

Q&A: Health and Disabilities and Health Data Plan for Wisconsin

Why is it important to develop a Health and Disabilities Data Plan for Wisconsin? Over the past several years a number of national and state organizations have spoken out on the need to more effectively document the health status of individuals with disabilities and to use that information to guide the ongoing design and implementation of health related policies, programs and services. These organizations have advocated for this attention for two primary reasons. First, in carrying out their work, these organizations have become increasingly aware of many instances when individuals with disabilities were not receiving appropriate health care and support and many of those instances resulted in a very serious health crises. Second, the existing public health and disability systems and programs in the state are struggling to determine the most effective and efficient strategies to utilize to better document and address the health needs individuals with disabilities. A State Health and Disabilities Data Plan, when implemented, would create common understanding of current health status, problems and needs, and provide the necessary information to assist individuals with disabilities, policymakers, care and service providers and advocates to determine the steps they might take in their work to assure the health of individuals with disabilities.

What is a Data Plan? A Data Plan is a document that defines details that concern how data would be collected and utilized for a variety of purposes within a selected programmatic or topical area. The plan that we envision would include action steps that could be taken to help those involved with health and disability issues and programs to more effectively capture, analyze and utilize health and disability related data to inform policy development, program planning and evaluation. A Data Plan considers such questions as: What data should be collected and/or otherwise accessed, and why should those data be collected and accessed? Are those data currently being collected, and if so, within what databases? How are those databases organized and preserved? How is data made available for retrieval and analysis? How is confidentiality assured? What modifications should be made to existing data systems to make data more accessible and useable? What new data systems should be developed?

How is disability defined for purposes of the Data Plan? Using the definition provided by the World Health Organization (WHO), disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. Approximately 54 million people of all ages, races, ethnicities, socioeconomic status and educational attainment in the United States live with at least one disability.

What national and state organizations have spoken out on the need to address health status of individuals with disabilities?

National Level - examples:

- In 2005 the Surgeon General issued a *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*.
- *Healthy People 2020*, the 10 year agenda for improving the nation's health includes a focus area to promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities among the U.S. population.
- The Centers for Disease Control and Prevention includes a Division of Human Development and Disability that works with States to promote the health of individuals with disabilities.

- The Administration on Developmental Disabilities provides national leadership to meet the goals of the *Developmental Disabilities Act* that includes health as one of its major Areas of Emphasis.
- Within the Health Resources and Services Administration, the Federal Maternal and Child Health Bureau is the lead agency to implement *Title V of the Social Security Act* and it works with states to ensure the health of children and youth with special health care needs. Also within HRSA, the Office on Disability oversees the implementation and coordination of programs and policies to enhance the health and well being of people with disabilities.
- The American Association on Health and Disability (AAHD) is a national, nonprofit organization dedicated to improving the health and wellness of people with disabilities and to reducing health disparities between people with and those without disabilities.

Wisconsin – examples:

- *Healthiest Wisconsin 2020*, the 10 year agenda for improving the State’s health, identifies individuals with disabilities as a population group that warrants increased attention and offers recommendations to both document and address their health related needs.
- A number of statewide agencies came together in 2003 to develop *A Wisconsin Blueprint to Improve the Health of Individuals with Developmental Disabilities*. While some of the action steps in that report have been addressed, progress has been slow.
- New models to provide health and long term support services to individuals with disabilities (e.g., Family Care and other managed care models) have been designed and implemented within the state over the past 10 years. Some of these have focused on reducing health disparities by promoting overall care coordination and others by working to reduce preventable illness, accidents and injuries. The impact of these new models on health status has not been adequately measured.

What factors led to the above activities at the national and state levels? Key civil rights policy at the federal level, including the Americans with Disabilities Act of 1990, The New Freedom Initiative and 1999 *Olmstead v. L.C.* Supreme Court, has helped everyone begin to understand that disability and health are not mutually exclusive terms. As previously stated in the *WHO* definition of disability, individuals with disabilities lead their lives with certain impairments, activity limitations, and participation restrictions. But living with those does not mean that the person with the disability cannot be healthy. And it does not mean that those with disabilities are any less entitled to access to the full array of health services and supports that every other citizen expects and receives. The fact is that the nation’s attitudes and assumptions about disability and health have changed and are evolving in ways that support inclusion and self determination of individuals with disabilities in all streams of community life. These changes require that our various systems make the corresponding adjustments and improvements to be responsive and accountable to the people they serve, including those with disabilities.

What steps are being taken to develop the State Health and Disabilities Data Plan? The effort is at the preliminary stage of development. The short term goal is to engage individuals and organizations within various discussions about the importance of the initiative, to identify and track current work, and to begin to learn from and build upon that work.

Have those who have been involved with the effort to date formulated a framework for how the Data Plan might be constructed? Yes. Some of the preliminary thinking is as follows.

- The overall goal of the project is to promote the optimal health of all of those with disabilities in Wisconsin (children and adults), and to document and reduce health disparities within the population group of individuals with disabilities.
- With optimal health as the goal, the objective of the Data Plan effort is to create a *Health and Disabilities Data Plan* that when implemented would document the health status of individuals with disabilities and engage key stakeholders in processes to use the information that is available to guide the ongoing design and implementation of public health and disability related programs and services.
- An initial track of work would be to conduct an environmental scan to identify the various databases that are currently in place nationally and within the state to capture data on individuals with disabilities and to answer the following questions: What information is collected? Who is it collected on? How are various terms related to disabilities defined? Who has access to the data? What are the strengths, limitations and opportunities within and across each of these databases? How might these databases be modified?
- One option that is being considered is to apply the analysis of databases on the health focus areas that have been identified within the *Healthiest Wisconsin 2020 State Plan* for individuals with disabilities. Those health focus areas are access to routine care within context of a medical home, oral health, obesity, and emotional and mental health. Using a *Determinants of Population Health* framework, the analysis would consider how the following “determinants of health” impact health status; health behaviors of the individual (e.g. diet and exercise, tobacco use, alcohol use, unsafe sex), clinical care (access to care, quality of care), social and economic factors (education, employment, income, family and social support, community safety), and the physical environment (environmental quality and the “built” environment).
- An important element of the plan will be recommendations to design a statewide committee (or some similar organizational form) to promote and oversee the ongoing promotion, design and implementation of the plan so that it is responsive to the needs of individuals with disabilities and draws upon the latest standards and technologies for data collection, analysis and application.

Who can I contact for more information on the effort to develop the Data Plan? A small workgroup has been formed that is drawn from the group that developed the *Wisconsin Blueprint to Improve the Health of Individuals with Developmental Disabilities* and the group that contributed to the disabilities related information within the *Healthiest Wisconsin 2020 State Health Plan*. For more information contact:

- Daniel Bier, Waisman Center, bier@waisman.wisc.edu
- Sharon Fleischfresser, MD., MPH., WI Division of Public Health, Sharon.Fleischfresser@dhs.wisconsin.gov