



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:

David Morstad, M.Ed., FAAIDD
 Chair, Governor’s Committee for People with Disabilities
david.morstad@gmail.com