



of Wisconsin Disability Organizations

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Wisconsin Personal Care Survey Report of Findings

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Background on the Need for the Survey

During 2011 many children and adults who receive personal care services through the Wisconsin Medicaid Program experienced changes in the number of hours they qualified for due to a new interpretation and a clarification of policies implemented by the Wisconsin Department of Health Services. Advocates for both children and adults with disabilities and special health care needs decided to survey families and individuals throughout Wisconsin to determine the impacts these changes/clarifications were having in the lives of individuals with disabilities and/or the ability of families to care for their family members who have a disability.

A survey was distributed via an online Survey Monkey by various disability organizations in October 2011. A total of 104 surveys were completed either by the individuals who receive personal care services or by their parents or other family members.

Survey Highlights

Families and individuals who depend on personal care workers are seeing a negative impact due to a decrease in the number of hours approved by the Wisconsin Medicaid Program. Of the 104 surveys completed, fifty one percent have seen a change in the number of personal care hours approved. Close to 95% of those who experienced a change said the change was a decrease in the number of hours approved. When asked if the change in hours was a result of changes in their family member's needs or condition, 90% answered no, it was not due to need or condition changes. Close to half also stated that the changes were not explained clearly or were explained but did not make sense.

Families who had a decrease in personal care hours experienced greater stress on a daily basis (58%). In addition their health or the health of their family members have been impacted (41%) and families' ability to work has been affected (32%).

Survey participants were also asked about a proposal to decrease payments for travel to personal care agencies. Most indicated that this change would have a negative impact on retaining their personal care workers, with 40% stating that they would lose most or all of their personal care staff. Travel payments can especially impact families who live in rural areas; over 10% of survey participants have personal care workers who must travel over 25 miles to get to their homes.

What We Learned From the Survey

Changes in Personal Care Hours

When asked if, since February 2011, the number of hours they or their family member were approved for had changed, one half (51%) answered “Yes.” Of the 43 responses, only 4 indicated that their number of hours increased. The rest had decreases in the number of hours. These changes varied significantly from having the number of hours cut in half (from 20 hours per week to 10 hours per week), to 1 hour less or 30 minutes less per day approved. A number of survey participants stated that there was a decrease of approximately 2 hours per day (from 6 to 4 hours). A few respondents stated that even though their need for hours has increased, they were not approved for additional hours.

- **Were Changes Based on Need or Condition Change?** When asked if these changes in the number of personal care hours were based on either a condition or need change close to 90% stated “No.” Only 9.5% answered “Yes.”
- **What Were Changes Based On?** For those who answered No, they were then asked what they thought the changes were based on. Examples on responses include: my condition is no longer considered “unique”; changes to the Medicaid budget, DHS deciding what my needs are; changes to the screening tool (and how ADLs are combined and how it has become more restrictive); the screening tool decreased hours even with no change of condition. One stated, “I was told that a new rating system had been implemented and everyone's hours were being lowered.”
- **Was decrease (if not based on need change) adequately explained?** Of the 61 who responded to the question, 40% stated no, an explanation was not provided for this change in hours. Only 10% stated that the reason for the change was clear and made sense. The remaining participants answered that the explanation was clear but did not make sense (23%) or some explanation was given but not enough (28%).

Impact on Wisconsin Families

Survey participants were asked how the change in the number of personal care hours is impacting their lives. For most, the changes are having multiple effects on their lives.

- 58% have experienced an increase in stress
- 41% have experienced an impact on their health and/or health of their family member

- 32% have had an impact on their ability to work

Other responses included:

- STRESS has increased for me and my personal care workers because we must do more with less time or they work without financial compensation.
- We are surviving but it affects us. I can only work part time in order to provide the appropriate care my son needs.
- It has put a tremendous burden on our family to provide the care that had been done by staff.

Travel Expense Payment Changes for Personal Care Workers

Survey participants were asked questions regarding their personal care worker and what impact a proposal by the Department of Health Services to decrease the payments to Personal Care Agencies for travel could have on their family.

- **Distance Personal Care Worker Travels to Get to your Home** – Close to 30% indicated that their personal care worker travels between 15 and 20 miles each way to get to their home. Eighteen percent had workers travel 5-10 miles each way; 16.5% had workers travel 10-15 miles each way and 11% reported that their personal care worker traveled more than 25 miles each way.
- **How Would Decrease in Payments for Travel Impact You?** When asked what they thought might happen if Personal Care Agencies received fifty percent less for travel:
 - 40% of survey participants thought they would lose some access to their workers
 - 25% thought they might lose most of their personal care staff and,
 - 15% said they would lose ALL personal care staff.

Additional Comments

A sampling of additional comments from survey participants include:

- Without personal care, I could not continue to live in the environment and family setting I am familiar with. I feel cutting hours or not providing hours that are required for my care will decrease my quality of life and may force me into a nursing home. This would be much more expensive and I don't think I would enjoy being there.
- My hours keep getting cut, despite the fact that my condition is degenerative and I need more hours. Due to that computer model that assesses what I need, I have received fewer hours. My worker may have to take on a second job which would end up forcing me into a nursing home since I need him here almost all the time.

- It is difficult to care for needs of others after coming home from work and being tired. It leaves no time for attending to family needs, keeping own house in order, It has caused depression and exhaustion as well as less attention to children’s needs.
- The most critical component in keeping my loved one out of an institutional setting is the personal care services provided by the staff. My loved one is a person with high needs and requires constant redirection, supervision and one to one staff to keep eyes and hands on him at all times. He requires hands on to keep him safe while standing or walking in his walker. This is a person with the mental ability of a 9 month old and the body and strength of an adult. Supervising the staff, setting the staff schedule and overseeing his activities, meals and safety already is a full time job for his family. I cannot care for him without the well trained, well bonded staff that we have invested time and money into. If our staff were impacted and had to leave, I would join my son as a patient in the household!

Next Steps

This report is being shared with the Wisconsin Department of Health Services and DHS Secretary Dennis Smith. These findings were presented to the Council on Children’s Long Term Support Needs and will be disseminated to others by the partner organizations that developed the survey including the Board of People with Developmental Disabilities, Family Voices of Wisconsin, Disability Rights Wisconsin and the Survival Coalition of Wisconsin Disability Organizations.

Details About the Survey

Who Completed the Survey – When asked what the age of the individual receiving personal care services is, the majority of survey participants answered that they were over the age of 18 (82%). 9% were ages 11 to 18; 5% were ages 5 to 11 and 4% were ages zero to 4.

Participants were evenly split between living in suburban areas (43%) and rural areas (40%). 17% live in urban areas.

Participants came from counties throughout Wisconsin. (Please note that 30% of survey participants did not answer the optional question about their city and zip code). Just under 15% indicated they live in Madison or surrounding areas and just over 5% live in the Milwaukee area.

Contacts

For additional information about this survey, contact Beth Swedeen, Board of People with Developmental Disabilities (**Beth.Swedeen@wisconsin.gov**), Barbara Katz, Family Voices of Wisconsin (**Barb@fvofwi.org**) or Lisa Pugh, Disability Rights Wisconsin (**Lisa.Pugh@drwi.org**).

Attachment 1 - Survey Questions

1. Age of person receiving personal care (0-5, 6-10, 11-18, Over 18)
2. Do you consider your location to be: (rural, urban, suburban/town)
3. Since February 2011, have you or your family member received notification about a change in approved personal care hours?
4. If you received a change in personal care hours, did you believe they were based on your or your family member's change in condition or needs?
5. If your/your family member's personal care hours have been decreased, what has the reduction been? (list both previous number of hours and the new number)
6. If the need for personal care hours has stayed the same but the number of hours approved were decreased, did you receive an adequate explanation for the change? (e.g., the condition of the person and their ability to perform certain activities of daily living)

Answer Options: Yes, explanation was clear and made sense; Yes, explanation was clear but did not make sense; Yes, some explanation was provided but not enough; No, explanation was not provided.

7. If you have experienced a recent change in personal care hours, please tell us how any changes have impacted you or your family member's life.

Answer Options: It has affected my ability to work; It has impacted our family finances; It has increased my stress; It has impacted the health of myself/my family member; I am satisfied with the change. It has not had an impact.

8. How far do you think your personal care workers travel to come to your house?

Answer Options: between 0 and 5 miles/minutes; between 5 and 10 miles/minutes; between 10 and 15 minutes/miles; between 15 and 20 miles/minutes; between 20 and 25 miles/minutes; over 25 miles/minutes.

9. Please indicate what you think might happen if personal care agencies receive 50% less money for travel expenses.

Answer Options: No Impact; I/we will lose some access to personal care staff; I/we will lose most of my personal care staff; I/we will lose all personal care staff.

10. OPTIONAL (So we can share anonymous stories from different legislative districts) Your city and zip code.

11. OPTIONAL - Please add any personal thoughts you may have on changes to personal care services in Wisconsin or why you value personal care services in your life or family.

**PERSONAL CARE POLICY RECOMMENDATIONS
BASED UPON RESULTS OF RECENT CONSUMER SURVEY**

1. Given statewide consumer survey responses, and DHS’ indication at public hearings that recent changes to the personal care screening tool were not a product of the current administration, **we request that DHS respond to the Survival Coalition with their ideas for addressing the concerns of consumers, as stated in the survey results, by February 1, 2012**
2. We request that DHS do a random file review of at least 50 personal care clients who had hours reduced in the last six months to objectively determine the change in condition circumstances, specifically changes related to new “modifiers” for medical condition and seizures. Reviewing 50 examples from personal care screenings that were completed in the last 6 months and comparing to last year’s authorized hours will provide helpful information. This request is based upon survey results showing that fifty one percent of families and individuals responding have seen a change in the number of personal care hours approved, with nearly all citing a reduction in hours without a change in condition. **We request that the file review be completed no later than February 1, 2012.**
3. We appreciate DHS’ recent verbal commitment to address concerns and change rural travel reimbursement back to 100%, however we remain concerned about how this policy is being defined and applied in urban settings. Therefore, given concerns identified in the survey and input on the travel reimbursement policy change provided to DHS at town hall meetings, **we request that DHS provide us with an update on implementation of the proposed reimbursement policy and any specific changes made as a result of consumer feedback by February 1, 2012.**
4. We request that DHS invite a small advisory group of consumers, advocates and family organizations into a discussion of current and expected changes to the personal care screening tool to include:
 - development and revision of the tool to address concerns identified in the survey;

- clarifying how the personal care screening tool is currently used to identify behavioral conditions as a modifier when the individual exhibits specific behaviors that require more time for cares to be completed;
- clarifying how the personal care screening tool has changed with regard to seizure conditions, meal set-up, and rare conditions, the rationale for these changes, and how these changes might impact care hours for a client; and
- whether or not the current personal care screening tool has ever been validated for use with children under the age of 18.

We request that an advisory group have an identified date to meet by February 1, 2012.

Please contact us with further questions and a response to these requests. We appreciate your time.

Survival Coalition Co-Chairs

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