Response to Request for Information on Current Population Survey Disability Supplement 2024

Prepared by:
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To: Office of Disability Employment Policy, U.S. Department of Labor
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Patient-Led Research Collaborative (PLRC) is a group of Long COVID patient-researchers who conducted the first and most comprehensive research on Long COVID. To date, there has been no representative studies in the US that estimate the impact of Long COVID on people's employment. Our study, which was a survey of people with Long COVID who were disproportionately white and highly educated, found that 45.2% of respondents who worked prior to COVID required a reduced work schedule and 22.3% were not working at all. Initial conservative estimates from Brookings in early 2022 estimated that Long COVID accounted for 15% of unfilled jobs, with that number only increasing with rising cases. Recent Household Pulse Survey data found that 7.5% of all adults in the US are currently experiencing Long COVID; given this prevalence, it is critical for the United States government to accurately measure the impact of Long COVID on the labor market in order to identify proper policy solutions. However, the Current Population Survey (CPS) Disability Supplement would not capture these effects as written. This is largely due to the inadequate measurement of disability in the CPS, which would not classify many people with Long COVID and associated conditions as having a disability and therefore be eligible for the Disability Supplement. More on this is discussed below in the General questions.

#MEAction is an advocacy organization fighting for recognition, education, and research so that, one day, all people with ME, Long COVID and other infection-associated chronic illnesses will have support and access to compassionate and effective care. We are people with ME and Long COVID, caregivers, family members and allies.

Preliminary studies are now showing that nearly half of people with Long COVID are presenting with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). ME/CFS is triggered by infection in up to 80% of cases.

As a recent publication on ME/CFS has noted: “ME/CFS is more debilitating than many chronic diseases including multiple sclerosis, chronic renal failure, lung cancer, stroke, and type-2 diabetes [1, 2]. As many as 75% of patients are unable to work [3, 4] and an estimated 25–29% are homebound or bedbound [1]. In fact, a study by Pendergrast, et al.

[5] that examined patients' functional status found that only 16% of patients were working part or full time. As a result, ME/CFS costs the US economy $18–24 billion a year in lost productivity and medical costs [1, 6]. Recovery is rare, estimated at 5%, leaving patients ill for years or decades [7]."

PLRC and #MEAction responded to selected questions from the Request for Information with the following recommendations for changes and additions to the Current Population Survey based upon PLRC's experience in conducting surveys of the Long COVID community, #MEAction's long-standing experience with barriers to work faced by people with ME/CFS, and our shared recognition of the need for proper measurement of Long COVID, ME/CFS and other infection-associated chronic illnesses impact on work.

Work History

1. Should the question about difficulty completing current work duties (location 1003-1004) be rephrased in any way? Should the response options be altered?

The answer options for 1003-1004 allow the respondent to answer about the SEVERITY of limitations. But another important axis of functional impairment for the chronically ill is the FREQUENCY with which they experience them. There should be an additional question to find out whether the respondents experience these difficulties always, often, or occasionally. The question should specifically make reference to fluctuation and use "ill health" as a prompting example of why difficulties could fluctuate.

People with complex chronic illnesses such as Long COVID and ME/CFS do not always identify themselves as having a disability, especially during early years when their disease state may fluctuate significantly. We need to have a better understanding of the workplace impacts of intermittent and fluctuating ill health.

2. Should there be more extensive questions about past work experience than the single one (location 1005-1006) previously used?

Yes, it would be helpful to include questions on the number of hours the person worked so that the survey can adequately measure whether a person has had to reduce their hours due to their disability and by how much.

3. Should the question on departure from a job (location 1007-1008) due to disability distinguish between voluntarily leaving a job and being terminated from a job in the response options?

Yes. In addition to distinguishing between a person voluntarily leaving a job and being terminated from a job, it is important to measure whether a person left a job due to lack of accommodations (or otherwise were not terminated, but were forced out of the workforce). We have seen all three situations occur within the Long COVID community.

Barriers to Employment

4. Should the set of questions about barriers to employment (locations 1009- 1010 through—1025-1026), also be asked of those currently employed and/or those who are not identified as having a disability?

Yes; these barriers can exist to people employed and to those who do not meet this survey's definition of having a disability.

5. Should the categorization of barriers (locations 1009-1010 through 1025-1026) be altered in any way, whether by adding to, removing, or rephrasing the existing categories?

Either incorporate the phrase "ill health" into one of the existing categories or have it as a separate category. While the functional limitation should theoretically include limitations from ill health, newly chronically ill do not always think of themselves as disabled. A specific question soliciting whether ill health is a work barrier would help ensure these people are captured in this survey.

Job Accommodations

9. Should the categorization of job accommodations (locations 1059-1060 through 1075-1076) be altered in any way, whether by adding to, removing, or rephrasing the existing categories?

Separate location 1065-1066 to be separate questions: one for "Changes in work tasks," and one for "changes in job schedule" as these are very different accommodations. Many workers are able to keep the same work tasks if they are able to have a flexible work schedule or work alternative hours. It is important to distinguish these so employers and employees can see what types of accommodations are available and helpful.

10. Should there be any questions asked about past requests for job accommodations, prior to the job in the current workplace?

There should be a question asking whether the respondent wanted to ask for a job accomodation but didn't either because they weren't sure how to request, or didn't believe the request would be accomodated.

Commuting and Work Hours

11. Should the categorization of transportation commuting modes (locations 1079-1080 through 1099-1100) be altered in any way, whether by adding to, removing, or rephrasing the existing categories?

An initial question asking whether the respondent commutes to work should be asked, with an option for saying that they telework/work-at-home, and if respondent says they do commute, show the various options of commuting.

12. Should there be any questions about how telework/work-at-home options have changed since the onset of the COVID-19 pandemic?

Yes. Include if they had worked from home before the pandemic, if they worked from home at any point since March 2020, and if they work from home now.

Financial Assistance

14. Should the categorization of financial assistance programs (locations 1133-1134 through 1151-1152) be altered in any way, whether by adding to, removing, or rephrasing the existing categories?

Add SNAP and TANF to the categories if not captured elsewhere in CPS as these are important safety net resources. Additionally, adding greater specificity on the type of disability insurance that is providing financial assistance could be useful since these policies have different requirements and barriers to access. Add categories for the following:

1) Short-term/temporary disability insurance payment
2) Employer-sponsored disability insurance payment
3) Individually purchased disability insurance payment

It is important to note when considering disability payments that commercial insurance plans can often have a limitation of 2-year maximum benefit payout for “mental/nervous” conditions or where the reported functional limitations are from “subjectively reported symptoms.” People with complex infection-associated chronic illnesses such as Long COVID and ME/CFS can have their disability claim classified as mental or subjective when their illnesses are not easily captured by typical medical lab testing. It would be helpful to understand the length of disability payment granted to respondents in order to have a better picture of their financial sustainability and outlook.

15. Should the question asking about having worked less due to a constraint from a financial assistance program (location 1153-1154) instead consist of a set of questions, with the response to each recorded separately, for each type of financial assistance program identified in the preceding set of questions?

Yes, it would be very helpful to understand which programs are most impacting respondents’ work constraints.

General

16. Are there any gaps in existing information about disability employment that have not been addressed by the questions contained in the past disability supplements but that could be considered for this future CPS Disability Supplement?

The CPS Disability Supplement should better capture the experiences of chronically ill workers. As the CPS is now, those who would be given the Disability Supplement do not encompass all disabled people. People who have symptoms that interfere with their work, like post-exertional malaise (the worsening of symptoms following exertion), fatigue, and insomnia, may not answer Yes to one of the six questions that aim to classify people with disabilities in the CPS. In order to properly assess the experiences of all disabled people in the US, it is critical to expand these questions and to ensure that all disabled people are eligible to answer the Disability Supplement.

In the CPS and/or Disability Supplement, please include questions specifically related to the impact of Long COVID on work. Unless the CPS is changed to ensure that all disabled people are asked the Disability Supplement questions, these questions would be more appropriately added to the main CPS. Below are example questions to include:

Since January 1, 2020, have you had a confirmed or suspected COVID infection?
- Yes
- No

[If yes] Have you ever experienced any symptoms that have been present for at least two months following your COVID infection (for example, brain fog/changes in ability to think, fatigue, shortness of breath, menstrual changes, changes to taste/smell, inability to exercise, abnormal heart rate, difficulty walking, vision deterioration, etc.)?
- Yes
- No

[If yes] Did those persistent issues/symptoms following your COVID infection impact your ability to work? [Check all that apply]
- Yes, I require/required accommodations, like flextime or teleworking, to do my job.
- Yes, I reduced my time spent on other activities (e.g. household chores, parenting, relationships, hobbies, etc.) to be able to work.
- Yes, I reduced my hours.
- Yes, I quit my job.
- Yes, I was fired.
- Yes, I am now on short-term or long-term disability.
- Yes, I am on medical leave.
- No, I have been/was able to continue working as normal.
- No, but I had to reduce hours or stop working for a reason other than my health (e.g. laid off, business closure, etc.).

Are you currently experiencing persistent issues/symptoms following your COVID infection?

- Yes
- No
- Occasionally