



COUNCIL ON
PHYSICAL DISABILITIES

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About the Emergency Preparedness Communications Folder

The Wisconsin Council on Physical Disabilities (CPD) and Governor's Committee for People with Disabilities (GCPD) have partnered to create the **Emergency Preparedness Communications Folder**. This folder was designed as a resource for health care providers and people with disabilities to address communication and access barriers. Accessibility applies to both communication and physical access. This folder includes several documents including:

- Know Your Rights
- Health Care and the Americans with Disabilities Act
- Emergency Preparedness Visual Communication Tool
- Getting a COVID-19 Vaccine Infographic
- Office for Deaf or Hard of Hearing COVID-19 Communication Card

For Use by Health Care Providers

It is our hope that health care providers will be able to utilize the information and communication tools enclosed in this folder to increase access to health care and that this information will be used to educate staff about reasonable accommodations and about the civil rights of people with disabilities. In addition, it is important for health care professionals to be aware of how to effectively communicate with patients who have a range of disabilities, including people who are Deaf or hard of hearing, or who have a speech, vision, or intellectual disability, and the communication tools enclosed can be helpful. The folder also contains information on how providers should ensure that accessible medical equipment is available for people with disabilities (such as scales, examination tables, or chairs) and should plan for additional time during examinations, if needed.

For Use by People with Disabilities

People with disabilities often need to submit a reasonable accommodation request for their communication and physical access needs so these needs can be met by their health care providers. Individuals should contact their health care providers to learn the process for requesting these accommodations. This folder contains information for people with disabilities about their rights, how to request a reasonable accommodation in a health care setting, and what to do if this request is denied. This information will assist individuals with disabilities to increase and maintain their access to health care services. This folder also contains communication tools that may be useful to people with disabilities for communicating in health care or emergency situations when a reasonable accommodation is being put into place, but urgent communication is needed, or when a reasonable accommodation has been denied.

For More Information or to Request a Presentation

If you or your organization would like more information on the Emergency Preparedness Communications Folder, the Emergency Preparedness Toolkit, or to request a formal presentation on disability etiquette, effective communication, or emergency preparedness please contact the Council on Physical Disabilities (CPD) at 608-716-9212 or ashley.walker@dhs.wisconsin.gov.

Background on the Development of the Emergency Preparedness Communications Folder

The Wisconsin Council on Physical Disabilities (CPD) is a Governor-appointed Council that specifically focuses on funding, policies, programs, and legislation that impact people with physical disabilities. CPD has developed an Emergency Preparedness Toolkit which serves as a resource tool providing all people, particularly those individuals with physical or other disabilities, emergency preparedness information including tips, checklists, wallet card, visual communications tool, and other resources to be prepared and have a plan for emergencies and natural disasters.

CPD is a member of the Governor's Committee for People with Disabilities (GCPD) and a member of GCPD's Executive Committee. GCPD is dedicated to enhancing the health and well-being of Wisconsin citizens who have disabilities. As a committee of Governor-appointed volunteers with cross-disability council representation (Board for People with Developmental Disabilities, Council on Deaf and Hard of Hearing, Council on Physical Disabilities, Statutory Council on Blindness), GCPD serves to advise the Governor, state agencies, and the state legislature on issues of concern for people who have disabilities.

GCPD and its constituent councils across the disability spectrum have been closely monitoring the impact of COVID-19 on people with disabilities. National data is clear that people with disabilities are at greater risk than the general population to contract the virus, to be hospitalized for it and, tragically, more likely to die from it. In the midst of this extreme level of concern, it is more important than ever that people with disabilities be afforded equal access to health care services.

Wisconsin is in a state of emergency which is the exact time when people with disabilities and other vulnerable adults need additional support. Yet, GCPD has learned that people with disabilities have been denied reasonable accommodations which has impeded their access to health care services. GCPD learned this when it recently conducted the *Right to Have a Support Person/Caregiver at Appointment Survey* (Executive Summary of Survey Results included in the Emergency Preparedness Communications Folder).

Based on the survey results, GCPD learned that in many health care settings, a common policy designed to control the spread of COVID-19 has unfairly infringed upon the rights of people with disabilities; specifically, by not allowing a disability support person (paid or unpaid) to accompany a person with a disability during medical consultation and treatments. The accompanying person would be in a position to provide personal care and positioning, clear communication, and explanation of medical options. Perhaps most important, the accompanying person would be in a position to provide personal advocacy. Regrettably, these policies may result in deleterious and sub-optimal clinical outcomes for people with disabilities.



SURVEY RE: RIGHT TO HAVE A SUPPORT PERSON OR CAREGIVER PRESENT AT MEDICAL APPOINTMENTS

BRIEFING DOCUMENT

Background

In November of 2020, the Executive Committee of the Governor's Committee for People with Disabilities (GCPD) began receiving reports that some people with disabilities were told by some health care providers that they could not have a disability support person present during medical appointments due to the COVID-19 pandemic. The GCPD agreed that not being allowed to have a support person present during medical appointments may adversely impact care due to the lack of communication support and physical assistance, as well as an assurance of patient understanding and appropriate follow-up. The GCPD views requests for presence of a support individual as a reasonable accommodation and a right under the American with Disabilities Act.

In order to assess the extent to which this was occurring, the GCPD developed an online survey that was released on February 1, 2021 to gain input Wisconsin residents, reflecting input from:

- The person with a disability;
- The person who provides support or caregiving to someone who has a disability, and
- An advocate (e.g., a family member, Family Care/Family Care Partnership care manager, IRIS consultant, professional advocate, etc.) for a person who has a disability.

The GCPD distributed the survey to its constituent disability councils and to a wide array of stakeholder organizations through Department of Health Services (DHS) distribution channels, along with a request that they further distribute through their communication channels.

Survey Results

- 437 survey responses were submitted during the one month survey period (February 1, 2021—March 1, 2021):
 - 140 were from people with a disability;
 - 109 were from support people or caregivers to a person with a disability; and
 - 188 were from advocates for a person with a disability.
- 95% of respondents with disabilities reported that they sought medical treatment, assessment, or consultation since March of 2020.
- 39% of survey respondents stated that a support person or caregiver usually goes with them to help them at their appointment or visit to provide accessible transportation, assistance with mobility (e.g., getting in the building, getting up on exam table, etc.), assist with communication, assist in understanding the information provided by medical staff, American Sign Language interpretation, emotional/behavioral support, and assist with filling out and reading forms for blind/visually impaired individuals.
- Almost 50% of survey respondents stated that someone from the doctor's office, clinic, or hospital told them that their support person or caregiver could not go with them and/or stay with them during their appointment.

- These were not isolated instances. When asked how often they were told their support person was not allowed to be with them, 55% responded it happened on three or more occasions.
- 80% of respondents indicated that it was a receptionist or security personnel who first denied access to the support person, 84% citing hospital or clinic rules or policies as the reason.
- Settings in which this occurred included:
 - 55.6% doctor’s office;
 - 38.9% emergency room;
 - 38.9% medical clinic;
 - 11.1% hospital inpatient; and
 - 5.6% dentist’s office.

Note: Respondents asked to check all that apply so percentages do not add up to 100%.
- When an explanation was offered to medical staff as to why the support person was essential, 64% of people with disabilities and 73% of advocates reported that their support person was allowed to accompany them. When caregivers offered explanation, however, only 32% were allowed to accompany the person.
- Narrative responses from caregivers indicated that:
 - “The hospital did not understand the person’s disability;” and
 - “The person had to be given additional drugs to control behaviors that may not have been needed if I was allowed to stay.”
- Narrative responses came from parents included comments such as:
 - [My daughter] “is non-verbal and cognitively impaired. She needs 2 people to transport her to push the wheelchair and pull the oxygen tank...She needs someone to stay with her 24/7 to make sure all her needs are met.”
 - “As a parent this has tremendously affected her medical needs overall, my daughter... has CP and is deaf with bilateral Cochlear Implants, among other special needs.”
- Survey respondents had to option to identify specific providers and locations where they had experienced difficulties. Fifteen provider systems were identified, representing all geographic locations of the state.

Actions and Recommendations

The GCPD hopes that the resulting data will be used as a platform for dialogue to improve access to health care for people with disabilities, both during the pandemic and into the future. As first steps, the GCPD intends to:

- Meet with interested stakeholders to further discover the extent to which accommodations are being denied to people with disabilities in medical or health care settings and collaborate on recommendations to make improvements.
- Request the Department of Health Services, in consultation with the GCPD:
 - Issue guidance to hospitals and medical providers on civil rights compliance.
 - Develop resources for people with disabilities regarding rights to accommodations, and channels for reporting discrimination in health care.
 - Offer training to medical providers regarding disability etiquette, effective communication, and accommodations.
- Issue a press release and host a virtual forum to share survey results with interested stakeholders.

For additional information, please contact:

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