

Appendix 5: Interviewer Instructions

Background

This document serves as a guide for “best practices” when interviewing people with disabilities. It is relevant for interview surveys but is particularly relevant for the Washington Group questions as they focus on disability. The test of the Washington Group question set will require interviewers to go in person to interview people with and without disabilities about their experiences.

Note: Interviewer procedures, including recruitment of respondents and recording sample characteristics, should follow each country’s usual practice. Sample selection is covered in the main implementation document entitled “Implementation Protocol for Testing the Washington Group Short Measurement Set on Disability”.

Administering the survey

Ideally, the interview will be completed with the respondent directly. Directly interviewing the respondent is important. It shows the person respect and allows them to speak for themselves. Often people with disabilities will not have been shown this respect in the past.

In some cases, it may not be possible to interview the person directly or alone, such as where sign language would be needed or where the person has a severe intellectual disability, dementia or is heavily medicated, or in the case of young children. In such cases, the person should be interviewed in the presence of an interpreter, facilitator or advocate (or parent/guardian, in the case of children under 16). In other cases, a proxy will have to be interviewed instead. In the case of young children, this would be a parent or guardian.

Good Practice in Interviewing People with Disabilities

Outlined below are some observations on the interviewing of persons with a disability or difficulty¹.

Good Practice in Interviewing People with Disabilities

This Section is intended to widen understanding of disability. It outlines general points on communicating with people with disabilities and provides information to assist in dealing with general issues that are pertinent to people with different types of disability. However, it must be stressed that no two persons with disabilities have exactly the same needs. The same condition may have a major effect on one person but a minor effect on another. Furthermore, while there are occasions when disability does severely affect the ability of a person to participate in an interview, a great many people with a disability can be fully effective respondents and speak for themselves.

The topics covered are as follows:

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¹ These guidelines have been developed from guidelines first developed and used in 2003-4, during the pilot project conducted in Ireland to prepare for that country’s first National Disability Survey (2006). A full report can be obtained from the website of the Irish National Disability Authority www.nda.ie or contact Dr Anne Good agood@nda.ie

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1. What is Disability

Disability is impossible to describe in one or two sentences, partly because it covers a huge range of things and also touches a large number of people. It is likely to affect everyone at some stage in their lives. Generally, a disability is inability or great difficulty in performing one or more major life activities in the person's current social environment, because of an impairment, e.g., missing, damaged or weakened body part or function.

Major life activities include the following:

- Having a full range of movement while standing, lifting, walking and so forth,
- Having intact senses (vision, hearing, touch, smell, taste, balance),
- Communicating with others (speaking and writing),
- Learning and working,
- Caring for oneself in hygiene and homemaking,
- Using mental processes such as thinking, concentrating, and problem solving,
- Interacting with others and developing and maintaining relationships.

Disability is not a specific medical diagnosis such as spinal cord injury, cerebral palsy, or intellectual difficulties. While this information is often important in a medical context, it is normally not what arises when you come into contact with someone with a disability. It is also important to recognise that, by changing the environment the person can be facilitated to increase their performance or, on the contrary, impeded from activities that they could perform in a more enabling environment.

2. Informed Consent

In all survey work, it is important to obtain informed consent from the respondent. This means that the person has understood what is involved in taking part in the survey, and has freely agreed to participate. In the case of children (under age 16 for our purpose here), a parent or guardian must be present during the interview and must agree that the child can participate. In interviewing people, it is important to ensure that the person understands what is involved in taking part –

- that you will be asking questions that the respondent will answer,
- what the questions will cover,
- the approximate length of time it will take,
- that the information is confidential (nobody apart from you and the researchers can link the answers back to this person),
- that the person is free not to participate or to refuse to answer any particular questions
- the purpose of the research
- who commissioned the research and
- that we cannot promise any immediate benefit as a result of the person taking part in the survey.

In the case of people with intellectual disability, depending on the severity of the condition, you may need to take some extra time to ensure that the person is freely giving consent to participate. When in doubt, suggest that the person may wish to have a friend or a family member present to give support or act as advocate.

It is also important to leave a copy of any information for potential respondents with each respondent in the appropriate format (e.g. Braille, easy-to-read, tape or disc). Alternatively, you could take some time to read it to the respondent.

3. Meeting People With Disabilities

- Meeting people with disabilities is no different from meeting anyone else - it is simply a matter of common courtesy. If in doubt, rely on your own common sense and ask the person if/how you can help.
- People with disabilities, like everyone else, have the right to say no.
- People with a disability want to be treated in the same way as people who do not have a disability. They should not be treated as special or incapable so you should not take over tasks that they could quite well do themselves.
- People with disabilities, like anyone else, may get upset and this can be for various reasons. For example, they may have been offered help 17 times that day already or they are simply being rude and unreasonable. You may need to explore these reasons with them in a respectful way.
- When the people you are meeting are adults you should treat them in the same way as you would treat any adults. Do not treat them like children. Do not treat them with more familiarity than you would anyone else.
- When interviewing people with a disability, especially if the person is present during a proxy interview, be sure to address the question to the person with a disability, and not to the interpreter or the person facilitating the interview.
- Do not be embarrassed about using common expressions, such as "see you later" or "I'll be running along now", which may seem to relate to the person's impairment.
- Always relate to the person with: respect, dignity, empathy and equality.

4. Meeting People with Hearing Disabilities

People with hearing impairments may be born with the impairment or may become (gradually or suddenly) hearing impaired through accidents, illness or environmental factors. They can have a range of hearing abilities, but a very small percentage may have no hearing at all.

It is important to note the difference between people who have developed a hearing impairment before learning to talk and read - pre-lingual deafness - and those who develop a hearing impairment after acquiring speech - post-lingual deafness. People with pre-lingual deafness will experience greater difficulties in acquiring speech and written language as this is generally learned through the spoken word. Many people with hearing impairment may have speech or speech patterns that are difficult to understand. However, this does not reflect their intelligence or their proficiency in language.

Communication and People with Hearing Disabilities

Most people with more severe hearing disabilities have a preferred method of communicating. It may be using speech, lip-reading, sign language, writing or through a combination of these methods. Before attempting to conduct an interview it is vital to establish the best method of communication for the individual respondent and to set up the supports necessary to use that method.

Lip-reading

Lip-reading involves watching the lips of the person who is talking and determining what is being said. This can be difficult, as several sounds have a similar appearance. Most people with hearing disabilities have some facility with lip-reading, and some use it as their main method of receiving communication. It also helps, with the lip reading, if the person is provided with contextual clues to provide extra information. However, it does take time to become accustomed to how a person speaks and getting used to different accents can be difficult.

Sign Language

A large proportion of people who are deaf use sign language. Sign language allows people to convey exactly the same meaning, through signs, as through spoken language. If a person uses sign language as their method of communication, it may be necessary to provide an interpreter for the interview. This may be a family member, friend, colleague or a trained interpreter.

Equipment

Hearing Aids

Many people, who are hearing impaired, use a hearing. These work by amplifying sound, but, as all sounds are equally amplified, it is important to eliminate background noises.

Induction Loop Systems

For many people who use a hearing aid, an induction loop system can also be useful. The 'loop' comes as either a room loop or an individual induction loop, and works in similar ways using radio signals to transmit sounds through a microphone to the person's hearing aid, which has to be turned to the 'T' switch to receive sound. Room 'loops' are either built in to the room or can be portable systems that are plugged into a wall socket. You need to check that there is good reception before use and that the microphone can pick up sound well.

Radio Aid

A radio aid works in a similar way to the induction loop system; the speaker clips the microphone to his/her clothes, and the person using the hearing aid carries the loop around his/her neck.

Telecommunications

Telephones can be adapted for use by people with hearing disabilities and many telephones may be fitted with amplification devices or a device that may be used with a hearing aid. Alternatively, some people with hearing disabilities attach a 'Minicom' to the telephone, allowing them to communicate through text.

E-mail, faxes and text messages via mobile telephones are also viable options for people who are deaf.

5. Interviewing People with Hearing Disabilities

The following is recommended: -

- Face the person at all times when speaking. Do not cover your mouth or rest your chin on your hand when speaking. Do not turn away when speaking - stop speaking when you turn to look at a screen or get information.
- Get the person's attention before you start speaking, using visual cues.
- Ensure that only one person at a time is speaking.
- If difficulties occur when you are speaking directly to a deaf person, you may want to use written notes or let them see the questions on the questionnaire.
- Do not assume the person can lip read. Even if the individual can lip read, it is never wholly reliable. Only about 25% of words are visible on the lips, so you will have to check that you have got your message across.
- If the person is lip reading, you should
 - Make sure you are facing the light and that your lips are visible (keep hands, etc. away from your mouth)
 - Speak slowly and clearly, at a steady rhythm. Shouting does not help and may in fact make it more difficult to understand.
 - Use facial expressions and gestures that emphasise the words you use.
 - If you think you have not been understood, do not repeat the sentence. Think of ways to rephrase your sentence.
- If an interpreter is present, speak directly to the deaf person. The interpreter will sign the conversation between you.

6. Meeting People with Physical Disabilities

People with physical disabilities may be born with an impairment or acquire one later in life. The causes of physical impairments are very wide and the impairment can affect the person's bones, muscles, joints, nerves, tendons, spinal cord and/or the brain. The condition leading to the impairment can be stable or degenerative, as in the case of multiple sclerosis. The person's impairment renders them unable to perform the same range of physical activities that able-bodied people do and, consequently, they may face barriers of access. Barriers of access may be overcome by examining:

- access to and within the physical environment;
- adapted or specialist equipment;
- use of personal and/or training assistants.

Overcoming Barriers of Access

Access to and within the Physical Environment

One of the key issues for people with physical disabilities is that of access to, and within, buildings. The individual may be a person who uses a wheelchair or with a mobility impairment. It may be an individual who has a perceptual or neurological impairment who may have difficulty with co-ordination. Staff should explore and discuss, with the individual, possible barriers within the physical environment that need to be considered and, where necessary, overcome these barriers. For example, it may be necessary to modify or change furniture in rooms to provide access, or they may need help in negotiating their way around an unfamiliar environment.

Some people with physical disabilities may have a car and may need reserved parking. Alternatively, they may face barriers with regard to access to public transport, so extra travel time may need to be allowed

Potential access problems, e.g., toilet facilities, parking, steps, etc should be identified and addressed as part of the interview planning process.

Adaptation to Equipment

Some people with physical disabilities may require adaptations or specialist equipment to help augment their mobility impairment(s). They may need tape recorders to record notes, notetakers and/or computers. They may also have specialist equipment to help them manipulate items or machinery.

Some individuals will have knowledge about the specialist equipment and computers that are available to them, but some will not and will need to be informed.

Personal or Training Assistants

Some people with physical disabilities may have a personal assistant to help with self-care skills, eating, writing, etc. The person may also need help with moving from place to place and carrying equipment or notes. It is important to note whether the individual with a disability has a personal assistant.

7. Interviewing People with Physical Disabilities

The following is recommended: -

- If you are talking to someone in a wheelchair try to put your head at the same level to avoid stiff necks.
- Do not push a wheelchair without asking the person first.
- People who use sticks or crutches may find it difficult to use their hands while standing so do not expect this.
- Never address the escort or personal assistant, instead of the person with a disability, always talk to the person.
- Remember that first impressions are often deceiving. New and stressful situations may increase muscle stiffness and decrease individual's control and dexterity.

8. Meeting People Who Are Blind or Partially Sighted

People with visual impairments may be born with an impairment or acquire one later in life. It is important to note that most people, while registered blind, may retain partial sight; only a very small percentage are totally blind. People with visual impairments will have different degrees of sight and their impairment may differ. Some people may have blurred vision, or may not be able to judge distances and speed, or to distinguish between objects that have a similar colour or shape. Other people with visual impairments may only see things that are very close, or have a restricted range of vision, such as tunnel vision that excludes periphery vision. A small proportion of people with visual impairments may have another impairment.

Mobility

Some people with visual disabilities will own guide dogs. These are highly trained and obedient animals and must be allowed to accompany their owner anywhere she/he goes. The dogs will need to have access to an exercise area at regular intervals and to water. Other individuals with visual disabilities will use a long cane, usually white in colour, to help them with their mobility.

Communication with People Who Are Blind or Partially Sighted

Most people with a visual disability will have a preferred method of accessing printed matter - be that through large print, tape, Braille, or a combination of these. Alternatively, many people with visual disabilities use voice activated computers and may require printed matter on disc or via e-mail. As a general rule of practice, printed material needs to be clear and simple, with a good contrast in colour - usually black ink on white paper - and an uncomplicated layout. The font size, depending on the font used, is normally 14 -16 and 1.5 or doubled spacing between sentences.

Large print

Large print is material printed using a minimum letter size of 14 point and preferably 16-18 point letters. It can be produced using either a word processing package on computer or enlarging material on the photocopier. It is important to note that, if the print is too large, it becomes difficult to read and retain a sense of continuity.

People with visual disabilities who prefer large print may also use an adapted VDU, which projects an enlarged version of a page onto a screen. They may also use computer software packages that enlarge print or via the Zoom on standard Word packages.

Tapes

Many people with visual disabilities opt for using tape cassettes. It is the preferred method for large amounts of print such as textbooks or large reports or reference material. While many computers can now output information through a voice synthesiser, this is not practical for large amounts of printed matter.

Braille

Braille is a system based on patterns of raised dots to represent letters. Very small proportions of people with visual disabilities use Braille, as it takes some time to learn. However, Braille offers a system that is exactly parallel to print. It is possible to get a Braille embosser that prints material from a computer so that the person can have unlimited access to materials, but most institutions send material away to be transferred into Braille.

Other Considerations

- When help is needed on unfamiliar ground - say, "Let me offer you an arm". Offer your arm to the blind person just above the elbow. This will enable you to guide, rather than propel, and your guide partner will be a half step behind you.
- Do not grab anyone by the arm unannounced - they might think you are a mugger.
- If you are guiding a blind person up or down steps, warn them that there are steps coming up and make sure you are a half pace in front of the person.
- When offering a seat, place the person's hand on the back or arm of the chair.
- When providing information or giving instructions, ensure they are precise and specific. For example, do not say 'over there' and accompany this with vague pointing; you need to state, 'left-hand side of the desk'.

9. Interviewing People Who Are Blind or Partially Sighted

The following is recommended: -

- When you approach a blind person remember to identify yourself clearly, and indicate anyone else who is present - e.g. "Hello, Mr. Clarke, I'm John Murphy and I have Pat Casey with me". You can touch them lightly on the arm to indicate you are addressing them.
- Do not leave someone talking to an empty space. Say when you wish to end the interview or move away.

10. Meeting People with Speech and Language Disabilities

Some people with speech and language disabilities may have difficulties in articulating sounds or understanding and formulating thoughts in spoken or written words (dysphasia). These difficulties may be immediately perceptible, e.g. the person has a bad stammer or if they have pre-lingual deafness (see unit in this section on People with Hearing Disabilities). Or they may not emerge until discussion focuses on more abstract matters. Difficulties in speech and language may be associated with particular conditions, e.g. when the facial muscles are affected, as in stroke and cerebral palsy.

Most individuals will have a preferred method of communication and you will have to negotiate with them as to what it is and what the optimum method of communication will be between you. It may be through written communication, speech synthesiser, sign language, lip-reading or via a Personal Assistant.

11. Interviewing People with Speech and Language Disabilities

The following is recommended: -

- People with a hearing disability will sometimes have speech that is difficult to understand since they have never heard others speak and have nothing to copy. Equally, people with conditions that affect the muscles of the jaw and mouth may not be able to articulate well, while others may have a severe stammer.
- Be encouraging and patient. Do not correct or speak for the person. Wait until the person finishes and resist the temptation to finish sentences.
- Where possible, ask questions that require short answers or just a nod or shake of the head.
- If you do not understand, do not pretend. Repeat as much as you do understand and use the person's reactions to guide you. Ask them to tell you again, if necessary.

12. Meeting People with Specific Learning Disabilities

People who encounter difficulties with learning, and using, particular skills, are referred to as having specific learning difficulties, the most common difficulties being language problems, particularly with reading and writing - sometimes referred to as Dyslexia. Others who may encounter specific learning difficulties are people who have head injuries, as well as people with cerebral palsy who may have specific learning disabilities, in addition to other physical and/or sensory disabilities.

People with specific learning difficulties may also have difficulties with spatial orientation, such as directions like left and right; hand-eye co-ordination; remembering common sequences such as the days of the week, tables and the alphabet; the sound of words or the order of numbers, such as phone numbers; and with arithmetic concepts, such as decimals. They may also be perceptually impaired, having difficulties with a specific modality such as vision, auditory discrimination, or their sense of touch. These types of impairments do not arise because of any associated medical condition.

A psychologist often identifies people with specific learning difficulties via educational and psychological assessments. People with specific learning difficulties do not have intellectual difficulties, but lack confidence in the educational/training environment because of their struggles with learning. Because of this, some people may require extra help with basic reading, writing and numeric skills and may need to be referred to a teacher or tutor trained in this area. Alternatively, they may have developed their own ability to compensate for the difficulties they experience by using alternative learning methods. Computer technology has also been a great help to people with specific learning disabilities. Most software packages include spell and grammar checks, and people can also use scanners, screen readers and voice-recognition software.

13. Interviewing People with Specific Learning Disabilities

The following is recommended: -

- If the person is having difficulties in understanding you, take time to explain, using a variety of formats and be prepared to explain it more than once. Concentrate on keeping your language straightforward and avoid using jargon. If necessary, offer to show them the questionnaire.

- Depending on the nature of the impairment, people with specific learning difficulties may require assistance in participating in the interview.
- People with specific learning difficulties may prefer using computers to provide legible output and to enable them to use a spell check. This is particularly relevant to the part of a questionnaire where the person is asked for feedback.

14. Meeting People with an Intellectual Disability (General Learning Disability)

The term intellectual disability is currently replacing use of general learning disability. Sometimes the latter term can lead to confusion with learning difficulties such as dyslexia, so the term intellectual disability is preferred. People with an intellectual disability have a degree of impairment to their intellectual abilities, which can range from a very mild to a severe impairment. Generally, a person with such a disability will not attain the full intellectual capacities of most adults and will, on average, be slower at learning and carrying out tasks.

Intellectual disability can have a variety of causes. These include brain damage during or immediately following birth, infections, chromosomal/genetic malformations and socio-environmental factors that may have affected, in particular the mother. However, the cause must occur during the developmental years 0 - 18.

People with a mild intellectual disability will be slower at learning but may be able to obtain employment in the open labour market. People with a moderately severe intellectual disability are impaired to the extent that they will probably require supported or sheltered employment. The condition is permanent, as it is the result of damage to, or malfunction of, the brain itself and is sometimes accompanied by other disabilities of a physical nature. In general, a person with an intellectual difficulty functions at a level that is significantly lower than their chronological age.

As an intellectual disability is often confused with mental illness, it is very important that staff fully understand the difference between these two conditions.

15. Interviewing People with an Intellectual Disability

The following is recommended: -

- People with learning disabilities, or intellectual disabilities, may have difficulties in reading and writing, or in understanding questions.
- It is important to go through the following points to make sure that the person is giving an informed consent to participate in the interview:
 - That you are conducting a survey on disability
 - That this means you will be asking several questions
 - That the information will be used for research
 - That the information is treated in confidence – nobody else, apart from the interviewer and the researchers, will be able to tell who the respondent is
- You should offer to explain forms or particular terms or language that may not be generally understood.
- Listen carefully to what the person is saying, not how it is said.
- Be prepared to explain more than once, if the person does not understand the first time.
- If necessary, suggest that the person may want to have a friend or relative present during the interview.
- Offer to write down your name and telephone number if the person wants to come back to you later for clarification.

16. Meeting People with Emotional or Mental Health Disabilities

The definition of mental health and mental illness is related to what is considered normal and abnormal in our society. It also relates to matching our perception of what one may cope with and what one may find threatening. Prejudice, or barriers of attitude, is often based on our perception of someone who has mental health difficulties and the fear which may arise as a result of that perception. It is important to remember that one in four people can experience mental health

difficulties at some point in their lives and that mental health problems do not manifest themselves all the time.

People with mental health difficulties may be affected across a continuum of disabilities. Some will have conditions that are temporary and easily treated through rest, medication and/or counselling. Some will have conditions that may become severe enough to disrupt their life and render them unable to cope with day-to-day living; others may have long-term conditions with periods of good health interspersed with bouts of poor health. Some people with mental health difficulties may need to take medication to alleviate the condition. This may interfere with concentration and stamina, impacting on timekeeping.

Mental Health Difficulties are divided into two broad groups: neuroses and psychosis.

Neurotic Illnesses

Neurotic Illnesses are an exaggerated way people usually respond to stress. A person's problems become so big that they interfere with normal life and the person can no longer cope with them effectively. Although their feelings become disturbed, a neurotic person is still able to reason and is well aware of the problems and difficulties he or she is going through.

Psychotic Illnesses

Psychotic Illnesses are where people lose touch, with what is going on around them, with ordinary reality. Their thoughts become disturbed as well as their feelings, and they are no longer able to sort out what is real from what is not. It is important to remember, though, even in a very severe psychotic illness the person experiences periods when he/she can think and reason perfectly.

Characteristic of some people with mental health difficulties is lack of confidence or self-esteem and feelings of vulnerability, so every effort needs to be made to put them at their ease. This means support and flexibility, through the occupational guidance process, and encouragement by highlighting small achievements.

17. Interviewing People with Mental Health Disabilities

The following is recommended:

It is important to remember that the side effects of some medications may interfere with the individual's concentration and stamina. In these circumstances, it is important to keep the interview focused and short. If necessary, arrange to come back at a later time or date to complete the questionnaire. Establish a good relationship and give the individual plenty of encouragement and support. Sometimes people with mental health difficulties may be withdrawn or disruptive because they have not understood, or experience frustration in trying to complete a task. Intervene and break the cycle by suggesting a break or another interview. Make allowances for stressful events. Either may contribute to the individual not performing at their potential.

18. Meeting People with Hidden Disabilities

Some people will have hidden or unseen disabilities; that is, disabilities that do not manifest themselves as an ongoing, outwardly visible condition. These include epilepsy, diabetes, ME, haemophilia, asthma, anorexia and other chronic conditions. Often these conditions may affect the person's health and stamina. For example, the person who has a hidden disability may have stable health for most of the time, but stress, some unforeseen incident or the condition itself, may cause their health to fluctuate occasionally. In addition, the condition itself or medication for the condition may have an effect on the person's stamina. It is important to remember that issues of health and stamina will vary from person to person - some people will not be affected in any way while others require regular breaks.

Often people with some of these conditions face considerable prejudice with regard to employment, education and social interaction and may be inclined not to disclose their disability to a potential employer. Therefore, it is important that you re-assure these individuals by stating how the information will be used and working out, together, the best way to disclose information about their particular disabilities.

19. Interviewing People with Hidden Disabilities

The following is recommended: -

- Ensure that stressful situations are minimised. This may be done by making the individual feel at ease and confident.
- Be prepared to make another visit to complete an interview, depending on the individual's stamina and energy levels.