



Right to Have a Support Person or Caregiver at Appointments Survey

Governor's Committee for People with Disabilities

March 2021

Governor's Committee for People with Disabilities (GCPD) Overview

In 1948, a Governor's Committee was established with one goal: to improve employment opportunities for people with disabilities. The group's mission was broadened in 1976 to cover many aspects of disability in Wisconsin and became the Governor's Committee for People with Disabilities. Unlike other disability councils in state government, the focus of the Governor's Committee includes all disabilities and six of its members represent specific disability constituencies.

GCPD is charged with the following duties:

- Advise the Governor and state agencies on problems faced by people with disabilities.
- Review legislation affecting people with disabilities.
- Promote effective operation of publicly-administered or supported programs serving people with disabilities.
- Promote the collection, dissemination and incorporation of adequate information about people with disabilities for purposes of public planning at all levels of government.
- Promote public awareness of the needs and abilities of people with disabilities.
- Encourage the effective involvement of people with disabilities in government.

Development of Right to Have a Support Person at Appointments Survey

- GCPD had been receiving public testimony about barriers people with disabilities were experiencing related to accessing healthcare or medical appointments.
- GCPD was also monitoring national and statewide research and data on the impact COVID-19 has had on people with disabilities including health and well-being.
- GCPD reached out to the Wisconsin Hospital Association in relation to COVID-19 Visitor Policies and to inquire if they had received any complaints or concerns from people with disabilities. They stated they had only received one.
- As a result GCPD decided to develop a survey to gain additional information regarding how this pandemic has affected access to health care and medical treatment and how modified policies and procedures implemented by health care providers may be impacting people with disabilities

Survey Design

- GCPD designed the survey to gain input on these issues from three categories of people:
 - Person with a disability
 - Person who provides support or caregiving to a person who has a disability.
 - An advocate (such as a family member, care manager, IRIS consultant, professional advocate, etc.) for a person who has a disability.
- GCPD plans to use this data to engage in conversations and dialogue aimed at improving access to health care for people with disabilities, both during the pandemic and into the future.

Survey Results

- The survey was open from February 1, 2021 through March 1, 2021.
- GCPD received 437 survey responses. Of which:
 - 140 were people with disabilities;
 - 109 were support people or caregivers to a person with a disability; and
 - 188 were advocates for a person with a disability.
- Of the survey responses received, 337 respondents completed the entire survey, and 100 respondents partially responded to the survey.

Survey Results: Person with a Disability

Survey Results: Person with a Disability - 1

- 95% of survey respondents stated that they had gone to a doctor's office, a clinic, or hospital to receive care since March 2020.
- 39% of survey respondents stated that a support person or caregiver usually goes with them to help them at their appointment or visit.
- When asked what type of support a caregiver provides responses included (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 55.3% accessible transportation;
 - 46.8% assistance with mobility (getting in the building, getting up on exam table, etc.);
 - 48.9% assistance with communication;
 - 44.7% assistance in understanding the information being provided by my medical provider; and
 - 23.4% reported other.

Survey Results: Person with a Disability - 2

- 47% of survey respondents stated that someone from the doctor's office, clinic, or hospital told them that your support person or caregiver could not go with them and/or stay with them during their appointment.
- Of those who responded that their support person was not allowed to be with them they were asked approximately how often this has happened:
 - 35% responded 5-6 times;
 - 20% responded 3-4 times; and
 - 45% responded 1-2 times.

Survey Results: Person with a Disability - 3

- Survey respondents were asked who told the individual their support person or caregiver could not be with them (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 55% Receptionist;
 - 25% Security personnel;
 - 45% Nurse;
 - 25% Health care provider (doctor, nurse, nurse practitioner, etc.); and
 - 25% Other.
- Survey respondents were then asked what the reason the person gave them was (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 36.8% Risk of spreading infection;
 - 84.2% Hospital or clinic rules or policies;
 - 15.8% Other.

Survey Results: Person with a Disability - 4

- Survey respondents were asked if they attempted to explain why it was important for their support person to be with them during their appointment or visit:
 - 58% responded yes; and
 - 42% responded no.
- Survey respondents were asked if their explanation resulted in their support person being able to stay with them during their appointment or visit:
 - 64% responded yes; and
 - 36% responded no.

Survey Results: Person with a Disability - 5

- People with disabilities were asked what happened during and/or after your visit if their support person or caregiver was unable to stay **with them** (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 56.3% responded everything worked out fine;
 - 6.3% responded the provider did not understand their problem;
 - 12.5% responded that they did understand what the provider was telling them;
 - 18.8% responded that they would not go back to that hospital, doctor, or clinic;
 - 18.8% responded other.

Survey Results: Person with a Disability - 6

- Survey respondents were asked in what type of setting did this occur (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 38.9% Emergency room;
 - 11.1% Hospital inpatient;
 - 55.6% Doctor's office;
 - 38.9% Medical clinic; and
 - 5.6% Dentist's office.
- Survey respondents were able to identify providers where they had experienced difficulties. Twelve providers were identified as systems where people with disabilities experienced issues related to support person/caregiver.

Survey Results: Person with a Disability - 7

- Survey respondents were also asked if there was anything else they wanted to share about policies and practices related to the right to have a support person at appointments.
 - These responses highlighted difficulties for individuals who are Deaf or hard of hearing.
 - Individuals forgoing medical care.
 - Not physically being able to access care.
 - Individuals not remembering or missing information.

Survey Results: Support Person or Caregiver to a Person with a Disability

Survey Results: Caregiver - 1

- 109 support persons/caregivers completed the survey.
- 85% responded that since March 2020, when the COVID-19 pandemic began, that they had been asked to accompany and assist a person who has a disability at a doctor's office, clinic, or hospital in order for them to receive care.
- When asked what type of support they provide to a person with a disability they responded (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 77.5% accessible transportation;
 - 70.4% assistance with mobility (getting in the building, getting up on exam table, etc.);
 - 85.9% assistance with communication;
 - 88.7% assistance in understanding the information being provided by my medical provider; and
 - 32.4% reported other.

Survey Results: Caregiver - 2

- 39% of support persons/caregivers responded that someone from the doctor's office, clinic, or hospital told them that they could not accompany the person they support during their appointment.
- Caregivers were then asked how often did this happen:
 - 14% responded 5-6 times;
 - 43% responded 3-4 times; and
 - 32% responded 1-2 times.

Survey Results: Caregiver - 3

- Caregivers were asked who told them they could not stay to provide support to the person who had a disability (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 89.3% Receptionist;
 - 21.4% Security personnel;
 - 53.6% Nurse;
 - 28.6% Health care provider (doctor, nurse, nurse practitioner, etc.); and
 - 10.7% Other.
- Survey respondents were then asked what the reason the person gave them was (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 60.7% Risk of spreading infection;
 - 92.9% Hospital or clinic rules or policies;
 - 14.3% Other.

Survey Results: Caregiver - 4

- Caregivers were asked if they attempted to explain why it was important for them to support the person with a disabilities during their appointment or visit:
 - 93% responded yes; and
 - 7% responded no.
- Caregivers were asked if their explanation resulted in them being able to stay with the person with a disability during their appointment or visit:
 - 32% responded yes; and
 - 68% responded no.

Survey Results: Caregiver - 5

- Caregivers were asked what happened during and/or after your visit if they were unable to stay with the person with a disability (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 17.4% responded everything worked out fine;
 - 43.5% responded the provider did not understand the person's problem;
 - 39.1% responded that the person did understand what the provider was telling them;
 - 39.1% responded the person was afraid to ask questions or did not know what to ask;
 - 30.4% responded the person did not get the medical treatment needed;
 - 13% responded the person didn't stay for the appointment;
 - 13% responded that the person would not go back to that hospital, doctor, or clinic; and
 - 47.8% responded other.

Survey Results: Caregiver - 6

- Caregiver were asked in what type of setting did this occur (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 69.2% Emergency room;
 - 23.1% Hospital inpatient;
 - 42.3% Doctor's office;
 - 38.5% Medical clinic;
 - 15.4% Dentist's office; and
 - 15.4% responded other.
- Caregivers were able to identify providers where they had experienced difficulties. Fifteen providers were identified as systems where support person/caregiver were unable to provide support to a person with a disability.

Survey Results: Caregiver - 7

- Caregivers were also asked if there was anything else they wanted to share about policies and practices related to the right to have a support person at appointments.
 - These responses highlighted support persons being essential for receiving appropriate care and follow-up.
 - Many parents of people with disabilities not being able to support their children during medical appointments or ER/hospital visits.
 - Not physically being able to access care.
 - Individuals not remembering or missing information.

Survey Results: Advocate for a Person with a Disability

Survey Results: Advocates - 1

- 188 advocates (including family member, care manager, IRIS consultant, professional advocate, etc.) for a person with a disability responded.
- 48% responded that since March 2020, when the COVID-19 pandemic began, had they learned of any individuals who have disabilities who were not allowed to have their caregiver accompany and assist them at a doctor's office, clinic, or hospital in order for them to receive care.
- Advocates were then asked how often did this happen:
 - 31% responded More than 6 times;
 - 2% responded 5-6 times;
 - 41% responded 3-4 times; and
 - 27% responded 1-2 times.

Survey Results: Advocate - 2

- Advocates were asked who told the person with disability that their support person or caregiver could not accompany them (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 57.8% Receptionist;
 - 20.3% Security personnel;
 - 32.8% Nurse;
 - 43.8% Health care provider (doctor, nurse, nurse practitioner, etc.);
 - 25.0% I don't know; and
 - 15.6% responded Other.

Survey Results: Advocate - 2

- Advocates were then asked what the reason the person with the disability was given as to why their caregiver could not stay with them (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 65.6% Risk of spreading infection;
 - 76.6% Hospital or clinic rules or policies;
 - 6.3% responded that they didn't give a reason;
 - 3.1% responded that they did not know; and
 - 9.4% responded Other.

Survey Results: Advocate - 3

- Advocates were asked if they were able to assist in intervening on behalf of the person who has a disability:
 - 83% responded no; and
 - 17% responded yes.
- Advocates were then asked if their intervention resulted in a support person or caregiver being able to accompany the person with a disability to their appointment or visit:
 - 73% responded yes; and
 - 27% responded no.

Survey Results: Advocate - 4

- Advocates were asked what happened if the support person or caregiver was unable to stay with the person with a disability during or after their visit (survey respondents were asked to check all that apply so percentages do not add up to 100%):
 - 17.5% responded everything worked out fine;
 - 25.4% responded the provider did not understand the person's problem;
 - 39.7% responded that the person did understand what the provider was telling them;
 - 42.9% responded the person was afraid to ask questions or did not know what to ask;
 - 27% responded the person did not get the medical treatment needed;
 - 15.9% responded the person didn't stay for the appointment;
 - 12.7% responded that the person would not go back to that hospital, doctor, or clinic;
 - 27% responded that they did not know what happened; and
 - 15.9% responded other.

GCPD Next Steps and Policy Recommendations

Call to Action

- Meet with ombudsman and other stakeholders to find out if they are also receiving complaints about accommodations being denied to people with disabilities in medical or health care settings.
- Work collaboratively with other disability organizations and advocates on policy and other recommendations to improve access to health care and medical treatment for people with disabilities.
- GCPD will issue press release and host a town hall forum to share these survey results with all interested stakeholders.

GCPD Policy Recommendations

- Request the Department of Health Services to issues guidance to hospitals and medical providers on civil rights compliance.
- Work on resources to provide people with disabilities who experience discrimination to be able to report these instances and know their rights to accommodations.
- Provide training on disability etiquette, effective communication, and accommodations to medical providers.

For more information, please contact:

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