability as a natural and normal part of the human experience. Rather than focusing on “fixing” the individual, the “new paradigm” focuses on taking effective and meaningful actions to “fix” or modify the natural, constructed, cultural, and social environment.

Robert Silverstein

The primary objective of health care to individuals with developmental disabilities is the same as it is for everyone else; to promote health and wellness, prevent disease, and intervene as health and circumstances warrant.

Shifting paradigm of disability: Robert Silverstein effectively explains the shifting paradigm as follows.⁶ “Society has historically imposed attitudinal and institutional barriers that subject persons with disabilities to lives of unjust dependency, segregation, isolation, and exclusion. Attitudinal barriers are characterized by beliefs and sentiments held by nondisabled persons about persons with disabilities. Institutional barriers include policies, practices, and procedures adopted by entities such as employers, businesses, and public agencies. Sometimes these attitudinal and institutional barriers are the result of deep-seated prejudice. At other times, these barriers are the result of thoughtlessness, indifference, or lack of understanding. . . . These barriers result from decisions to follow the “old paradigm: of considering people with disabilities as “defective” and in need of “fixing”. . . . In response to challenges by persons with disabilities, their families and other advocates, our nation’s policymakers have slowly begun to react A “new paradigm” of disability has emerged that considers disability as a natural and normal part of the human experience. Rather than focusing on “fixing” the individual, the “new paradigm” focuses on taking effective and meaningful actions to “fix” or modify the natural, constructed, cultural, and social environment. In other words, the focus of the “new paradigm” is on eliminating the attitudinal and institutional barriers that preclude persons with disabilities from participating fully in society’s mainstream.”

The implication of this shifting paradigm of disability on health care is that health care planners and providers must not make assumptions about an individual with a developmental disability, simply because that person has that disability. Like everyone else being served in the system, individuals with DD must be treated as “people first” who have a range of lifetime needs, preferences and expectations of the health care system. The primary objective of health care to individuals with developmental disabilities is the same as it is for everyone else; to promote health and wellness, prevent disease, and intervene as health and circumstances warrant. During the course of care, the circumstances of their disability must be considered along with other aspects of their life, but the disability is simply one factor, however complex, in their lives.

Health care quality improvement processes: Under the leadership of the Institute of Medicine⁷, the Committee on Quality Health Care in America issued a series of “simple rules” that are intended to advance health care systems that provide safe, effective, patient-centered, timely, efficient and equitable care.⁸ These rules advocate that health care move away from its traditionally paternalistic attitude where the provider presumed to know what was best for the patient. The new rules are designed to more effectively recognize and serve the needs of patients, to ensure that they are fully informed, retain control, participate in care delivery whenever possible, and receive care that is respectful of their values and preferences.

The implication of this approach on health care is that it suggests that steps must be taken to assure that care occurs within the context of a relationship that is freely entered into and nurtured by the care provider and the person being served. It is a relationship that supports greater patient access to information, and a shared decision making process that assists the individual and family to exercise the degree of control that they wish. Research has shown that physicians typically underestimate the extent to which patients want information about their care.⁹ However, research has also shown that “informed patients who participate actively in decisions about their own care appear to have better outcomes, lower costs, and higher functional status than those held to more passive roles.¹⁰



Simple Rules for the 21st Century Health Care System - Institute of Medicine -

Current Approach	New Rule
Care is based primarily on visits	Care is based on continuous healing relationships
Professional autonomy drives variability	Care is customized, according to patient needs and values.
Professionals control care.	The patient is the source of control
Information is a record.	Knowledge is shared and information flows freely.
Decision-making is based on training and experience.	Decision-making is evidence based.
Do no harm is an individual responsibility.	Safety is a system property.
Secrecy is necessary.	Transparency is necessary.
The system reacts to needs.	Needs are anticipated.
Cost reduction is sought.	Waste is continuously decreased.
Preference is given to professional roles over the system.	Cooperation among clinicians is a priority.

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Self-determination and consumer driven service models: Individuals with developmental disabilities and their families want to be in a position to control and direct resources in order to promote their own health and well being, live where they want to live, and be involved in meaningful work and other social activities. In the “old paradigm” this level of control was denied most individuals with DD and families.¹¹ They were left in the awkward, if not demeaning position of relying upon others in the system that defined their status as dependent persons in need of system services, and then set the terms and conditions that had to be followed to access necessary services. Many states including Wisconsin are implementing methods that change this way of working. Referred to by such terms as *consumer directed services, self-determination models, and person and family centered care*, their intent is to position the individual and family being served at the center of the service relationship. In that position all activities that occur around them are based on their preferences and needs, as defined by them. (often with assistance from a service broker or care coordinator who is chosen by or otherwise agreed to by the individual/family)

This movement toward a greater level of consumer/family involvement does not imply that the service providers relinquish their professional responsibilities to provide guidance and direction. To the contrary, it means that they must become even more skilled and dedicated. . .

Health issues for those with developmental disabilities should not be seen solely as a social service or health care system issue, but should also be viewed within the context of public health. . . as the public health system explores its role in the 21st Century, it must determine what it will do to address health issues of those with developmental disabilities

This movement toward a greater level of consumer/family involvement does not imply that the service providers relinquish their professional responsibilities to provide guidance and direction. To the contrary, it means that they must become even more skilled and dedicated as they work to recognize the unique characteristics that each individual and family bring to the professional relationship. The nature of that professional relationship is very important, because once established, it becomes the context within which the provider supports the individual/family to understand and articulate their needs, and to determine the strategies they wish to pursue to address those needs.

The implication of these consumer driven approaches to health care is that they offer specific methods for how health care providers can engage individuals with DD and their family in their own health care, and thereby improve the quality of that care.

A comment about developmental disabilities and Public Health: Health issues for those with developmental disabilities should not be seen solely as a social service or health care system issue, but should also be viewed within the context of public health. The mission of public health is to “fulfill society’s interest in assuring conditions in which people can be healthy. Its aim is to generate organized community effort to address the public interest in health by applying scientific and technical knowledge to prevent disease and promote health. The mission of public health is addressed by private organizations and individuals as well as by public agencies.”¹² Therefore, as the public health system explores its role in the 21st Century, it must determine what it will do to address health issues of those with developmental disabilities.

Recommendations:

Issue: Assurance that services are delivered in ways that respect individual and family preferences and needs.

Action Step 1: Provide training to care providers to increase their level of skill and comfort to provide services in ways that respect the preferences, needs and choices of individuals with DD and their families.

Action Step 2: Develop a set of wellness indicators that can be used to monitor the health and wellness of individuals with developmental disabilities. Incorporate these indicators within various public and private health reporting systems that collect data to assess health status of these individuals.

Issue: Supporting individuals with development disabilities to assume greater control of their own health and wellness.

Action Step 3: Develop and implement various strategies to assure that individuals with DD maintain healthy habits that prevent illness and encourage positive health outcomes. Such strategies should include:

- Access to information on healthy habits that is provided in a variety of formats; written, video, web-based, etc.

- Peer support system to maintain healthy lifestyles.
- Support to community based health programs to encourage them to welcome individuals with disabilities, e.g., local health clubs.
- Training of direct care staff to position them to support positive health habits of individuals they serve – exercise, diet, mental health.
- Review K-12 curriculum to determine how it can be revised to incorporate information on health concerns for students with disabilities and special health care needs.

Issue: Viewing developmental disabilities within the context of public health.

Action Step 4: Consider the many ways that the public health system can advance the health of individuals with developmental disabilities. This should include work to promote the availability of sound epidemiological data that speaks to the distribution and determinants of health for those with developmental disabilities, and use of that data to inform public health planning.

Issue: Freedom from violence, assault, exploitation, harassment, abuse and neglect. (Note: This issue is raised because individuals with disabilities are often in dependent care situations, where they are vulnerable to harm.)

Action Step 5: Apply legal and reporting protections to individuals with disabilities to the same standard they are applied to individual who do not have a disability.

- Provide training for individuals with disabilities, support workers, care providers and others on such issues as sexuality, sexual abuse prevention, protective behaviors.
- Ensure medical professionals ask questions that allow them to monitor abuse or neglect during routine health exams.
- Provide information and training on how such provisions as guardianship, limited guardianship, advanced directives and power of attorney should be used to promote access to appropriate health care, and to prevent or intervene on suspected cases of abuse and neglect.
- Assure occupational health standards are met at sites where individuals with disabilities are employed.
- Replicate legal advocate model for coordinating with law enforcement.

Quality of Care is the degree to which health services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge.

The Institute of Medicine

For many individuals, the nature and intensity of their developmental disability requires that they receive both traditional health care and long term care services. Ideally, these services would operate in concert with one another; for the success of one is often dependent upon how well it is integrated with the other

ORGANIZATION AND FINANCING

The primary goal of organizational and financing structures within the health care system should be to assure the effective and efficient delivery of quality services that meet the needs and expectations of the individuals they are intended to serve. Organizational structures are concerned with the effectiveness of the organization, and the manner in which components are arranged and interrelate to achieve predetermined outcomes that are based on best practices and patient/consumer preferences. Financing structures are concerned with the efficiency of the organization, and the manner in which funds and other resources are generated and utilized to achieve predetermined outcomes in ways that minimize duplication and waste. Together, the organizational and financing structures serve as the foundation upon which health care services are arranged and delivered.

Services to individuals with developmental disabilities are delivered within our traditional health care system and our long-term care system. The traditional health care system is charged to provide what is often referred to as essential health services that include routine primary preventive health care, short term general hospital care, pharmacy, dental and mental health services, and emergency medical services. The role of the long-term care system is to provide personal care and other social and support services appropriate to the specific needs of the individual and family.

While private insurance pays a significant portion of traditional health care for individuals with a variety of disabilities¹³, the Medicaid program is the primary payer of traditional health care and long-term services for most individuals with developmental disabilities. These services include institutional care in nursing homes, public and private facilities for people with developmental disabilities, community based services through the Home and Community Based Waiver Program, and MA card services.

Challenges in current health care system

There are several issues within the current health care system that make it challenging for individuals with developmental disabilities to receive the type and quality of health care that they need and prefer.

Traditional health care and long-term care systems function as separate systems. For many individuals, the nature and intensity of their developmental disability requires that they receive both traditional health care and long term care services. Ideally, these services would operate in concert with one another, for the success of one is often dependent upon how well it is integrated with the other. For example, all individuals regardless of their disability require routine primary preventive health care that is typically accessed within the medical clinics and community health centers of the traditional health care system. However, many individuals with developmental disabilities require specialized transportation services to go to those locations, and assistance from a personal attendant to interact successfully with their health care provider during those visits. Each of those services is accessed within the long-term care system.

Policy bias toward institutional care. While there are many legal, financial and ethical reasons to favor home and community based care over care in an institution, the historical policy bias at both the federal and state level has been to fund care within an institution rather than care in the community. This bias stems from the fact that institutional care is an entitled service for eligible individuals under Medicaid, while care in the community for those same individuals is not an entitled service.

Olmstead and its implication on community based services.

In 1999 the United States Supreme Court ruled that States are required to provide community based services for persons with disabilities who would otherwise be eligible to institutional services when (a) the State's treatment professionals reasonably determine that such placement is appropriate, (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking in to account the resources available to the State, and the needs of others who are receiving State-supported disability services.

Two Georgia women with mental retardation and mental illness who lived in State-run institutions brought the case. They asserted that continued institutionalization was a violation of their right under the Americans with Disabilities Act to live in the least restrictive and integrated setting that was appropriate.

Health benefit package difficult to understand. As mentioned earlier, individuals with DD are often eligible for health and related services from a variety of traditional health and long term care programs. However, there is no single point of contact or source of consumer friendly information that can assist an individual, their family members, or care providers serving the individual to understand the range of services a person is eligible for within those programs and the circumstances that must be met to access those services.

Community health care processes not adapted to address special needs, circumstances and preferences of individuals with developmental disabilities. Health care and service protocols have been developed for the most part, without consideration for how a developmental disability impacts the course of care, or the processes the care provider should utilize to engage the individual with DD in their own care. This often results in a low level of communication between the care provider and the individual with DD that impacts the quality of care provided.

Specialized health care services are often difficult to access. The standard of care for most individuals who receive health care is that their primary care provider assesses their overall needs and refers them on to specialty care providers as those needs dictate. However, for individuals with developmental disabilities this process can be compromised in two ways. First, the primary care provider may view the developmental disability as the presenting condition to be treated, and they may not give adequate attention to the need to consider referral to specialists when it may otherwise be warranted. Second, when a specialist receives a referral to treat an individual with a developmental disability, that care may be compromised because the provider may not be trained or supported to provide the specialty care in a manner that also considers the how the developmental disability impacts the course of care for that individual.

Recommendations

Issue: Financing

Action Step 6: Continue to explore creation and testing of models that integrate/blend traditional health care and long term care within a seamless system. These models must be mission driven and based on values and principle that support community based care, rather than care in an institution. (See Sidebar on Olmstead.)

Action Step 7: Promote publicly accountable organizations to assume full financial risk to deliver quality outcomes for traditional health and long term care services, provided that the organizations are adequately funded to assume the risk.


Issue: Care management and linkages

Action Step 8: Create advocacy and benefit specialist staff positions that can assist individuals with a developmental disability and their family to know what traditional health care services and long term supports they are eligible for as enrollees in private insurance programs, Medicaid, (waiver and card services), and/or other pilot programs. Funding to support this independent advocacy should come from a portion of the capitated premium rate that is paid to the insurer.


Action Step 9: Assure that each individual with a developmental disability receives an annual comprehensive assessment of their health, social and long term care needs, based on their preferences. Utilize interdisciplinary teams to conduct this assessment. At a minimum, these teams should include a registered nurse, social worker, consumer and other family member as appropriate.

Action Step 10: If the person with the disability is unable to communicate his/her health care needs and preferences to their health care provider (i.e., needs that are documented in the annual assessment per Action Step 9), then an alternate person should be designated to assist the person to communicate those needs and preferences. A specific organization should be designated to provide this staff support to assist the individual to communicate with their health care provider. For individuals enrolled CIP services, that organization should be the county human service agency.

Action Step 11: Expand the MA targeted case management benefit so that it is available to primary care providers/clinics that reach out to serve individuals with developmental disabilities, particularly those who are not receiving long term support services from county human service agencies.

Issue Area: Delivery of services

Action Step 12: Develop guidelines for what constitutes quality health care, that is chronologically and developmentally appropriate, based on best practices and consensus of medical/health opinion. These guidelines should be incorporated into a booklet format that can be used to structure the consumer visit to the care provider. It should include questions to ask the provider and other information to share. The booklet should be added to the “health care tool kit” that is currently available.¹⁴



Action Step 13: Develop a continuum of primary and specialized medical, dental and mental health services at the local, regional and statewide levels. Primary services should be available within or near the individual's home community and include those prevention and wellness strategies that are routinely provided to those without disabilities. Specialized services should be available in the multi-county or regional area, and the more highly specialized low incidence services should be available on a statewide basis. Providers at the regional and statewide level, should be available to consult with local providers, and to work with them to plan and sponsor continuing education programs to increase capacity to serve those with DD at the local level. The model for regional perinatal services that was developed in Wisconsin could serve as a reference to develop this continuum of service and consultation.¹⁵ The model should also incorporate the concepts of the Medical Home.¹⁶

Action Step 14: Use state authority to standardize the definition of medical necessity and the definition of benefit categories in all insurance plans.

Issue: Quality improvement/quality assurance: Self correcting systems

Action Step 15: Create mechanisms to design and conduct special studies, assessments, and investigations in areas of special need related to health of individuals with developmental disabilities. Adapt the approach that Pennsylvania has utilized to implement a Health Risk Assessment and Health Assessment Units.¹⁷ One of the initial studies should document the level of services now being provided by psychiatrists and other mental health professionals to children and adults with developmental disabilities.

Action Step 16: Utilize existing provisions of public authority to promote access to quality services. (1) Utilize provisions of Americans with Disabilities Act to promote access and quality, and to educate consumers and providers about reasonable modifications at the provider level. (2) Use public health authority to reduce disparities via licensing standards and quality assurance requirements.



Drawing From Wisconsin Experience

For the past several years, Wisconsin has been working to design more effective and efficient methods to deliver traditional health and long term care to the elderly and to individuals with physical and developmental disabilities. Such methods include the Medicaid Home and Community Based Waiver Programs, and pilot demonstration programs such as Family Care and the Wisconsin Partnership Program.

The Medicaid Home and Community Based Waiver Programs utilize funds that once were intended for institutions to provide services to otherwise eligible individuals in the community. The major problem with this program is that it is not an entitlement, which means that individuals are served only if the state budget or county dollars provide the required 40% state match. Because adequate match dollars have not been provided to draw the federal dollars, many individuals are not receiving services.

Family Care is a long-term care program being piloted in Fond du Lac, La Crosse, Milwaukee, Portage, Richland, Kenosha, Jackson, Marathon, and Trempealeau counties. It has two major organizational components: (1) Aging and disability resource centers, designed to be a “one-stop shop” where older people and people with disabilities and their families can get information and advice about a wide range of resources available to them in their local communities. (2). Care management organizations (CMOs), which manage and deliver the Family Care benefit, which combines funding and services from a variety of existing programs into one flexible long-term care benefit, tailored to each individual’s needs, circumstances and preferences.

The Wisconsin Partnership Program is a comprehensive program of services for older adults and people with physical disabilities that is operating in Madison, Milwaukee and Eau Claire. The program integrates health and long-term support services, and includes home and community-based services, physician services, and all medical care. Services are delivered in the participant’s home or a setting of his or her choice. A key component of the Partnership Program is team-based care management. Under this arrangement, the participant, his or her physician, and a team of nurses and social workers develop a care plan together. The team coordinates all service delivery. Participants often keep their own physician who, in most cases, is added to the Partnership provider network.

“... If Wisconsin is going to build on all the time and effort it has put in on studying and piloting long term reform, it must use the best aspects of Family Care, the current system, and the results of experiences in other states. This can be done in a way that gives counties some choice in how long term care is organized and balances institutional and community care funding.”

Gerry Born

2002 Think Piece: Making Sense Out of Long Term Care Reform -

TRAINING OF HEALTH CARE PROVIDERS

The Institute of Medicine recommendations for the health care system that are described in an earlier section of this report speak directly to many of the issues that have been raised by those interested in improving the quality of health care for individuals with developmental disabilities. Namely, that a broad systems approach must be taken. That approach must rely upon collaboration of multiple disciplines and evidenced based practice. All activities must be centered on the needs and preferences of the individuals being served.

While steps must be taken at many levels to implement those recommendations, perhaps the most important area to focus attention is within our health related preservice training and continuing education programs. Attention to these education programs is critical because this is where practitioners and administrators learn about individual and family needs, evidenced based practice, and how the overall health system functions. Within these programs they will formulate their personal and professional views of the health care system and the underlying values and principles about disability and health that will guide them throughout their careers.

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Challenges of Current Training System

Assuring the relevancy of current training programs to the realities of the changing health care system. As we look to the future of the health care system, we must answer several questions. What types of professional are needed to work within the system? What do these professionals need to know from their own disciplinary perspective, and what do they need to know from the broader clinical, administrative, regulatory and political perspectives? What adjustments should be made in current training programs so that individuals who are graduating from those programs enter the system with an understanding of the directions the system is going to promote quality care and the roles they will play to support movement in those directions?

Keeping up to date on trends in service organization and delivery. There are many fine examples of effective programs functioning in various clinics, communities and states throughout the nation.¹⁸ However, despite a proliferation of health information available from multiple sources (e.g., professional journals, governmental publications, conference reports, internet websites) effective processes are not always in place so that others can readily draw from that information and modify their programs as appropriate. The result is significant delays in efforts to translate what is known about best practices into routine practices of local programs and services. For example, with regard to clinical services, it takes an average of 17 years to incorporate the new knowledge generated in randomized clinical trials into practice.¹⁹

Need to increase the number of health care providers who have specific interest and skills to address health needs of individuals with developmental disabilities. Many health care organizations, clinics, and community support programs include staff who have made a personal commitment to serving individuals with developmental disability. (Several of those individuals participated in the invitational conference) However, such individuals are the exception, rather than the norm in the overall health care workforce.



Recommendations

Issue: Adequacy of current preservice training programs to address health needs of individuals with developmental disabilities at the undergraduate and graduate levels.

Action Step 17: Review curricula of health related disciplines to determine how well they incorporate attention to health issues for those with DD. Adapt curricula as appropriate to assure health professionals are trained to provide quality service and support to individuals with DD.

Action Step 18: Advocate for more specific research on health issues of those with disabilities across the lifespan, the results of which can contribute to the creation and application of new knowledge. Research design must engage individuals with DD and their families within the process, giving appropriate consideration to legal and ethical issues.

Issue: Keeping up to date on care practices that meet the needs and preferences of individuals with disabilities.

Action Step 19: Promote a process of shared learning between care providers and individuals with disabilities and their families, within a context of best practice and quality improvement. Elements of a shared learning model could include:

- (a) A process to continually review literature on best practice, with consideration for how that information could be applied to improve current programs. Consider using groups such as health sciences librarians to catalog articles.
- (b) A collaborative process for an annual “health status review” to replace the annual physical. Such a process could engage multiple contributors and link relevant information about the individual with DD with a learning opportunity for the provider, the individuals with DD, family members, and the direct serviceworkers who may be involved.
- (c) Development of forms and other tools that give guidance to provider/individual/family about the relevant health issues to address in a patient encounter, provide references to resources that are customized based on information that is learned from the patient visit, and guidance that assists providers/individuals with DD/family/direct service workers to understand when referral to another source is appropriate. (Note: Action Steps 19b and 19c may link with Action Steps 9 and 12.)
- (d) Utilization of family mentor type experiences²⁰ to help providers and those in training to better understand the life experience of individuals/families.



Issue: Models to deliver continuing education

Action Step 20: Organize a statewide strategy to promote collaborative approaches to address continuing education needs in developmental disabilities.

- (a) Consider adapting models such as those used for Wisconsin Birth to 3 Personnel Development Project, or the Pennsylvania Health Care Coordination Units.²¹
- (b) Link the patient referral process with opportunities for continuing education. That is, when a referral is made, use the opportunity to document issues and needs that precipitated the referral, and consider if a training program could be designed to increase the skills and confidence of the referring individuals to address subsequent cases.
- (c) Nurture providers as they develop informal networks of peer support
- (d) Support existing efforts of various disciplines and professional societies to encourage them to give more attention to educational programs that address health for those with DD.
- (e) Make best use of the variety of new technologies to deliver continuing education that are now available.

Issue: Nurturing the next generation of health care providers and retention of current providers.

Action Step 21: Create a statewide initiative to recognize and retain current providers who have a special interest in serving those with disabilities, and to foster the development of the next generation of health care providers to serve those with disabilities. Such an initiative should include:

- (a) Surveys of current providers who are serving those with disabilities as well as current trainees in disability related programs, to document why they chose to work within this field, or are considering this field. Capture information from individuals who have chosen to leave the field.
- (b) Creation of a special initiative to increase the education and employment of people with disabilities in health related occupations.
- (c) Outreach efforts to middle and high students to help them understand disabilities and health fields so they may consider getting involved in these areas.



Issue: Looking toward new opportunities that can strengthen the engthen the education and training infrastructure.

Action Step 22: Link recommendations of this report with the UW System Technical College System initiative to address the health care provider shortage in Wisconsin. Include a DD training component within this initiative and have dollars committed to funding that training.

Action Step 23: Determine if and how the Blue Cross/Blue Shield conversion dollars can be utilized to support training of DD providers/initiatives, as well as other recommendations in this report.

Action Step 24: Link recommendations in this report with efforts of Wisconsin Council on Developmental Disabilities to address the direct service worker shortage. In order to plan appropriate training for direct service workers, the specific training objectives should be clarified and include objectives related to promoting health of the individuals they are serving.

INFORMATION, ASSISTANCE AND ADVOCACY

The complex nature of our health care system, coupled with the fact that individuals with developmental disabilities and their families enter the system with a wide range of special needs and issues, requires that user-friendly information, assistance and advocacy systems (IA&A) be in place. Such systems must be available to assist these individuals and families to understand what services are potentially available and steps they should take to access those services.

Parents and professionals need accurate and timely resource information to help find solutions to problems they face as services in the community become scarcer and family needs continue to be unmet. Parents are most often their own service coordinators for their children with cognitive disabilities, but they still need advice and support along the way.

*Wisconsin Listening Session
Participant, October 2001*

Information systems are typically designed to respond to contacts initiated by a telephone call, email or in-person contact and handled in one or two relatively brief encounters. During this time an information specialist screens the request and provides information that the individual who called can follow up on without further assistance. This information may include names of individuals, clinics and/or agencies to call to address their specific need, resource materials to read to better understand the issue they called about, and/or other guidance to help the person to better understand, frame and address their issue of concern.

Assistance systems take information dissemination a step further by providing direct assistance to the individual to help them follow up on the options that have been discussed during the screening process. This assistance may include making a series of telephone calls on behalf of the person and returning a call to share what was learned, meeting with the person directly to review information or to provide more focused assistance, assistance to link the caller with relevant parent and or consumer groups, forwarding their name (with appropriate authorization) to another individual who has specialized information and asking that person to call the individual, and supporting the individual by joining them during a visit to an individual, clinic or agency to present their issues and needs.

Advocacy systems provide intensive and longer-term supports, during which time the IA&A staff assume a more active role to speak for and with the individual in an effort to strongly represent their interests and concerns. Typically, advocacy efforts are utilized when the individual is experiencing some resistance from an individual, clinic or agency to provide a service or benefit. Advocacy efforts also address policy and other system changes that work to modify existing practices to increase the availability of services and access to those services.

Information, assistance and advocacy (IA&A) services are organized in a variety of forms in various parts of the state. Some programs, such as *First Call for Help (United Way 211)*²² are organized to provide information and assistance (often called information and referral) across a broad range of health and social issues. Other programs, such as the network of regional *Children With Special Health Care Needs Centers (CSHCN)*²³ provide more specialized assistance. Some resource centers are organized as freestanding programs, and others are incorporated into an agency that provides a variety of other services in addition to information and assistance.

While agencies that provide information and assistance may also assume prominent advocacy roles for and with the individuals who call them, these more intensive levels of advocacy are typically provided by agencies that are organized for that purpose. Two such agency examples are the *Wisconsin Coalition for Advocacy*²⁴ that provides protection and advocacy for people with disabilities throughout the state, and *ABC for Health*²⁵ that provides health related information, advocacy tools, and legal support.



The Alliance of Information & Referral Systems – AIRS (www.airs.org) was organized in 1973 to improve the quality of information delivery in human services. AIRS states that the main functions of I&R agencies are to:

- Develop and update files about community resources in the human service area.
- Provide information over the phone about resources and make formal referrals to appropriate service agencies.
- Follow up with clients and service agencies to determine if needed service was obtained.
- Participate in community education activities
- Engage in advocacy for the development of new human services.
- Prepare statistical reports on service requests and local needs to help community planners and funders.

Gaining an understanding of the variety of resources that are available. While agencies should be applauded for their efforts to create accessible IA&A programs, these programs for the most part promote and conduct themselves independent of one another. As a result, an individual who is seeking assistance on a particular health related issue might have a difficult time determining who to call for different types of assistance.

Potential gaps and duplications in information sources. There is no statewide inventory that lists the variety of general and specialized information and assistance resources that address disability issues across the lifespan. As a result, although it is widely acknowledged that there are both gaps and duplications in our current information, assistance and advocacy resources, it is very difficult to precisely determine where those gaps and duplications exist. The Wisconsin Division of Public Health has addressed this issue in part through its statewide database *First Step*.²⁶ However this resource is focused primarily upon resources for those age birth to 21. The Department of Health and Family Services has funded Family Care Aging and Disability Resource Centers, but they function only in selected counties.²⁷

Needs for specialized assistance not readily available. Many individuals with developmental disabilities and their families need technical and specialized information and assistance that pertains to legal issues or issues related to a specific disability. Most resource centers, particularly those that respond to broad based human service issues, do not have personnel who are trained to understand and respond to these special requests. Specialized organizations such as the Wisconsin Coalition for Advocacy, United Cerebral Palsy, and Arc-Wisconsin have been created to address some of these needs, but the need for additional skilled and specialized personnel remains. Needs are especially difficult to address when the individual has multiple disabilities or dual diagnosis, such as the case when a person has been diagnosed with mental illness and a developmental disability.

Care coordination/case management services not available statewide to assist with information, assistance and advocacy. For many individuals with a disability and their family, their needs are such that they cannot be met by a resource center. Individuals in these circumstances need a skilled person to assist them on an ongoing basis to understand and navigate through the complex system. In response to this need, some health and social service programs (such as the Family Care Pilot Program described earlier) have created care coordinator/case management staff positions. These staff (often a nurse or social worker) assist the individual/family to identify and access the various services they need. While these positions have been shown to be important staff positions for the individual/family, they are not available statewide.

Attention to cultural diversity. . .

At its basic level, cultural sensitivity implies knowledge that cultural differences as well as similarities exist... (it) further means being aware of the cultures represented in one's own state or region, learning about some of the general parameters of those cultures, and realizing that cultural diversity will affect families' participation. . . Cultural knowledge helps a professional to be aware of possibilities and to be ready to respond appropriately.

*National Center for
Clinical Infant Programs*

Recommendations

Issue: Statewide Planning Approach

Action Step 25: A statewide initiative should be developed to identify and address current issues and needs related to IA&A for individuals with developmental disabilities. Such an effort should identify current capabilities in various locations throughout the state, assess where gaps and duplications exist and how they should be addressed, and propose recommendations for how programs could work more closely together under the umbrella of a more unified IA&A system.

Action Step 26: All efforts that are taken to strengthen IA&A services must be guided based on principles of family and person centered service, cultural and linguistic competency, and universal access. Planning efforts should build upon existing IA&A structures, rather than create new and potentially duplicative structures.

Action Step 27: The IA&A System should include:

- (a) A designated lead agency that works to coordinate the variety of IA&A providers and eliminate gaps in the system. This agency would have close linkages with various stakeholders of the service system, including existing IA&A programs, county services, health care providers, tribal health centers, and disability related advocacy organizations;
- (b) A separate and independent lead resource center or centers for health related advocacy and policy issues for those with disabilities. The rationale for this separation is that staff involved in advanced level policy and advocacy work require a different set of skills than those involved in provision of information and assistance. Unlike many information and assistance centers, these centers would not likely be affiliated with a direct service agency, and would therefore be better positioned to approach issues from an "outsiders" perspective.

Issue: IA&A for special populations and needs

Action Step 28: Explore and decide upon best options to accommodate the information and assistance needs of all ages, cultures, and disabilities. For example, should centers specialize on populations divided by age (birth-21 and 18 and beyond, with each addressing 18-21 age group), type of disability, or geographic location? Compare these options to what is current practice and make modifications as appropriate. Regardless of their configuration, effective linkages must be created between centers in order to assure ongoing sharing of information and other program collaborations.



Issue: Training of IA&A staff

Action Step 29: IA&A staff at all centers must be trained to implement the processes they should follow to screen and respond to inquiries, understand and provide disability related information and resources, document calls and needs with adequate provision for confidentiality, and follow up on requests as appropriate. This may require training some staff to specialize in certain areas of information complexity, such as health benefits, cultural issues, or utilization of assistive technologies. Explore creation of core competencies for IA&A staff.

Issue: Public awareness of IA&A resources

Action Step 30: A public awareness program should be developed to inform individuals, family members, care providers and others about IA&A services that are available, and how to access those services.

Issue: Documentation of unmet needs

Action Step 31: Procedures should be designed to continually review data that is collected by IA&A programs during the course of their work, so that such information can document unmet needs, which can serve as the basis for policy and system changes to address those unmet needs.

ENDNOTES

¹ U.S. Senate Committee on Appropriations, Senator Ted Stevens, Chair. *Special Hearing on Promoting Health for People With Mental Retardation*, March 5, 2001, Anchorage, Alaska.

² The *Special Olympics Healthy Athletes Program* is designed to help Special Olympics athletes improve their health by, improving access and health care for Special Olympics athletes at event-based health screenings, making referrals to local health practitioners when appropriate, training health care professionals and students in the health professions about the needs and care of people with mental retardation, collecting, analyzing and disseminating data on the health status and needs of people with mental retardation, and advocating for improved health policies and programs for person with mental retardation. Website: http://www.specialolympics.org/healthy_athletes/healthy_athletes1.html

³ Horwitz, S., Kerker, B., Owens, P., Zigler, E., (December 2000). "The Health Status and Needs of Individuals with Mental Retardation," Yale University School of Medicine, New Haven, Connecticut.

⁴ U.S. Public Health Service. (February 2002). *Closing the Gap: A National Blueprint for Improving Health of Individuals with Mental Retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. Washington, D.C. Copies of the report may be viewed or downloaded from: <http://www.nichd.nih.gov/publications/pubs/closingthegap/index.htm>

⁵ The following books and reports are provided as examples of recently completed work:

Birenbaum, A., (1999). *Disability and Managed Care: Problems and Opportunities at the End of the Century*, Praeger Publishers, Westport, CT.

Children's Committee on Long Term Supports, Wisconsin Department of Health and Family Services, (2000). *A Foundation for a System of Long Term Support for Wisconsin Children and Families*

Committee on Quality of Health Care in America, Institute of Medicine, (July 2001). *Crossing The Quality Chasm: A New Health System for the 21st Century*, Washington D.C., National Academy Press.

Committee on the National Quality Report on Health Care Delivery, Institute of Medicine, (March 2001). *Envisioning the National Health Care Quality Report*, Washington D.C., National Academy Press.

National Center on Outcomes Resources, (October 2000). *Wingspread Conference Proceedings: Measure for Measure - Person-Centered Quality Assurance*, Racine, WI.

⁶ Silverstein, Robert and the Center for the Study and Advancement of Disability Policy, (2000). *Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy*, 85 Iowa L.REV. 1691.

⁷ The Institute of Medicine was established in 1970 and acts under the responsibility given to the National Academy of Sciences by Congress in 1863 to be an advisor to the federal government. The Institute acts upon its own initiative, to identify issues of medical care, research and education.

⁸ Committee on Quality of Health Care in America, Institute of Medicine, (July 2001). *Crossing The Quality Chasm: A New Health System for the 21st Century*, Washington D.C., National Academy Press.

⁹ Ibid, p 71.

¹⁰ Op.cit., Committee on Quality Health Care in America., p. 70.

¹¹ The reader may be interested in the following book that offers an interesting perspective on the relationship between those providing and receiving health and social services. McKnight, J., *The Careless Society: Community and its Counterfeits*, (1995). Basic Books, New York

¹² Institute of Medicine (1988). *The Future of Public Health*, National Academy Press. p.7.

¹³ For more information on health payment sources for services to individuals with disabilities, contact Bob Griss, Center on Disability and Health, Washington, D.C., (202)-842-4408.

¹⁴ This *Health Care Tool Kit* was developed in 1998 by Maureen Arcand with support from the Wisconsin Council on Developmental Disabilities. It includes a set of printed materials that support a system of communication between consumers, health care providers, and support personnel. For more information contact the Council at 608-266-7826. Website: <http://www.wcdd.org>

¹⁵ For more information on this model of services, contact the Wisconsin Association for Perinatal Care, 1010 Mound Street, Madison, Wisconsin. Telephone: 608-267-6060. Website: <http://www.perinatalweb.org>

¹⁶ The concept of the Medical Home has been advanced most actively by the Title V Maternal and Child Health Program, the American Academy of Pediatrics, and Family Voices. A medical home is not a building, but rather an approach to providing health care services in a high-quality and cost-effective manner, that has health care professionals and family members working as partners to identify and access all the medical and non-medical services that their needs dictate. For more information contact the website of the Medical Home Initiatives website at: <http://www.medicalhomeinfo.org/>

¹⁷ The Pennsylvania Health Risk Assessment (HRA) is designed to screen for physical and behavioral risk factors and provision of healthcare services for individuals with mental retardation. Health Care Coordination Units (HCCUs) serve counties in Pennsylvania to assist them in meeting overall health status needs of individuals in MR by assessing individual health and systems of care, providing clinical health care expertise and other health related training and support to counties in order to assure that individuals served by each county are as healthy as they can be in order to fully participate in community life. Information on the Pennsylvania model is available under the products search at <http://www.qualitymall.org>.

¹⁸ Braden, K., (December, 2001). *Health Disparities and Mental Retardation: Programs and Creative Strategies to Close the Gap*, This unpublished work was completed to serve as a resource for the Surgeon General's Conference on Health Disparities and Mental Retardation. It provides brief summaries of service programs that have developed creative strategies to provided health care to people with mental retardation living in the community. For more information contact the author. Kathleen Braden, M.D., Eunice Kennedy Shriver Center for Developmental Disabilities., University of Massachusetts Medical School., Worcester, MA.

¹⁹ Balas, E.,A., and Boren, S., (2000). "Managing Clinical Knowledge for Health Care Improvement". *Yearbook of Medical Informatics.*, National Library of Medicine, Bethesda, MD


²⁰ Within a family mentor experience, an individual is paired with a family that includes an individual with a disability. The purpose of this pairing is to give the individual being mentored, an opportunity to increase their appreciation and understanding of what it is like for an individual and their family to live with a disability.

²¹ Information on the Pennsylvania model is available under the products search at <http://www.qualitymall.org>.

²² These resource centers have been organized with support from United Way, Originally called First Call for Help, they are in the process of converting to United Way 211, so that they can be accessed in various communities by simply dialing 211. These centers provide free information and assistance with basic life issues such as family stability, mental health, financial challenges or alcohol and other drug abuse.

²³ This network of centers was organized by the Division of Public Health – Title V Program to provide information and assistance, parent-to-parent support, and local service coordination in cooperation with local public health departments. CSHCN Centers are located at: *Northeastern Region:* St. Vincent Hospital, Green Bay, 800-236-3030, ext.8296. *Northern Region:* Family Resource Connection, Rhinelander, 888-266-0028. *Southeastern Region:* Children's Hospital of Wisconsin, Milwaukee, 800-234-5437. *Southern Region:* Waisman Center, UW-Madison, 800-532-3321. *Western Region,* Chippewa County Dept. of Public Health, Chippewa Falls 800-400-3678

²⁴ Wisconsin Coalition for Advocacy. Telephone 608-267-0368. Website, <http://www.w-c-a.org>



²⁵ ABC for Health, Inc., Telephone 608-261-6939. Website, <http://www.abcforhealth.org/>

²⁶ Wisconsin First Step serves as the central directory of services for Wisconsin's Birth to 3 Program and links parents and professionals to five Regional Children with Special Health Care (CSHCN) Centers across the state. The hotline is available 24 hours a day at 1-800-642-7837. Website, <http://www.mch-hotlines.org>

²⁷ Family Care Aging and Disability Resource Centers are located in Fond du Lac, Lacrosse, Milwaukee, Portage, Richland, Kenosha, Jackson, Marathon and Trempealeau counties. For more information, contact <http://www.dhfs.state.wi.us/LTCare/Generalinfo/RCs.htm>



APPENDIX

Surgeon General Listening Session: Health Disparities and Mental Retardation

Summary Listing of Concerns of Wisconsin Participants

Hosted By: Waisman Center, University of Wisconsin-Madison - October 10, 2001

MY PRIMARY CONCERN IS . . .

Inadequate health insurance, providers who accept MA

Providers who are aware of health care issues and willing to work with individuals and families

Communication: - Who helps consumers identify and communicate their concerns to health care providers; need for health care guidelines for families, personal care workers, service coordinators, job coaches, etc. to know better what possible "red flags" to watch for with individuals who may not communicate well

Awareness: of needs specific to those with certain conditions, i.e., Health Care Guidelines for Individuals with Down Syndrome - a model that offers practice issues based on what is known about people with a common condition; develop guidelines for other conditions

Gynecological care for women with MR - issues to watch for, ways to communicate, protection

Mental Health Care for people with MR - how to identify issues, coverage and lack of trained personnel.

Dentistry top issues: (see next five rows)

-Caregiver education. Caregivers lack adequate training in oral hygiene techniques; little accountability for daily oral hygiene. Caregiver turnover contributes to lack of consistent care. Even with adequate dental services, daily care is critical.

-DDS Access issues as identified in Surgeon General report on oral health are magnified for persons with mental retardation. This population requires special accommodation because of physical disabilities, cognitive disabilities and potentially related behavioral issues. Important medical information and consent for treatment are many times difficult to obtain for dental treatment. Getting to appointments can be limited by the caregiver's sense of the importance of those dental appointments. Routine care is sought, based upon caregiver's knowledge and interest, not necessarily policy.

-DDS -General dentists have very limited training in special care dentistry. Dental offices are often not configured for adaptive transport devices, medical complexities of patient care, or behavioral management. Medicaid reimbursement is sufficiently low to be a disincentive for the general population; in fact, it is a greater disincentive for this group.

-The supply of dentists is diminishing, and the safety net (typically pedodontists in urban areas) for persons with mental retardation is also diminishing.

-There is little data on the oral health needs of people with mental retardation.

Insurance and Financing: 1. Private insurance, 2. Medicaid, 3. Medicaid waivers, 4. Community based long term care

The process to get preauthorization of medical services is too complicated and does not get work well for my family and other families. Standard forms should be developed for therapists to use to get PA approved.

Assure therapies are given, if they are approved. With my son, we were approved for 16 sessions, then school started, and they were stopped by the health care provider because it was a school responsibility because school was in session.

Difference between intensity of therapy in school. In school it is only 15-30 minutes, and an hour if by health care provider

Give parents training and tools (parent friendly/easy to understand forms) so that they know to do ABC, if you need XYZ.

Long term care, including transition from the Children's to Adult support system...Waiting Lists - role of self-advocate

Community Inclusion - role of self-advocate

Trained M.D.'s who care about the needs of people with DD

Aging issues

We don't engage people with cognitive disabilities to take an active interest in their health. We don't provide them with information they need to practice self-determination in relation to their own health and participation in health care system.

People lack access to health care services they need to preserve and strengthen their health (e.g. dental care). Lack of access to service to meet one need can lead to other more serious health problems.

People lack income to engage in healthy lifestyles. Income to become involved in exercise and fitness-related activities. They lack income to purchase healthy, nutritious, fresh foods, as well as vitamins and other preventative items.

People are often put on too many medications. Medication is seen as the standard response for people with cognitive disabilities, who are still viewed by and large as "sick" by those in the medical profession. The negative impact of these medications, either individually or when taken together, is often ignored or overlooked.

Health care professionals are not educated about how to communicate respectfully and effectively with people who have cognitive disabilities. They often see people's inability to understand as the person's intrinsic problem rather than their own problem with the mode of communication they choose to use. They often assume there is no point in even trying to explain things, which means these individuals receive unequal treatment, often to the detriment of their health and well being.

<p>It is virtually impossible for parents to access MA funding for in-home care. When I called (our home care provider) for help with our son's morning care, I was told that even if I accessed funds (and no one, including the people at MA would tell me how to do that) they would not be able to find personal care workers to come in the a.m. They refused to even try.</p>
<p>Hospital discharge planners know nothing about what it takes to support a person with special health care needs and a developmental disability in the community. In spite of the fact that our son was not keeping his oxygen and his CPAP on at night even in the hospital, we couldn't get any kind of intermediate care (an ICF-MR) or any in-home overnight care to help him. As a result, he became so exhausted from sleep apnea and lack of oxygen that he couldn't work. This went on for 18 months until I took legal action for residential placement.</p>
<p>Most dentists don't take MA so dental care is hard to find. Paperwork needs to be simplified so more dentists participate.</p>
<p>Hard to find good psychiatrists for people on MA. They don't want to spend hours on paperwork.</p>
<p>States should be mandated to provide residential care for adults with special health care needs and developmental disabilities much like the schools are mandated to provide a free and appropriate public education when people with developmental disabilities are younger. The system as it stands is way too crisis driven. No one listens until the person or the caregiver is nearly dead!—and that's not an exaggeration.</p>
<p>People with borderline cognitive disabilities and people who, because of the death of a parent, are placed on S.S.A. instead of S.S.I., and they do not qualify for an M.A. card. This of course is an insurance issue, but without insurance....</p>
<p>Inability of people with M.A. cards being able to find dental care. Even with an MA card, the care provided being only the cheapest alternative. I know numerous people who have had all their teeth pulled because of a problem that could have been taken care of with route canal work.</p>
<p>There is a problem of having more and more medications placed on the "over the counter" list and therefore not being covered by M.A. When people have exactly \$75 to spend each month, buying necessary medications limits their potential for enjoying the inclusive experiences we believe to be so important.</p>
<p>Lack of female-specific care that women with disabilities receive. For some reason many doctors do not think it is especially important to provide women with disabilities (especially those in wheel chairs) with routine pap smears, mammograms, etc. I know of numerous doctors who do not like to touch some of the women for whom I provide care.</p>
<p>Limited number of C.O.P. and C.I.P. 1A and 1B slots and the widening disparity between available funding and cost of services. The ripple effect of a lack of quality services/no services cannot be separated from questions of quality health care.</p>
<p>People with disabilities won't be allowed to make their own, informed decisions about their health care.</p>
<p>There is an assumption that people with cognitive disabilities can't make their own decisions, so health care professionals aren't motivated to interact directly with patients.</p>
<p>There is no mechanism for ensuring that follow-up care and medical protocols are understood by the patients and can be carried out by the patients themselves once they leave the health care facility.</p>
<p>People with disabilities aren't given a complete range of choices and full information about medical options.</p>
<p>Health care providers don't have links and aren't included on teams of providers who work with people with disabilities. (lack of coordinated, interdisciplinary, community-care encompassing medical, employment, housing, recreation, friendships.</p>
<p>Inadequate training in the area of disability across all health professions.</p>
<p>Access issues (a) attitudinal barriers. Health care professionals need to avoid treating and viewing disabled people as a "diagnosis" that is strange, defective, or a problem. Health care providers need information about privacy and confidentiality issues for people with disabilities. (b) architectural barriers - Communication barriers may prevent people with visual or hearing impairments or learning disabilities from receiving health education information in an understandable format, programmatic barriers, such as, inflexible appointments that fail to accommodate transportation difficulties or a lack of staff to assist in the examination room, many examination tables are too high for transferring from a wheelchair, lack of accessible rest rooms, or lack of signage regarding the accessible entrances.</p>
<p>Health promotion and protection - Due to diagnostic overshadowing, health care providers relate symptoms to the disability and neglect routine screening tests and other health promoting and protecting activities. Need health promotion programs that include the person with cognitive disabilities, along with their support persons.</p>
<p>Biases and Prejudices: Majority of advocacy efforts are led by the thought that all individuals should be served in a community setting and that such a setting will be the cheapest. While the majority of individuals can and should be served in a community setting, the small minority who are so profoundly retarded, or medically fragile, or with challenging behaviors should not be forced into a community setting that may actually harm them more than the benefit that will be derived. A full continuum of residential settings and services must be available to appropriately serve all.</p>
<p>Level of training/expertise in caregivers in community-based settings must be raised to level of training for caregivers in institutional settings. Centers of Excellence should be utilized as training facility for caregivers in all residential settings.</p> <p>Uniform standards of care across all residential and program settings: State Centers are currently held to much higher standards of care due to federal regulations which do not exist for community based settings. All residential settings serving identical populations and receiving federal Medicaid dollars should adhere to and be judged by the same standards</p> <p>Monitoring and oversight must be increased in community settings: As a fragile and vulnerable population is being relocated from the State Centers, they are being placed into facilities that may be staffed with only one staff person per shift. How will the profoundly mentally retarded non-verbal resident be protected from neglect and abuse without adequate monitoring and oversight? The current system is investigating abuse and neglect - not preventing it from happening.</p>

<p>Wages and benefits for caregivers in community settings must be raised to a competitive and comparative level with caregivers in institutional settings and competitive with other employment opportunities. Low pay does not attract nor retain quality workers. Low pay in results in high turnover of staff resulting in untrained or under trained caregivers, which impacts the level of care the resident receives. Wages must be competitive with other employment opportunities to attract persons away from other employment and into healthcare.</p>
<p>Specific health care needs4a) mental health issues - screening for mental health concerns (e.g., depression, violence/abuse related to disability, oppression, “burn-out” related to the stress of day-to-day living with a disability.4b) reproductive health care needs4c) transition services - Need health care services once adolescent transitions into adulthood.4d) independent living services - Health care providers need to learn about and to disseminate information regarding independent living services and civil rights issues.4e) healthy aging - need to learn more about aging issues for people with cognitive disabilities.</p>
<p>Lack of coordinated healthcare network for case management and referrals—perhaps Rehab Medicine could serve as physician managers</p>
<p>Poor access to Dental Care</p>
<p>Poor access to Psychiatric/Psychological services including intermittent inpatient care (rather than correctional)</p>
<p>Nutritional Management with poor access to GI and Nutritionist services</p>
<p>Minimal availability, poor quality of Rehab Tech assistive devices, e.g., custom wheelchairs, positioning devices, lifts....</p>
<p>Access to research-oriented and evidence-based/creative-thinking (University) Epileptologists/Neurologists; Respiratory Therapists/Pulmonary Medicine; Gynecology; Orthopedics are also problematic)</p>
<p>Dental- lack of dentists willing to use Medicaid (related to that, Medicaid regulations that do not promote prevention; tooth pulling is one of the few covered services)</p>
<p>Transportation-lack of providers due to low Medicaid reimbursement</p>
<p>Psychiatry—lack of psychiatrist willing to use Medicaid due to low reimbursement, huge and exacting amount of paperwork..</p>
<p>Home Health—lack of RNs and Home Health workers. This service is significant in preventing out-of-home placements. Rules regarding Home Health workers don’t allow them to leave the home with the person lead to isolation and are unnatural..</p>
<p>HMOs/private insurance unwilling to pay for needed therapies for children with long-term needs. The term “medically needy” has been narrowed for this group of kids</p>
<p>Rigidity of some of the Medicaid rules; under-reimbursement by Medicaid, Medicaid paperwork. People around here did not complain about medical personnel attitudes or prejudices; they seemed to get generally high marks for sensitivity. I don’t know if that’s because we’re here in Dane County, or if it’s a general improvement</p>
<p>Individuals with mild/moderate disabilities do not get the same level of care as persons with more significant disabilities.</p>
<p>Families are not considered primary members of the team as individual’s transition into adulthood.</p>
<p>Medical personnel are not well prepared for individuals with complex medical needs and are not always able to distinguish between the disability and an acute illness.</p>
<p>Individuals with health problems are socially isolated in schools, workplaces and communities.</p>
<p>Insurance restrictions regarding length of care and payments</p>
<p>Availability of quality services willing to accept patients with MA</p>
<p>People with CD (cognitive disabilities) being overlooked because they can’t advocate for themselves as well</p>
<p>People with CD have problems accessing specialized AODA programs</p>
<p>Informed Providers regarding CD.</p>
<p>Health care services for dental care and mental health services. In our family, it is necessary for us to travel two hours one way for dental care, as there are not dentists in our area that have a specialty practice in working with individuals with cognitive disabilities. They do not have equipment to efficiently perform the necessary dental work that my children require, nor do they have the expertise or patience to put my children at ease in order to do the dental work. They do not have the staff to support them when working with my children and that, too, does hinder their ability to do the required dental work.</p>
<p>In the area of mental health services, just do not exist. As a parent, this has been one of the most puzzling aspects of parenting a child with a cognitive disability. My daughter is not able to communicate in any fashion except through negative behaviors when things that are not right. We have been on a long journey trying to solve behavioral issues that, in some instances, I believe, are mental health problems related to depression. The literature and research in this area is very limited, making it difficult for parent and professionals to appropriately diagnose the health problem and solve it through medication and/or behavior management techniques.</p>
<p>Special education has been an arena in which my strong advocacy skills have been taxed and needed. It has been my experience that special education professionals just do not understand the relationship between necessary medical and health care needs and those of education. It has been very difficult to meet the needs that both of my children have for physical and occupational therapy. PT and OT through the individualized education plan (IEP) is seen as an unnecessary cost to the district, therefore, if those services can be avoided or neglected, my district through our director of special education, would not agree to provide the resources for such services. For my oldest child, many IEP meetings were held to access these services, and then, after getting the service into</p>

<p>the IEP, there were not physical or occupational therapists available to provide the important therapies. School supervisory personnel, directors of special education, and teachers need to be better trained the area of health care needs and providing, within the school setting, education plans that address both the educational and medical needs of children with cognitive disabilities.</p>
<p>Specific Health Condition: Alzheimer’s Disease: assessing differences between behavior, depression and Alzheimer’s. Medical issues, i.e. Alzheimer’s meds are mainly for memory loss. what about eating problems, mood swings.</p>
<p>Family supports for people with severe mental retardation and terminal illnesses. Home care—including physicians, nurses, care givers. End of life — support for person with severe mental retardation.Funding for home care and /or nursing home care.</p>
<p>Parents tell us they feel overwhelmed and exhausted when they first learn their child is diagnosed with mental retardation. They have many questions about what the future holds and kinds of help their child might need. Most parents feel anxious about their ability to care for their child and fear for their ability to provide for their child’s health and developmental needs.</p>
<p>Parents are frustrated by waiting lists that put their child’s need for needed services and equipment aside, sometimes for years. In many places, the families who are waiting on these lists have no access to service coordination to help problem solve solutions to these unmet needs such as respite and recreational opportunities.</p>
<p>Parents and professionals need accurate and timely resource information to help find solutions to problems they face as services in the community become scarcer and family needs continue to be unmet. Parents are most often their own service coordinators for their children with cognitive disabilities, but they still need advice and support along the way. “One-stop-shopping” makes the chaos of multiple appointments and providers, easier to coordinate, especially when parents need to work outside of the home. This can be a true crisis for single parents who have no one else to help carry the additional load of having a child with cognitive disabilities and qualified caregivers are increasingly difficult to find and pay for.</p>
<p>Parents often want to network with other parents who understand the problems they are having in accessing health care, therapies, home care, special education services, transportation and other needed resources. Access to a parent-to-parent network would give families’ greater support and confidence as they connect with the “veterans” who have experience with these challenges and are interested in mentoring others.</p>
<p>Even parents who have access to Medicaid benefits often need assistance in determining how it can help them find services and providers for their child. Once again, a lack of available service coordination is often the barrier here.</p>
<p>Isolation and lack of awareness are also problems that parents with disabled children in rural areas often face. The services that are needed may have waiting lists in more populated areas, but aren’t available at all in some rural counties. The internet has been an invaluable tool for some of these families to reach beyond their isolation. It isn’t as readily available to people who can’t buy their own equipment, or those who lack the skills to use the public access sights like schools and libraries.</p>
<p>While individual with MR have health care needs like everyone else, care providers need to distinguish specific needs that they may have because of their specific conditions. Provider must understand impact the condition has on health status.</p>
<p>Move away from a strict medical model that focused on health providers involved with periodic care, to more of a public health approach that is ongoing and involves multiple professionals and paraprofessionals.</p>
<p>Success requires more of a partnership between the person with MR, the provider, and very often a 3rd party for translation.</p>
<p>The front line person who interacts with the family must be able to relate to the family and the person with the disability. Understanding and sensitivity. They need to be able to pull out the information they need from the family to help them.</p>
<p>The Patient Advocates with the HMO have too high caseloads, and can’t be an advocate for the family.</p>
<p>Policies to replace durable medical equipment (wheelchairs) should recognize it wears out, and kids grow out of it.</p>
<p>Reimbursement rates for vendors. My daughter waited six months for a new mattress because vendor wanted more money.</p>
<p>Many families have basic survival needs (housing, food, clothes,) that must be met, before they can address some health problems. Help them deal with those, then you can help them address health issues better.</p>
<p>A number of support issues within the disability system impact on health care for this population: Transportation, Salary for attendants, Access to get around, Physical accessibility</p>
<p>A number of health issues need attention: Nutrition, Mental Health Occupational Health, Dental, Substance Abuse, Aging.</p>
<p>It is difficult to make the transition from adult to pediatric care. (The parent is the advocate for the child, but when the person is an adult, the advocate is often in a paid role... this is not always ideal.)</p>
<p>We need to consider the isolation that individuals with MR/disabilities often find themselves in.</p>
<p>Our approach should be a broader systems approach.</p>
<p>Medical model is important for what it offers, it is not an adequate model to address the full spectrum of health issues for those with MR.</p>
<p>Our unifying theme should recognize the value and importance of working together. No one can navigate the complex system alone. We must build the support systems, support networks, that people can trust, and in-turn support and strengthen.</p>
<p>Our approach should acknowledge and incorporate current work in area of self-directed services, self-determination, etc.</p>

Concerns with Managed Care Model consider points in Wisconsin AAMR Policy Statement on Legislative and Social Issues that addresses Managed Health Care
Lack of respect among health care “professionals”; e.g., assuming that consumers can’t understand their medical conditions, or not being willing to take the time to converse with someone who has difficulty communicating.
Discounting a consumer’s complaint because “such problems are to be expected when you have a disability”.
Lack of understanding how aging affects people with DD.
Need to promote interdisciplinary evaluation and follow along that includes medical and behavioral specialists. Promote this statewide; provide resources to enable county programs and managed care providers to access trained specialist.
Training of primary care medical and behavioral providers to the needs and issues of those with developmental disabilities. They could work in concert with regional specialist teams.
Lack of knowledge by the health care professions: I frequently see delayed or missed diagnoses of significant medical diagnoses. The literature has many examples of this, also. Medical diagnoses are too commonly diagnosed as behavioral and psychiatric problems. For example, people with Down syndrome have been diagnosed with Alzheimer disease when they have cervical spine disease and cord compression. Or alternately, psychiatric diagnoses are missed because their behavior is considered part of their disability. Even a prestigious academic medical center misdiagnosed for dislocated kneecaps as failure to walk because the patient had Down syndrome. It took them 10 years to make the correct diagnosis. Medical professionals generally don’t know how to interpret symptoms in people with developmental disabilities. Unfortunately the disability overshadows the diagnosis, even in professionals who mean well and want to do the right thing. I know it is difficult. I have had delays in making a diagnosis in my own son. I deal with a lot of diagnostic uncertainty. Time becomes an important diagnostic tool. I believe some relatively simple knowledge based interventions and more research will help us to better help people with developmental disabilities.
The biggest difficulty in the coordination of care is the need for a professional point person that is identified as case manager. Since that professional person does not exist, that role, by default, falls to me. (parent) I did not have the training to be his advocate. I have evolved into that role. What I need to be more effective advocate is to be part of a collective voice of parents and advocates that is working to advance the coordination of care for children with developmental disabilities. I envision this program to be one that has a base of support that is ongoing and sustainable. Similar to the Older Americans Act and the establishment of Protection and Advocacy Agencies in each state, there needs to be a commitment to train and sustain parents as professional advocates for their children. In this realm, parents would then be able to develop the skills necessary to access those services that their children require to live healthy and meaningful lives.
I feel that people with disabilities are not treated with respect by health care providers.
Many individuals depend on public funding (Medicaid) for care. and public funding is inadequate to obtain the services of some essential professionals. MA rules are extensive and confusing. Many providers unwilling to provide services, problem is severe when individuals have dental, mental health, or home nursing care needs.
Individuals may have idiosyncratic reactions to medications or treatments, may demonstrate challenging behaviors, or struggle with significant health problems which can greatly complicate otherwise simple health maintenance choices.
They need to see us as people first, with health issues like any other person. One time I was at the doctor and a student doctor was there. Instead of dealing with the problem I was having, the doctor started by saying to the student doctor that I was a woman with Down Syndrome. He didn’t focus on my problem - he focused on my disability. And he was wrong about that. I don’t even have Down Syndrome!
They need to use words that we can understand. They need to give us the whole story about our health so we can make good decisions for ourselves. This is self-determination and we as self-advocates want to have more control over our lives. We want to be treated like adults.
They also need to give us information that helps us understand what we should do to take care of ourselves. They need to help us understand how to stay healthy. They don’t bother helping us learn about being healthy and that just makes more problems for us and them
Lots of athletes (Special Olympics) have not gotten good dental care. And if they take seizure medication, it can really ruin their teeth. Without good dental care, people end up with bad teeth problems. Families and people with disabilities can’t afford dental care if they can’t find a doctor that takes MA. Sometimes, dentists just want to pull the teeth of people with disabilities instead of taking care of them because it’s cheaper to just pull the teeth out.
I would like to see programs that take care of the whole body next. People need more help with seizures. They need to develop better medication. A lot of people with disabilities also have diabetes. We need better medication for this, too. And people with disabilities need more help with learning about healthy eating.
Serious communication problems when care/service provider does not speak the same language as the parent or person with a disability. While 3 rd party translators are often used, this is not adequate because many words are hard to translate between languages, and the meaning of those words is often interpreted or applied differently by different cultures. The result is poor communication with the patients and family. This makes it difficult for health/school providers to make accurate assessments/ diagnoses, which can be incorrect because of inaccurate or insufficient information being communicated because of the language problems. The parents/person with a disability become very frustrated, and this further complicates the interaction. They often withdraw, which only makes it more difficult to work with the families to address their health needs.
Respite across the Lifespan

Workforce Shortage,
MA, Personal Care - Prior Authorization
Wisconsin and Olmstead
How to insure that individuals with DD are not sexually abused by health care providers and other caretakers.
Promotion of cardiac health via exercise and diet is virtually absent from many community programs. Funding for this should be permitted and encouraged. Training staff should cover this.
I see many deaths from natural causes, which may have been preventable. These occur after what appears to be a premature hospital discharge. Consider a review process with ability to autopsy to predict outcome, guide practice & policy.
Identification of abuse and neglect is a random occurrence usually the result of accidents. Promoting protective services should be considered a key component of any prevention program or program addressing health and safety.
Explaining birth control options and providing adequate information about sexual health/ gynecological care for those individuals who are sexually active.
The existence of physicians who specialize in treating children with DD so that the office visits are less stressful for the child and parent (often other parents/children will stare at your child and the office staff does not remain informed about the child's diagnosis(es). As a parent, I've found myself repeating information about "what happened" and "what's wrong with her" to the nurses, receptionists, etc. It's very frustrating to have your child treated like an alien.
The willingness of medical professionals to recommend second opinions and further diagnostic testing for individuals w/ DD, rather than the hopeless, "take it or leave it" attitude that seems to prevail.
Physicians, particularly specialists, who treat parents like idiots. Those who either fail to explain things completely, use jargon, or assume that the parent has no knowledge about their child's condition and don't encourage the parent to be a part of the treatment plan.
Children with DD have ongoing and comprehensive medical care by professionals who are trained to understand people with developmental disabilities and their families. There needs to be a link between primary care providers and specialists who can help provide support around diagnosis and intervention so that people with MR and DD can live and thrive in their own families and communities. Also schools can deal with the educational needs of children, but they can't/don't deal with medical needs. address the needs of children that don't fall within the realm of education.
My sense is that the biggest challenge for clinicians is not money, time or unfamiliarity — though those are not insignificant factors either — my sense is that it is discomfort with the inability to use the usual process of information gathering in the assessment process. When the patient is an individual who has significant cognitive and/or communication limitations, this complex process must be substantially modified.
Clinician discomfort is further increased by the paucity of available population-specific research data that would facilitate evidence based decision making or even of broadly disseminated clinical guidelines that would offer "best practice" approaches to common problems. Better data is necessary, but the barriers to doing substantial research are many. Our health care system, like our society, is fundamentally based on personal choice, with the patient as the source of control. This premise is challenged in the day-to-day care of people with disabilities. There can often be an ongoing tension between an individual's expressions of autonomy and the substituted judgment of others as to what is in that person's best interest. This can occur in dietary choices, risk taking behavior and other aspects of lifestyles. And it can be particularly true when invasive medical evaluations are considered.



NEXT STEPS

Following the Invitational Conference, representatives of the sponsoring organizations met to discuss steps that would be taken to follow up on the recommendations that were developed. They agreed to the following:

- Given their respective organizational missions, the organizational sponsors will continue to assume responsibility to promote greater understanding of the Health Disparities and DD Initiative, to bring attention to the issues and recommendations that have been developed at the state and national levels, and to monitor progress throughout the year.
- A report of the October 8-9, 2002 Invitational Conference will be prepared to document the issues that were raised and the action steps that had been developed.
- Shortly following the release of the conference report, conference participants will be invited to a meeting to review the action steps that were developed, and to document efforts that are being taken by various agencies and organizations that support those action steps.
- Within the next two years, a follow up conference will be held to assess progress on action steps developed at the invitational conference and to develop new action steps as appropriate.

“They need to see us as people first, with health issues like any other person.”

*Participant, Wisconsin Listening Session
October 10, 2001*



To view or download a copy of the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation, contact <http://www.nichd.nih.gov/publications/pubs/closingthegap/index.htm>



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