



Using the Washington Group Tools to Assess the Impact of COVID-19 on Persons with Disability

Introduction

The COVID-19 pandemic has provided additional and strong evidence of the need for data disaggregation to determine whether the rights of persons with disability are being protected¹. There is a growing need to rapidly gather and analyze data on COVID-19 among persons with disability. These data are essential for program and policy development at the national and global levels so that interventions and the allocation of medical, public health, social and economic resources are inclusive of persons with disability.

Data now clearly show that COVID-19 is disproportionately affecting people who are ‘at-risk’ – individuals who have chronic health concerns, people who are poorer, older, or members of marginalized groups including members of many ethnic and minority communities. People with disability fall into these categories in disproportionately large numbers. The increased vulnerability of this population to COVID-19 makes it imperative that both locally and globally public health officials, governments and researchers track the pattern of COVID-19 appearance among people with disability to assess current risk, to anticipate and plan for appropriate clinical and public health interventions, and to maximize the overall safety and dignity of the population.

Data Need Examples

Accurate data on persons with disability are particularly relevant in light of the COVID-19 pandemic. While not everyone who lives with disability is in poor health or at increased risk, many persons with disability do have underlying conditions and experience barriers to care which place them at higher risk for poor outcomes.

Examples where data would be important include:

- Medical Concerns – Some people with disability will have medical conditions that place them at increased risk of contracting COVID-19. Those with underlying medical conditions, such as diabetes and high blood pressure, are at increased risk of more severe outcomes should they become infected. Diversion of health resources to fighting the virus will also mean that the availability of many of the established basic health services on which persons with disability depend, will also be absent or limited. Decisions regarding the distribution of scarce health services and resources may also create inequities in access to, and the provision of, care for persons with disability.
- Care and Support Systems – Many people with disability depend on caregivers, support networks and long-term supports and services to enable them to function in various aspects of their lives. This includes assistance with daily activities, such as getting dressed, taking medication, preparing meals, residential supports, job coaching, transportation and managing money. Factors such as

social distancing recommendations, illness among the care providers themselves, and the competing demands on nursing and caregiving to help the population infected by COVID-19 may place multiple strains on those who provide this support. In turn, those with disability may experience increased costs and decreased availability of these essential supports and services.

- Economic Concerns – Due to a complex negative feedback cycle of social and political factors, persons with disability often receive less education, less job training and have less employment opportunities than those without disability. At the same time, persons with disability often confront higher expenses for accessible housing, daily living supports, transportation, and health care. This means that people with disability are often, on average, poorer and more likely to lose employment or income in times of economic downturn. Persons with disability, and their families, will be disproportionately affected by the anticipated economic downturn linked to COVID-19.
- Age-Related Concerns – Rates of disability increase significantly with age in many countries. For older persons with disability, and those who live with limitations in functioning, the COVID-19 situation can be especially challenging. Difficulties with seeing, hearing and mobility, for example, may complicate their ability to get the services and resources they need in times of quarantine and social distancing.

The WG Tools

The Washington Group on Disability Statistics (WG) has developed a number of data collection tools for use in collecting data from and about adults and children. The question sets reflect advances in the conceptualization of disability and use the World Health Organization’s International Classification of Functioning, Disability, and Health² (ICF) as a conceptual framework. The sets were developed to support the principle of “leave no one behind” and designed specifically for the purpose of disaggregation.

To maximize international comparability, the WG tools obtain information on difficulties a person may have in undertaking basic functioning activities that apply to people in all cultures and societies and of all nationalities and so are universally applicable. The WG tools include:

- The WG Short Set on Functioning (WG-SS)
- The WG Short Set on Functioning – Enhanced (WG-SS Enhanced)
- The WG Extended Set on Functioning (WG-ES)
- The WG / UNICEF Child Functioning Modules (2-4 years and 5-17 years) (CFM)

The question sets are well-positioned to address the growing need for information on COVID-19 and disability.

More information on the Washington Group tools can be found at the Washington Group’s website: <http://www.washingtongroup-disability.com/> or by email to the WG Secretariat at WG_Secretariat@cdc.gov.

Assessing the Impact of COVID-19

There is a critical need to understand how COVID-19 has impacted persons with disability in such areas as employment, income, food security, access to health care and health outcomes including mental health. Equitable access for people with disabilities to testing for COVID-19 and the medical, social and economic resources put in place for those affected by COVID-19 must also be part of all COVID-19 planning and programs.

The use of the WG tools in monitoring the impact of COVID-19 is very similar to the adoption of the WG tools to monitor the Sustainable Development Goals³ (SDGs) or the requirements of the UN Convention on the Rights of Persons with Disability⁴ (UNCRPD) in addition to their use in refugee and humanitarian responses. The WG tools were designed to be included in other data collections, and if included in COVID-19 targeted data collections or ongoing data collections that are being used to monitor the impact of COVID-19, it will be possible to simultaneously monitor the impact of COVID-19 on persons with disability and people without disabilities in the same populations. When the information collected is combined – both the data that identify persons with disability as well as the data collected about health, health care access and utilization, and COVID-19 itself – determinations may be made as to whether the impact varies by disability status, and to identify areas where intervention is needed to address the burden of COVID-19 on persons with disability.

Implementing the WG Tools

The WG question sets are widely acknowledged among those who work on national and global disability concerns as the disability data collection standards. They provide a quick, well-established and efficient means for COVID-19-related data collection efforts.

The WG has developed a suite of implementation guidelines for each of the WG data collection tools that can be used for disaggregation. Each question set varies in the number of questions needed for disaggregation and the types of functioning domains covered.

WG-SS: 6 questions (seeing, hearing, mobility, cognition, self-care, communication)

WG-SS Enhanced: 12 questions (seeing, hearing, mobility, cognition, self-care, communication, upper body functioning, anxiety, depression)

WG-ES: 37 questions – 20 of which are used for disaggregation (seeing, hearing, mobility, cognition, self-care, communication, upper body functioning, anxiety, depression)

CFM 2-4: 16 questions – 12 of which are used for disaggregation (seeing, hearing, mobility, dexterity, communication/comprehension, learning, controlling behavior, playing)

CFM 5-17: 24 questions – 19 of which are used for disaggregation (seeing, hearing, mobility, self-care, communication/comprehension, learning, remembering, attention and concentrating, relationships, coping with change, controlling behavior, anxiety, depression)

Each of the questionnaires and additional guidance, including information on translation, cognitive testing, questions specifications, and interviewer and analytic guidelines, can be found on the WG website or requested from the WG Secretariat.

Responses to the questions are based on an individual's self-assessment (or in some cases, proxy assessment) of their ability to undertake universal, basic activities. The WG tools are not intended for use as a clinical diagnostic tool or for determination of disability at the individual level. This is important in light of COVID-19 because although millions of people face limitations in their ability to function, not all would identify themselves as having disability. All question sets were designed to be included in censuses and surveys and can be added to any data collection system such as administrative systems or program intake systems. The WG-SS can be included with minimal additional costs and burden. The addition of the WG-SS to any data collection, for example, typically adds about 1.5 minutes to the overall administration time (the WG-SS – Enhanced set adds about 3.5 minutes and the WG-ES adds between 10-12 minutes).

No modifications are needed to the question sets for use in monitoring the effects of COVID-19. In many cases, existing data collections are being used to monitor the pandemic. If these collections do not already include a WG question set, including one of the sets will allow for the disaggregation of any COVID indicator to be disaggregated. Any new data collection should include one of the WG question sets so disaggregation can be conducted.

Data Collection Mode Considerations in light of COVID-19

The COVID-19 pandemic has affected some frequently employed data collection methods. Collections using in-person interviewing have been most affected with the majority of such data collections being suspended or transitioned to other data collection modes including telephone or web-based interviewing. Given the current COVID-19 pandemic situation, the option of delivering a survey over the telephone or on the web can be attractive. The WG has received several queries about the use of the WG question sets in telephone or web data collections and provided the following guidance for these administration modes. Several advantages result when adopting these alternative administration modes:

- data collection efforts may continue during quarantine and social distancing restrictions;
- interviewers, who would otherwise be in the community interviewing, are safeguarded from possible risk of exposure and infection;
- respondents are safeguarded from exposure to interviewers;
- response rates, which may otherwise decline given respondents' reluctance to speak face to face with someone they do not know in the middle of a health-related crisis, may be maintained.

The WG tools have been thoroughly tested, through both cognitive and field testing, but they have not been tested thus far specifically for administration in a telephone or web survey. While direct experience or evidence with how the questions work in these modalities is limited, generalizable experience with implementing phone and web surveys and reports received from organizations that have included the WG questions in phone or web surveys indicates that the WG questions can be fielded using these modalities.

It is important however to take into consideration a few issues when implementing these methods, many of which are not unique to questions on disability.

Sample Bias – As with all telephone or web surveys there is a chance of sample bias because not everyone has a telephone or uses the web. This is more of an issue, of course, in countries that have lower rates of telephone ownership and internet usage. But the issue is exacerbated when it comes to disability. Evidence from several recent national disability surveys (e.g., Thailand and Vietnam) demonstrates that people with disability have less access to telephones and to the internet. This is true at

the household as well as the personal level. That is, at least in these two countries, households with a person with disability are (a) less likely to have a telephone or the internet, and (b) within households that do have access to a telephone or the internet, persons with disability in those households have less access. For example, a household may have internet access but not have a screen reader or other software a person with vision difficulties requires. The latter issue is not as important if a respondent is responding for the entire household.

Stigma can also introduce sample bias, and this might occur more frequently in telephone or web surveys. In some cultural contexts a lot of stigma exists around disability. In fact, people have been known to hide household members with disability from view. This is even easier to do during a telephone survey or web survey where the interviewer is not able to see any evidence of an additional person and prompt their inclusion in the survey. For that reason, it is even more important to not refer to the word “disability” in any way as well as to gently prompt the respondent on telephone surveys to make sure they are including everyone in the household and to pay special attention in web surveys to ensure that all household members have the opportunity to participate in the interview.

General Considerations for Telephone and Internet Surveys – In general, simple more straightforward questions work well in telephone or internet surveys and the WG questions were designed to be simple and easily understood. The WG Secretariat is aware of surveys administered by telephone and the web that include the WG-SS, WG-ES and the CFM with no reported administration issues.

Telephone Interviewing Persons with Hearing and Communication Difficulties – People with hearing or communication difficulties may have more problems responding over the telephone, and if excluded from the data collection, could bias the survey results. Therefore, there must be some way to interview deaf persons – either by using a proxy, sign interpreter, video relay service (VRS), paper questionnaire or a mechanism where voice is transformed into written communication. In these cases, the question can be asked as written with all the answer categories presented for the interviewee to choose. Another concern is that the interviewer might feel uncomfortable asking a question that they believe they know the answer to (for example, asking a deaf person if they have difficulty hearing), but there are standard techniques for dealing with this type of situation including allowing interviewers to tell the respondents at the beginning that they are instructed to ask *all* questions and read *all* response options. These same concerns could also apply to the communication question.

Internet Administration for Persons with Vision, Cognition or Other Difficulties – People with vision, cognition or other difficulties that affect the use of a computer (or other types of internet accessible devices) may have more problems responding to questions administered via the web which, again, could bias the survey results if they are not included in the survey. Therefore, procedures must be developed to create accessible web-based surveys, and when that is not available, to interview persons with cognition, vision or other difficulties that limit the use of a computer. There are many assistive devices that accommodate vision and other difficulties in using a computer. Some of these, such as translating written text to spoken words may assist those with reading difficulties. If assistive devices are not available, a proxy can be considered.

Translation of Survey Questions for Administration During the COVID-19 Pandemic – The WG has developed an implementation guide for translation of the question sets (see Translation of the Washington Group Tools). While following the guidelines will maximize obtaining a translation that reflects the original intent of the questions and therefore also maximize international comparability of the resulting data, there are circumstances, such as during a humanitarian response or a pandemic when

timeliness is of utmost importance and it is necessary to interview in local languages for which no translation is available. In these situations, it may not be possible to follow the guidelines as written but, a version of the questions in the local language should be available prior to data collection. Translation by the interviewer at the time of the interview (e.g., “on the fly”) should be avoided since small differences in interpretation of a phrase or even a single word can destroy the reliability and validity of the data. As an alternative, the WG suggests that teams of interviewers from those specific localities/regions get together before data collection to agree, amongst themselves and with supervision, on a local language version that can be used consistently in the field.

References

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