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Foreword

In February 1981, (The International Year of the Disabled), The Special Committee on the Disabled and Handicapped published its report entitled "Obstacles". This report made 130 recommendations to various areas of the Federal Government. Recommendation 113 of the "Obstacles" report reads in part:

"That the Federal Government direct Statistics Canada to give a high priority to the development and implementation of a long term strategy which will generate comprehensive data on disabled persons in Canada, using population-based surveys and program data."

The Federal Government, wishing to respond positively to this recommendation, requested that Statistics Canada undertake a survey on Canadians with disabilities.

In 1986, Statistics Canada conducted the first Health and Activity Limitation Survey. A second survey took place in 1991. The survey was designed to identify Canadians with disabilities and to determine what limitations they experienced and barriers they faced.

The 2001 Participation and Activity Limitation Survey is being conducted by Statistics Canada and is funded by Human Resources Development Canada. It will draw a current profile of Canadians with disabilities and gather new information responding to new data needs that have emerged since the last survey. As reflected in the new name, the 2001 survey will focus on the participation of persons with activity limitations.

Chapter 1: General Information

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Purpose

The Participation and Activity Limitation Survey is a national survey that will gather information about Canadian adults and children whose everyday activities may be limited because of a health-related condition or problem.

Government and private organizations need to identify and address the barriers faced by Canadians with activity limitations in all areas of daily life, whether at home, at work, at school or in their communities.

Background

The Participation and Activity Limitation Survey (PALS) is a post-censal survey which means that it will be conducted shortly after the 2001 Census. One of the benefits to a post-censal survey is cost reduction, as some of the operational costs are shared by the 2001 Census.

PALS will be conducted in two steps. The first, the Census of Population, includes two questions on activity limitations. These questions are part of the long census form, which is administered to one out of five households in Canada. The aim of this step is to select a sample of respondents who answer "yes" to either question. This will identify the target population of the Participation and Activity Limitation Survey. The second step of PALS is the actual survey, which will take place in the fall of 2001.

Survey collection will be conducted mostly through telephone interviews although some personal interviews will be done with respondents unable to respond over the phone. Prior to data collection, an introductory letter and brochure will be sent to respondents which will inform them about the upcoming survey and impress upon them the importance of their participation.

To maximize direct participation of deaf persons, the letter will also provide an e-mail address and a phone number whereby these respondents can contact us to set up a personal interview via a Sign language interpreter.

Why we conduct the Participation and Activity Limitation Survey In 1991, there were 4.2 million Canadians who had health-related problems or conditions that limited their ability to hear, see, communicate, walk, climb stairs, learn or do other everyday activities in the way most Canadians take for granted. These Canadians face barriers, which must be identified and addressed if all citizens are to participate fully in Canadian society.

The Participation and Activity Limitation Survey is designed to identify:

- Canadians with an activity limitation;
- the type and severity of activity limitations that they experience; and
- the difficulties and barriers that they may face.

Survey Sample

PALS Sample

The sample includes children and adults who reside in private dwellings and in some specific collective dwellings.

The <u>estimated</u> sample sizes by Census Site and Regional Office are given in the following table. These figures are based on projections. There could, therefore, be differences between these estimates and the actual sample size, depending on the answers provided in the census.

Sample distribution by provinces			
Province	Interview by phone	Interview on site	Total
Newfoundland	3001	140	2005
Prince Edward Island	1856	82	1171
Nova Scotia	5036	220	3149
New Brunswick	4155	184	2628
Quebec	4433	195	2786
Ontario	5228	228	3254
Manitoba	4533	197	2816
Saskatchewan	5207	226	3235
Alberta	4920	212	3022
British Columbia	5028	215	3067
Yukon	461	17	244
Northwest Territories	608	24	338

Schedule of Activities

Activity	Duration	Time Frame	
Complete the self-study		prior to training	
Installation of program		As per technical support group	
(Access Programs)	1 day	schedule	
Classroom training	2 days	August 14, 15, 16, 2001	
Data Collection		September to December, 2001	
Interviewer debriefing	-	After data collection	
Survey clean-up	_	December (2 days)	
Final shipment	-	December, 2001 ⁱ	

Chapter 2: Your Job as an Interviewer

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Legal Authority and Confidentiality

Statistics Act

The *Statistics Act* is one of two acts of Parliament, which affect you and the respondent. You must be aware of certain provisions of this Act and ensure that you conduct yourself in an appropriate manner at all times.

The *Statistics Act* states that all information collected in any Statistics Canada survey must be kept strictly confidential. Under the *Act*, all Statistics Canada employees must take an oath of secrecy. No personal information, which could identify respondents or their families, can be given to anyone or any other government department without permission.

Legal authority

This survey is conducted under the voluntary provisions of the *Statistics Act*.

To obtain a high response rate in a voluntary survey, it is essential that you become familiar with the purpose of the survey. Your ability to convey the importance of the survey is the best way to obtain the respondent's cooperation.

Never discuss the *Statistics Act* with respondents. If a respondent specifically requests information about the *Act*, you should answer that while the *Statistics Act* contains the authority to collect information, we are seeking the cooperation of respondents.

Guidelines to ensure confidentiality

To protect yourself against a breach of confidentiality

- do not discuss any information about your interviews with any unauthorized persons (e.g., family, friends, neighbors).
- When the label has been applied on the questionnaire, the questionnaire becomes confidential. Keep it face down.

Note: Whenever you contact someone about a respondent, DO NOT DISCLOSE any information other than the respondent's name. Any information collected under the Statistics Act is strictly confidential and must remain so.

Local Interview

If you encounter a situation where you recognize the address or know the respondent:

a.				
Step	Action			
1	Upon contact with the respondent, ensure that he/she feels comfortable allowing you to conduct the interview.			
	If the respondent feels	Then		
	• comfortable	Conduct the interview.		
	• uncomfortable	Tell him/her that another interviewer will be in touch. Assure him/her that you will not see the completed questionnaire. Thank him/her for his/her time and leave.		
2	Record everything you do in the Record of Visits section of the questionnaires.			
3	Advise your senior interviewer that this case may have to be transferred to another interviewer.			

Official Languages

Official Languages Act

The *Official Languages Act* is the second of the two Acts of Parliament which affect you and the respondent. The *Official Languages Act* states that service to the public must be provided in the official language (English or French) of the respondent's choice.

You must always respect a respondent's choice of official language.

Bilingual interviewers

If you are bilingual, you must be prepared at all times to communicate and to conduct interviews in either official language.

Unilingual interviewers

If you cannot conduct an interview in the respondent's official language choice, you must inform the respondent that a bilingual interviewer will call back.

Need more
information?

Further details of the *Official Languages Act* can be found in the "Introduction to Interviewing" booklet.

Roles and Responsibilities

Your role

Your role as an interviewer is not strictly confined to interviewing respondents. Other responsibilities include:

- completing all required training
- tracing
- completing administrative forms

Your supervisor

Your supervisor will guide and assist you throughout the survey period. Direct all your questions to this person, especially if you encounter a difficult situation while you are interviewing.

Your supervisor may monitor your interviews to ensure that you are following survey procedures correctly.

Training

You will complete the following types of training:

Type	Description
Self-study	You are required to read this manual prior to attending a classroom training session.
	Complete the quiz.
	New interviewers to Statistics Canada are also required to read the "Introduction to Interviewing" booklet.
Classroom	During the classroom training session you will conduct
Training	several mock interviews.
	Receive answers & explanations to quiz
	This will allow you to become familiar with the
	questionnaire and basic interviewing procedures.
On-the-job	If you are a new interviewer, your senior interviewer will
Training	probably observe your first few interviews and help you with any problems you are experiencing.

Survey Materials

List of supplies

In addition to this manual, you will be given the following survey supplies to conduct interviews:

- Telephone with a headset
- Laminated outcome codes list

Chapter 3: Getting Started

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Introduction

Survey collection will be done by telephone interviews conducted in Census sites and through personal interviews conducted by field interviewers in Regional Offices.

Conversion of personal interview to telephone interview Some cases have been pre-identified as being personal interviews in the original sample. However, some respondents may prefer to do the interview over the telephone rather than in person. In these cases, please do the interview by telephone and indicate in your notes that the interview has been completed by telephone instead of by visit. At the end of the interview, advise your supervisor of the change and in turn, your supervisor will update the database in order to indicate the change.

Conversion of telephone interview to personal interview

If a respondent cannot complete an interview over the telephone because of a condition or health problem, you can offer to have the interview completed in person. You will give the questionnaire to your supervisor who will ship it to the nearest regional office. The Census site will update its database to indicate the change.

If the label has already been affixed, make sure to ship the questionnaire in a Versa Pack as you would a confidential document. Use the same mode of shipping for any label. These documents are confidential and must be handled as such, always using a courrier service.

Interview in the "Outback"

In your sample, you may have respondents located in very remote areas. In these cases, please contact your supervisor and verify if he approves a personal interview or if you should conduct the interview by telephone.

Adult or Child questionnaire

There are two PALS questionnaires:

The "Adult" questionnaire, used to interview respondents who were 15 years or older on Census day, May 15, 2001.

The "Child" questionnaire used to interview the parent or guardian of a child who was under 15 on Census day, May 15, 2001.

The assignment of an Adult or Child questionnaire is initially made using the date of birth on the 2001 Census form for the selected respondent. If the respondent was born AFTER 1986 05 15 (after 1986 May 15), a Child questionnaire is assigned. Otherwise, an Adult questionnaire is assigned.

When conducting <u>telephone interviews</u> make sure to have extra copies of adult and child questionnaires on your desk. In case you are doing <u>personal interviews</u>, make sure that you carry extra copies of the questionnaires on your visits.

Adult Questionnaire -Who Should Respond?

The intended respondent for the adult interview is the selected adult 15 yrs or older. It is important to try to get responses from this person, as it is their perception of their own reality that is important to us. If this adult is available but for some reason (hearing limitation, does not speak English or French etc.) is only able to respond through an interpreter, then we will accept the interpreted responses. The interpreter must relay questions from the interviewer to the respondent and then relay the respondent's response back to the interviewer for each question. Only as a last resort should a proxy be interviewed and this is only after all other avenues have been exhausted.

Child Questionnaire Who should respond?

The intended respondent for the child interview is a parent or guardian of the child. We do not want the child to respond because many of the questions are difficult for a child to answer. For example, some questions relate to the family's economic situation, parent's work arrangements and social supports.

As with the adult questionnaire, if the parent or guardian is available but for some reason is only able to respond through an interpreter, then we will accept the interpreted responses. As a last resort, once all other avenues have been exhausted, a proxy is interviewed.

Front page of questionnaire

How to fill in front page of questionnaire

At the very top of the page is the title of the Survey as well as two possible different sub-titles which is the status of the respondent (Adults -15 and over) and (Children - under 15

Next is the introduction to be read to the respondents. At times, you may have a respondent who is in a hurry and asks you to skip the introduction. You have to tell the respondent that "all information will be kept confidential and that a supervisor may listen in to evaluate the survey." These few words are essential and you cannot skip them. By law, a respondent needs to be advised that he will be listened to.

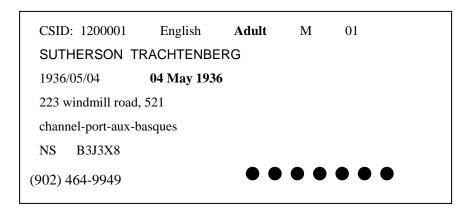
The section entitled CONFIDENTIAL WHEN COMPLETED means that when a label is applied, it becomes a confidential document. This is where you apply the label, which displays the following: the case identification number, the respondent's language, sex, name, as well as the date of birth, address, phone number and bar code.

On the first line you have the case ID that comprises 7 digits the first two being the province number. Then you will find the language of the respondent, his/her status and his/her sex (M or F). A number is showing at the end of this line. When you have a 01, you know you are dealing with a single respondent per household. Any number higher than 01 indicates that you are dealing with a multi. (several respondents within the same household)

Single – means that there is only one respondent in the household

Multi – means several respondents within the same household.

- On the second line, you find the respondent's first name then family name.
- On the third line, you will see the respondent's date of birth given in a
 numerical way as well as in alpha. Remember that when you correct a date
 of birth on the questionnaire, you should do it numerically only.
- The fourth line will show the address
- The fifth line show the city
- The sixth line displays the province abbreviation and postal code
- The seventh line shows you the respondent's telephone number and the bar code that represents the electronic case identification. You NEVER touch these bars.



• Right below the label, are the boxes for corrections related to the information on the label. If you have any corrections to enter, please print your corrections. Correct the date of birth by numbers only (do not attempt to write in the month).

Change of Status/ Questionnaire

When confirming the label information with the respondent, if the DOB provided by the respondent differs from the label, first verify that you have the right respondent. For example, you could encounter a household where there is a John Doe, Senior and a John Doe, Junior. If indeed the DOB is different from the label, record the proper DOB on the front cover of the questionnaire. If the DOB indicates a change of status, proceed as follows:

1) From a child to an adult:

If the DOB on the label is AFTER 1986 05 15 (after 15 May 1986) and the new confirmed DOB is BEFORE OR ON 1986 05 15, transcribe the information from the label onto the appropriate questionnaire (enter this information in the boxes reserved for corrections). On the obsolete questionnaire, cross out the label and enter code 19 in the FIELD STATUS CODE in order to identify that this case has a change in status. If you are not already speaking to the actual respondent him/herself, ask to speak to him to complete the interview.

When the interview is completed, give it to your supervisor who will update the database. If the label had already been affixed on the wrong questionnaire, ask your supervisor for a new label. Upon reception of this new label, affix it on the right questionnaire and staple both questionnaires together before shipping it all to Ottawa.

2) From an adult to a child

If the DOB on the label is BEFORE OR ON 1986 05 15 (before or on 1986 May 15) and the new confirmed DOB is AFTER 1986 05 15, transcribe the information from the label onto the appropriate questionnaire (enter this information in the boxes reserved for corrections). On the obsolete questionnaire, cross out the label and enter code 19 in the FIELD STATUS CODE in order to identify that this case has a change in status. If you are not already speaking to the actual respondent him/herself, ask to speak to the parent or guardian of the selected respondent.

Replace Labels

If you need to replace a label, ask your supervisor for it. He will request it from Ottawa. In the coming days, your region will receive it electronically and you will print it at your office.

Number of residents

Number of residents in the household: You have to record in each box respectively the number of adults and children living in the household.

Information Source - Adult Ouestionnaire

The possible sources of information for the adult questionnaire are divided into three broad groups only. Your source of information will fit into one of these groups. Fill out the Information Source Box on the cover page as follows:

<u>Respondent:</u> The respondent is the original household member chosen to answer the questionnaire.

Respondent (via interpreter): This is when the respondent's own answers to the questions are relayed through a third party interpreter who repeats each question to the respondent and then repeats the respondent's answer to the question directly to the interviewer. These include interviews conducted using a Sign language interpreter and interviews where the respondent cannot speak English or French and someone is available in the household to interpret. For the latter case, if an interpreter is unable to interpret for the whole interview or decides instead to answer for the respondent for a major portion of the interview, then the interview is by proxy.

<u>Proxy:</u> A proxy source of information is when a responsible person who knows the intended respondent well, answers on behalf of the respondent who is unable to answer. Examples include:

- a respondent who does not speak English or French and an interpreter is not available at all,
- a respondent who is away for the duration of the survey,
- a respondent who is unable, because of their condition, to speak for themselves.

The first and family name of the proxy, his/her relationship to the respondent and the reason for proxy must be recorded on the cover.

There are five possible categories for relationship of proxy to the respondent.

- (1) Parent
- (2) Guardian
- (3) Child
- (4) Other household member: another member of the same household who is not a parent, guardian or child of the respondent.
- (5) Other, specify a proxy: not fitting any of the above categories. For example, a caregiver, not living in the same household.

Reasons for proxy can fall into one of four specific categories:

- (1) Does not speak English or French: the intended respondent is unable to speak English or French and there is no interpreter available.
- (2) Unable to respond: an intended respondent is unable to respond because they have an illness or condition that prevents them from doing so. For example, an intended respondent has a developmental disability and is unable to answer for himself/herself, or the intended respondent has a disability affecting speech or hearing and there is no available interpreter.
- (3) Absent duration of the survey: the intended respondent is absent for the total survey collection period, for reasons such as hospital stay or vacation.
- (4) Parent wishes to respond for child 15 or older: a parent or guardian may insist on responding for a young "adult".

Information Source - Child Questionnaire

The Information Source box on the children's cover page should be completed as follows:

Non-proxy:

Parent/Guardian: the parent/guardian of the selected child is the respondent for the Children's questionnaire.

Parent/Guardian (via interpreter): is when the parent or guardian is unable to respond but there is a person available to interpret for them so that the responses are from the parent/guardian. For example, a parent or guardian who has a hearing or speaking disability but answers through a Sign language interpreter, or a parent or guardian who does not speak English or French but a person is available to interpret for them.

Proxy:

Other household member: this is a member of the household the child belongs to, other than the parent or guardian of the child. For example, an adult sibling of the child, or caregiver of the child.

Other, specify: is a responsible adult who knows the child well enough to answer the questions, for example, a sibling or a biological parent not living in the same household.

There are three (3) categories for reasons for proxy in the children's questionnaire:

Parent or guardian does not speak English or French: you must select this category if a proxy interview was done because the parent or guardian of the child can't speak English or French and there is no one available who can and

will interpret through the whole interview.

Parent or guardian unable to respond: the parent or guardian is unable to respond because of an illness or health condition and a responsible adult who knows the child responds for them.

Parent or guardian absent – duration of survey: the parent or guardian will be absent for the duration of the survey for reasons such as vacation or hospital stay.

Completing the interview

Sensitivity Issues

Some of the questions in this survey may seem sensitive to respondents. In addition, it is very important to keep in mind that you are interviewing a particular population with whom you must try to remain as perceptive and tactful as possible. To support you in this, there is some information in Appendix 2, "Sensitivity Issues- Reference Material". Ensure that you have read it before starting to interview.

Guidelines – Filling out the questionnaire

General guidelines for completing the questionnaire are as follows:

- Use a pencil HB2
- A scanning (imaging) process will capture the data on the questionnaires. A 'picture' is taken of each page of the questionnaire and specific data is captured. It is very important, therefore, that the response circles and boxes be clearly marked. When the respondent provides you their answer, preferably fill in the circle or box completely. If, however, you check it or mark it with an X, ensure that you restrict your mark to the inside of the circle or box as much as possible. As the answers recorded in the circles and boxes will be scanned (imaged), it is important that they be VERY neat and clear.
- If you need to make a correction in a write-in box, do not erase the original answer. One type of box is the hatched write-in box, that is to say, a box with one confined space for each number. These are used, for example, for hours, dollars or quantities. For this type of box, cross out the original entry and write the correct numbers as near as is possible to the box.
- The other type is the free form…beside the crossed-out text.
- If you need to make a correction of a response in a circle, cross it out, then fill in the right answer circle
- For hours and dollar amounts, the answer must be right justified.

• For example, if a respondent worked 40 hours last week, you would enter that as follows:



The answers on the front cover for name, address, proxy name, etc. should be left-justified as follows:

1988 Woodwind Crescent

Alexandrea, Ontario

Answers recorded anywhere else on the questionnaire are NOT data captured. That is why it is important that the answers be INSIDE the circles and boxes.

If there is a conflict between the instructions given in the questionnaire and the instructions in the manual, follow the questionnaire instructions

What not to do

- If you must make a note to yourself on the questionnaire, keep it away from the answer circles and boxes, write-in boxes between the stars at the top and bottom of the pages.
- Do not put circles around, for example, skips, etc. on the questionnaire.
- Do not put diagonal lines or arrow marks through question(s) or section(s), which the respondent does not answer.
- Do not put notes, check marks, etc. anywhere on the labels.
- Try to keep dirt or scuff marks on the questionnaires to a minimum.

Questionnaire Design Rules

Design conventions are used throughout the questionnaires to ease the interviewing task. Please ensure that you understand these conventions and follow the guidelines below:

- The introduction to a section or question is in bold and should be read to the respondent. A blank line separates it from the question.
- The text of the question is in bold and should be read to the respondent. In addition to being in bold, words, which should be emphasized, are

capitalized. Additional explanatory text, which is in brackets, is just for clarification if required by you and/or the respondent.

- Interviewer instructions are in italics underneath the question.
- The Edits are in white text inside a black box.
- There are write-in boxes for response categories such as "Other, specify", "another aid specify", "Specify", etc. Please record the answer starting at the left side of the box and ensure that all of the text is inside the box. Ensure as well that the answer could not have been marked in one of the categories provided.
- Always right justify numeric entries; for example, hours, days, income, etc.
 C 27 Page 32
- The response categories "Don't Know" and "Refusal" are separated by a line from the rest of the answers. These two responses are not read to the respondent, even when the Interviewer instruction says "Read list/categories". C 27 Page 32
- For all questions which are "Mark all that apply", the response categories have squares, rather than circles. C 40 Page 35
- In Sections C, D and E of the Adults Questionnaire, there are some "calling" and "pop-up" question combinations. For example, Question C3 and Question C3A:

Since C3A is only asked when the respondent answers "Yes" to C3, the response categories for Question C3 had to be laid out in the reverse order from the usual order on the questionnaire. Therefore, the "Yes" response (in C3) is in the right-most position and can be linked to the pop-up question on the right-hand side. This layout is used for every "calling" and "pop-up" question combination. It is important to keep this in mind to ensure that the proper circle is checked.

Important Interviewing Guidelines

- Ask the questions as worded and in the order they are listed on the questionnaire.
- For all proxy interviews AND phone interviews via a language interpreter, use the phrasing inside the brackets to reflect the fact that you are asking a question to a third party about the respondent. Note that when conducting a personal interview via a Sign or other language interpreter, because you always address the respondent directly, and NOT the interpreter, you must use the regular wording.
- Important! In a proxy interview, when asking questions like "Are there any aids… thinks he/she needs…" or "Does… believe that his/her condition…", if the proxy responds they do not know what the respondent thinks or believes, rephrase the question as follows: "Are there any aids you think he/she needs…" or "Do you believe that his/her condition…"
- Do **not** read aloud instructions to or information for the interviewer.
- Do **not** read aloud "INTERVIEWER" items to respondents.

- Do not read aloud the response categories of "Don't know" (or DK) and "Refusal" (or REF).
- For certain questions in Section F in both the Adults and Children Questionnaire, there is an interviewer note which reads "Round to the nearest full hour." If the respondent provides an answer, which includes under .5 hours or under ½ hour, you would round the response down. For example, if they say "3 1/4 hours" a day, you would record 3 (hours). If, however, the response is equal to or more than .5 hours or over ½ hour, it must be rounded up. For example, if the respondent says "3 3/4 hours" a day, you would record 4 hours.
- If there is a conflict between the instructions given in the questionnaire and the instructions in the manual, follow the questionnaire instructions.

The Profile Sheet

The back cover of each questionnaire has a foldout page titled Profile Sheet. When completing the interview, this "backflap" should always be opened out.

This Profile Sheet constitutes a very important record of:

(for both adults and children)

the types of limitations reported by the respondents,

whether they need any aids or specialized equipment,

(for adults only)

whether they receive any help with everyday activities,

whether they need any help with everyday activities.

As you complete the interview, you will be directed to check the appropriate boxes on the Profile Sheet when respondents answer Yes to questions about various limitations, about aids used or needed, or about help received or needed.

Important! In many interviewer edits throughout the interview, you will use the Profile Sheet and its contents to decide on the proper flow of questions to follow. It is therefore CRUCIAL that these checks on the Profile Sheet be made accurately.

An example (adult questionnaire):

A respondent answer Yes to only ONE question on limitation and that question is at the very beginning of the questionnaire. he/she answers NO to all others after that.

At B94edit, the interviewer is instructed as follows:

If any box is checked in the Limitation column on the Profile Sheet, then continue; otherwise, go to the Follow-up question on page 81.

The Profile Sheet serves to remind the interviewer that the respondent did report a limitation very early on in the interview, even though there never was any mention of it again. Without this reminder, the interviewer might take the wrong path, i.e., go to the follow-up question and end the interview.

The Profile Sheet also serves as a useful overview of the particular situation of the respondents. The interviewer can use this information to maximize consistency throughout the interview, at least to probe further when a possible inconsistency is detected.

Follow-up Question

Just before the end of the interview for both the Adults and Children Questionnaires, there is a **Follow-up** question. This question must be asked of every respondent. If a second phase of this survey is conducted in a year or two, it is important that we have a contact if the respondent moves or we have difficulty reaching them. This person would only be used to help us contact the respondent.

Providing comments and where to enter them

Comments are extremely important in assessing the information we receive. Explain any difficult or unusual cases encountered during the interview in the "Comments" section of the questionnaire. Mostly, we rely on YOU to record any information that could help explain an answer.

Please enter comments regarding the questionnaire content, on page 81 for (Adults – 15 and over) and on page 52 for (Children – under 15). Always enter the question # to which the comments apply.

Back page of questionnaire

How to fill in the back page of questionnaire At the very top of the page 82 for Adults and page 53 for Children you will find the section titled **RECORD OF CALLS/VISITS**. This section is used to enter telephone calls and appointments as well as visits to complete interviews.

Record of calls and Visits

Each time you call and/or visit the respondent, add an entry in the column Visits/Calls Number (1,2,3, etc.). Enter the day's date and month in the Date Column as well as the Time you tried to reach the respondent by telephone. Enter appropriate notes for that call in the Observations section (busy, answering machine, details of an appointment). If a questionnaire is not completed on your first visit/call and you need to visit/call again to complete it, notes should be entered in the Observations section indicating the follow-up appointment date. It is important that clear notes be put in these comments line.

For comments regarding subject matter, please enter them on page 81 for Adults and on page 52 for Children.

Record of Interviews/Call

In the **RECORD OF INTERVIEWS** section, note beside the appropriate interview number, the day's date under the <u>Date</u> column, the month under the <u>Month</u> column, the time the interview started under the <u>Began</u> column and the time the interview ended under the <u>Ended</u> column. Please use the 24-hour clock standards. It should be noted that the start time of the interview is actually the time at which you started to read the introduction to the respondent and not the time at which you arrived at the respondent's house/or started dialing the number. Enter such information for each visits/calls it takes to complete the interview.

Field status codes are next. Please refer to the chapter 3 on page 15 of the

Interviewers' Manual for the description of these codes.

FIELD STATUS CODE: Means that these codes are used when the interview has not been started is in progress or has not yet been completed.

FINAL STATUS CODE: Means that these codes are final. Ex.: codes 00 complete, code 50 Refusal and code 54 Impossible to contact.

At the very bottom of the page print your name, telephone number and your interviewer identification number.

Questionnaire review

Once you have completed your work assignment for the day, please review each questionnaire. Make sure all the necessary information is indicated. Verify the flows chosen in each questionnaire. If you make a mistake, cross it off instead of erasing it. If there are many new questions to be asked, you will need to call the respondent.

The respondent may not be available when calling back. Please use a proxy as a **last resort**. Make sure to indicate in your comments what questions the proxy answered.

Confidentiality: Whenever you contact someone about a respondent, DO NOT DISCLOSE any information other than the respondent's name. Any information collected under the Statistics Act is strictly confidential and must remain so. When the label has been applied on the questionnaire, the questionnaire becomes confidential. Keep it face down.

Coding

What is coding?

coding?

What is the purpose of

Often times in survey, you will have questions dealing with economic and employment questions such as type of employment, employer type of business, rate of pay, etc.

In order to produce statistics, we have to code these answers. We code the type of work as well as the type of business and the daily activities.

Coders need a minimum of details to be able to come up with proper codes. Your supervisor will go through two exercises with you so that you can determine what kind of probing needs to be done

Regarding Labels

Replace Labels

IF YOU NEED TO REPLACE A LABEL, ASK YOUR SUPERVISOR FOR IT. HE WILL REQUEST IT FROM OTTAWA. IN THE COMING DAYS, YOUR REGION WILL RECEIVE IT ELECTRONICALLY AND YOU WILL PRINT IT AT YOUR OFFICE.

Labeled questionnaires shipping

All labeled questionnaires must be sent by a courrier service such as Purolator. Inside the Versa Pack, a list with questionnaire numbers must be included.

List & Description of Codes

CODES#	DEFINITION OF CODES	EXPLANATIONS OF CODES	
00	Interview completed	Complete data obtained	
01	Interview partially completed	Partial data obtained	
07	Request for telephone interview	To be used when a respondent scheduled for a personal interview requires a telephone interview instead.	
09	Request for personal interview.	To be used when a respondent called on the telephone mentioned that he could do the survey only in person. The request from the respondent is justified by a physical or mental condition that prevents him from completing the survey over the telephone.	
10	Strange noise, fast busy signal, dead silence, fax machine	Self-explanatory.	
11	Non-working number (out of service)	Out of service from the telephone company.	
12	Repeated wrong number	Self-explanatory.	
19	Status change	This code is used when the status of a respondent changes from adult to child or child to adult.	
20	Duplicate (already interviewed for this survey	Verify with a few questions of the actual survey that it is actually Participation and Activity Limitations Survey before coding this as duplicate.	
28	Death of respondent	Self-explanatory	
50	Refusal	Self-explanatory	
52	Non-interview: special circumstances	To be used if a respondent cannot respond due to illness, disability or death in the family and there is no proxy available.	

53	Non-interview: language barrier	To be used if the respondent doesn't speak either English or French and there is no substitute or translator to complete the survey.	
54	Non-interview: unable to contact	To be used when the required numbers of attempts have been tried and the respondent still cannot be contacted.	
55	Non-interview: unable to trace	To be used when all tracing efforts have been made and the respondent is still untraceable.	
56	Non-interview: respondent absent for duration of survey	To be used when the respondent is absent throughout the survey period and there is no proxy to complete the interview.	
57	Non-interview: respondent no longer living in Canada	Self-explanatory.	
60	Tracing required	Self-explanatory.	
69	Back from tracing	Self-explanatory.	
70	Ring – no answer	Self-explanatory.	
71	Regular busy signal	Self-explanatory.	
72	Answering machine or service	Indicate on the questionnaire the date you left a message. Do not leave more than a message every two days.	
74	Incorrect telephone number	Self-explanatory.	
77	Hard appointment	To be considered a hard appointment, you need to have a specific date and specific time of appointment with the respondent.	
78	Soft appointment	To be considered a soft appointment, you need to have a specific period of time for the appointment. i.e. tomorrow morning.	
79	Call screened or blocked from telephone company.	Self-explanatory.	

81	Survey verification	The respondent questions the validity of the survey and wants to call Statistics Canada to verify before he completes the survey.
82	Supervisor hold	This code is used when this case needs supervisory help or assistance, when the respondent wants to speak to someone in authority or that you feel he should speak to someone in authority.

Chapter 4: Adult Questionnaire Content

Content

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Introduction

The Adult Questionnaire is used to interview respondents who were 15 years of age or older on Census day, May 15, 2001. It is divided into 7 sections as follows:

A: Filter Questions

B: Activity Limitations

C: Help with Everyday Activities

D: Education

E: Employment Status

F: Social Participation

G: Economic Characteristics

This chapter presents a summary of the content of the questionnaire, with specific emphasis on the flow of questions in each section.

Important! For additional information on concepts and definitions of terms used throughout the questionnaire, please see Chapter 9.

Adult Questionnaire Who Should Respond?

The intended respondent for the adult interview is the selected adult 15 yr. or older. It is important to try to get responses from this person, as it is their perception of their own reality that is important to us. If this adult is available but for some reason (hearing limitation, does not speak English or French etc.) is unable to respond other than through an interpreter then we will accept the interpreted responses. The interpreter must relay questions from the interviewer to the respondent and then relay the respondent's response back to the interviewer for each question. Only as a last resort should a proxy be interviewed and this is only after all other avenues have been exhausted.

Providing comments

Comments are extremely important in assessing the information we receive. Mostly, we rely on you to record any information that could help explain an answer.

Please ensure that all comments are complete. As a general rule, **always** identify the question number (and response category identifier if applicable) to which the comment refers.

Section A - Filter Questions

Filter questions

These filter questions are the same as the ones on the 2001 Census Form. They basically ask if respondents have any difficulty seeing or hearing, walking, etc. and if a physical condition or a mental condition or a health problem reduces the amount or the kind of activity they can do at home, work or in any other activities.

All respondents are asked these questions and their responses may be different than the ones given on Census Day (May 15, 2001).

NOTE: If respondents answer "Yes" to any of the questions included in this section, the interviewer should check the "General-Limitation" box on the <u>Profile Sheet</u>. For additional information about the Profile Sheet, please see Chapter 3 – Getting Started.

Section B – Activity Limitations

Activity limitations -Summary

The questions in this section are intended to identify the type of limitations respondents have in their day to day activities because of a condition or health problem. We are interested in limitations or difficulties that have lasted or are expected to last six months or longer, and this even when using aids or specialized equipment such as glasses, hearing aids, braces, artificial limbs, etc.

There are ten types of limitations:

- 1) Hearing
- 2) Seeing
- 3) Communicating
- 4) Mobility
- 5) Agility
- 6) (Due to) Pain
- 7) Learning
- 8) (Due to) periods of confusion or difficulty remembering things
- 9) Developmental disability or disorder
- 10) (Due to) an emotional, psychological or psychiatric condition

For each of these, if a limitation is identified,

- 1) the interviewer checks the appropriate "Limitation" box on the <u>Profile</u> Sheet;
- 2) for some types of limitations, respondents are asked about the <u>aids and specialized equipment they use</u>, as well as <u>those they need but do not have</u>. If aids are used the interviewer checks the appropriate "Use aid box on the <u>Profile Sheet</u>. If aids are needed the interviewer checks the appropriate "Need aid "box on the <u>Profile Sheet</u>.

At B94edit, all questions identifying limitations have been asked.

At this point, if any limitation has been identified in Section A or in Section B (if any box is checked in the Limitation column on the Profile Sheet), then the interview continues.

Otherwise, this is the end of the interview questions and the interviewer goes to the Follow-up question on page 81.

Respondents who continue are then asked about the following:

- 1. Disadvantage created by the limitation;
- 2. Age of onset of the limitation;
- 3. Main condition causing the limitation and the cause of this condition;
- 4. Secondary condition and its cause;
- 5. Use of medication and out-of-pocket costs for medication in the past

twelve months;

- 6. Use and need of other aids and specialized equipment;
- 7. If any aids used in Section B (if any box is checked in the Use aid column on the Profile Sheet), what were out-of-pocket costs for these aids in the past twelve months;
- 8. If any unmet needs of aids in Section B (if any box is checked in the Need aid column on the Profile Sheet), what are reasons why they do not have the aid(s).

Hearing

Respondents are first asked whether they use a hearing aid or not.

If they do, we ask them about the degree of hearing difficulty they have (with their hearing aid) in three different situations: in a conversation with one other person, in a conversation with three or more persons, and in a telephone conversation.

If they do not use a hearing aid, we first ask them to describe their ability to hear. If they select the response category "... have difficulty hearing", we ask them the 3 follow-up questions about degree of difficulty. However, if they select "... cannot hear", they skip the 3 questions on difficulty.

Seeing

Two activities are used to assess the respondent's ability to see. These activities are:

- seeing ordinary newsprint; and
- clearly seeing the face of someone across a room (that is, from 4 meters or 12 feet)

For the sake of clarity, a filter question first determines whether the respondent wears glasses/contact lenses or not to see up close or at a distance. The appropriate version of each question then follows, i.e., with or without the preamble "With your glasses or contact lenses..."

Communicating

To assess whether the respondent has difficulty communicating, the two elements of communication are examined:

- speaking; and
- being understood.

While these two elements are closely linked, there are individuals who may have difficulty speaking yet can be understood, for example, someone with a severe stutter. Conversely, there are individuals who can speak the words clearly but due to a physical, mental or other health condition, the words are so mixed up or disconnected that the message cannot be understood.

These questions are not intended to identify individuals who occasionally get "tongue tied" or need to repeat or elaborate on a statement in order for the message to be understood. The difficulty must be as a result of a physical, mental or other health condition.

If the respondent has difficulty speaking and being understood only because his/her mother tongue is neither English nor French, but he/she can speak and be understood in his/her mother tongue, he/she **does not have** a limitation in this activity.

Mobility

The mobility section is broken down into questions assessing the respondent's ability to walk, to stand in line for more than 20 minutes, and to move from one room to another.

Three activities are used to assess the respondent's ability to walk:

- walking a distance without resting (half a kilometer or a quarter mile or three city blocks);
- walking up and down a flight of stairs (10 to 12 steps) without resting; and
- carrying an object of 5 kg or 10 pounds, like a bag of groceries for 10 meters or 30 feet.

However, to create a more efficient flow, a preliminary question serves to identify those respondents who cannot walk at all. These respondents then skip questions on walking ability and go to questions on standing and moving from one room to another.

Note: We are not measuring the respondent's endurance to do all three walking activities consecutively.

Agility

The following activities are used to measure the respondent's flexibility and agility (with artificial limbs, supports or aids, if that be the case):

- bending down and picking up an object from the floor;
- dressing and undressing;
- getting into and out of bed;
- cutting his/her own toenails;
- using his/her fingers to grasp or to handle an object;
- reaching in any direction (for example, above the head);
- and cutting his/her own food.

Pain and discomfort

Some respondents may experience some form of long-term pain or discomfort that reduces the amount or the kind of activities they can do. Examples include a person with multiple sclerosis, AIDS, recurring back pain, migraines or arthritis. We are interested in constant pain or discomfort that has lasted or is expected to last six months or more, OR periods of pain or discomfort that have reoccurred and are expected to reoccur over time.

Since the <u>presence of pain does not in itself constitute a limitation</u>, we ask a follow-up question about whether this pain reduces the amount or kind of activities they can do. <u>We consider the respondent to have a (pain-related)</u> limitation ONLY IF the pain does limit their activities.

Non-physical disabilities

A series of questions are used to identify persons who have limitations because of a learning disability; memory problems or periods of confusion; a developmental disability or disorder; or an emotional, psychological or psychiatric condition.

The respondent may consider these questions sensitive. Be conscious of the respondent's feelings and be prepared to reassure the respondent concerning the confidentiality of the information and the fact that all respondents are asked these same questions.

Important! Ask the questions exactly as they are worded. Be very familiar with the different concepts and definitions in order to properly inform the respondent to get an accurate response.

Learning disabilities

A first question attempts to identify those adults who believe they have a condition that makes it generally difficult for them to learn. All adults are also asked whether they have ever been diagnosed with a learning disability.

If they say Yes to either question, we then ask a follow-up question about whether this condition reduces the amount or kind of activities they can do. Note however that we consider the presence of a learning difficulty/disability to be a limitation in itself, regardless of whether or not it limits their activities.

Confusion / Memory

As we grow older, most of us have a bit more difficulty remembering things. That is not the kind of memory loss we are trying to identify here. As well, we are all endowed with different levels of ability, including the ability to remember. Again, here we are not trying to identify persons whose ability to remember may always have been less than great.

Question B85 is designed to identify respondents who FREQUENTLY have periods of confusion or difficulty remembering things. The examples of associated conditions provided (Alzheimer's disease, results of a brain injury) are very important to convey this to the respondent.

Respondents who indicate they have such difficulties, are then asked if these difficulties limit their activities. <u>They are considered to have a limitation</u> ONLY IF they answer Yes to this follow-up question.

Developmental Disability or Disorder

Many other terms are used to refer to a developmental disability. Some are politically correct, such as developmental delay, intellectual impairment or mental handicap; others, like mental retardation, mentally retarded or retarded, are not.

However, interviewers should be aware of all such terms, especially when dealing with older respondents who might not be familiar with the newer and politically correct terms.

A <u>developmental disability</u> refers to a condition such as Down syndrome or a brain impairment due to oxygen deprivation at birth. A <u>developmental</u> <u>disorder</u> refers to brain disorders such as autism, Asperger syndrome and others.

Although we do ask these respondents if their disability limits their activities, we consider them to have a limitation, regardless of whether the condition limits their activities or not.

Emotional / Psychological / Psychiatric

Although the type of condition we are trying to get at here is fairly well understood by everyone, it is very important to note that we are interested ONLY in conditions that have lasted or are expected to last 6 months or more. This is especially important when we are talking about conditions like depression (including post-partum depression).

If the presence of an emotional, psychological or psychiatric condition is identified, we ask a follow-up question about whether the condition limits their activities or not. Respondents are considered to have a limitation ONLY IF they answer Yes to this follow-up question.

Section C - Help with Everyday Activities

Help with everyday activities

This section is designed to provide information on the impact of the respondent's health problem or condition on his/her ability to perform everyday activities. The data obtained allows one to determine the level of help required by persons with activity limitations, in order for them to continue to live independently. Questions on the help needed identify gaps in the types of help available.

Note that this section concerns only "human", and not technical, assistance.

Everyday activities include:

- 1) preparing meals,
- 2) everyday housework,
- 3) heavy household chores,
- 4) getting to appointments and running errands,
- 5) taking care of personal finances,
- 6) child care,
- 7) personal care,
- 8) receiving specialized nursing care or medical treatment at home,
- 9) moving inside the residence.

For each of these activities, <u>if help is received</u>:

1) the interviewer checks the appropriate box on the <u>Profile Sheet</u>;

- 2) questions on who provides the help and how often (frequency not asked for moving about inside residence) are asked;
- 3) a question on additional help needed is asked; and
- 4) <u>if additional help is needed</u>, the interviewer checks the appropriate box on the <u>Profile Sheet</u>.

If help is NOT received,

- 1) a question on help needed is asked; and
- 2) <u>if help is needed</u>, the interviewer checks the appropriate box on the <u>Profile Sheet</u>.

At C38edit, all questions identifying help received and needed have been asked.

At this point, if any help is <u>received</u> with everyday activities (if any box is checked in the Receive help column on the Profile Sheet), then respondents are asked about the following:

- 1) Difficulties making arrangements for the help received;
- 2) Who pays for the help;
- 3) Reimbursement and sources of reimbursement;
- 4) Out-of-pocket costs for the help received.

If any help or additional help is <u>needed</u> with everyday activities (if any box is checked in the Need help column on the Profile Sheet), then respondents are asked about the following:

THE REASONS WHY THEY DO NOT RECEIVE THE HELP.

ALL respondents are then asked questions about the following:

- 1) Control in making decisions;
- 2) Contacts with health care and social service providers in the past twelve months, because of their condition;
- 3) Out-of-pocket expenses for these health care and social services
- 4) Any unmet needs for health care or social services in the past twelve months and the reasons why these needs were not met.

Section D - Education

Education

The intent of Section D is to determine the impact of long term conditions and health problems on a person's educational experience and their level of schooling. The questions in this section are only asked of person's aged 15 to 64. They are not asked of person's 65 years of age and over.

There is a **Stop sign** and an instruction at the beginning of the section to advise interviewers about this. Please see **Appendix 1** for school equivalency details (Quebec versus the other provinces.)

If the respondent was attending school in April, 2001, they are asked a few questions about their schooling. They are then asked if they required modified building features or assistive devices to attend school; and if so, if they were available to them. Finally, they are asked about the highest level of schooling they have obtained and a question about their experience in the education environment.

If the respondent was not attending school in April 2001 but did attend after April 1996, they are asked if they required modified building features or assistive devices (and if so, if they were available to them). They are then asked if they had their condition before completing their formal education and if so, if they discontinued their schooling. The last two questions are about the highest level of schooling obtained and the respondent's experience in the education system.

If a respondent was not attending school either in April, 2001 or after April, 1996, they are only asked if they had their condition before completing their education, the highest level of schooling obtained and about their experience in the education system.

Section E – Employment status

Employment status

The purpose of this section is to provide insights into the labor market barriers faced by persons who have an activity limitation. The questions in this section are only asked of person's aged 15 to 64. They are not asked of person's 65 years of age and over. There is a **Stop sign** and an instruction at the beginning of the section to advise interviewers about this. The working age population is divided into three classifications according to their labor market activity; employed, unemployed and not in the labor force.

The respondent answers a series of questions in the first part of this section, which determines which one of the three subsections you (and they) will then

go to. The subsections are "Employed", "Unemployed" and "Not in the Labor Force". The respondent answers only one of the subsections.

In the **Employed** subsection, the respondent is asked how many hours they work per week, the location of their work and their occupation. If they are working for wages or salaries, they are asked a series of questions on union membership, the number of employees where they work and the permanency of their job. Respondents are then asked some questions regarding the impact of their condition on their work. Finally, they are asked about their need for modified building features and technical aids; training and the perception of disadvantage at work.

Respondents who go to the **Unemployed** subsection are asked the same set of questions (hours, location of work and occupation when last employed) at the beginning as for the Employed subsection above. They are then asked some questions about the impact of their condition on their work. Finally, they are asked the same questions as above regarding their need for modified building features and technical aids; training and the perception of disadvantage at work.

At the beginning of the **Not in the Labor Force** subsection, respondents are asked when they last worked. Those who have never worked skip to the questions about whether their condition prevents them from working. Those who do report a year are then asked if they are permanently retired. If they are permanently retired, they are asked if this is due to their condition. They then skip to a short series of questions on barriers, need for modified building features, etc. and the perception of disadvantage.

Those who are not permanently retired are asked the same questions as in the first two subsections regarding hours worked location of last job, and occupation. The next questions ask about the impact of their condition on work. The final questions are about barriers, the need for modified building features and technical aids; training and the perception of disadvantage at work.

Section F – Social Participation

Social participation

This section will collect information on the participation of respondents in social activities, such as leisure and recreation, and unpaid voluntary activities. It also includes questions on transportation and housing since these facilities play a major part in defining accessibility to full social participation.

The first three questions concern the respondent's health in general, as well as cigarette and alcohol consumption. We then ask questions about activities they do in their spare time such as exercise and watching TV, and how often they practice these leisure activities. Another question asks about unpaid volunteer activities they may have participated in over the past year.

However, the bulk of the questions focus on local and long distance transportation for personal or business reasons. We ask respondents if they are prevented from traveling by car, bus, train or plane, and the reasons why they cannot use them. We also ask about the level of difficulty they have using these modes of transportation and about the costs of transportation services they require because of their condition.

The last part of this section deals with housing facilities and the special features they use in their home, as well as the costs associated with these features. Respondents are also asked about any unmet needs for special features and the reasons why they do not have them.

Section G – Economic Characteristics

Economic characteristics

The purpose of this section is to obtain information about whether respondents have medical insurance coverage, claimed certain tax credits; and the sources and amount of their income. This information will provide a better understanding of the financial situation and economic burden encountered by persons with activity limitations.

The first question asks about insurance coverage. The next series asks whether the respondent claimed various taxes credits on their 2000 Federal Income Tax return. If they did claim a Medical Expense or Disability Tax Credit, the respondent is asked if they received it. If they did not claim the Disability Tax Credit, they are asked about the reasons why they did not.

In addition to the sources of income, the final questions ask about the amount of personal income and the household income for the year ending December

31, 2000. The respondent is asked for their personal income and then they are asked if they live in a one-person household. If they say "Yes", they skip the next questions on household income. If, however, they say "No"; that is to say there is more than one person living in the household, they are asked the household income question(s). Respondents are asked to provide their best estimate of their income. If they cannot do so, they are given a list of income ranges from which they choose one answer (or range).

A respondent may ask why doesn't Statistics Canada use the income information from the Canada Customs and Revenue Agency (formerly Revenue Canada). You can advise them that the income tax records do not cover all people and they do not provide important characteristics of persons with income. Through this survey, the income information can be combined with other factors such as education, occupation and age. The Canada Customs and Revenue Agency does not have access to individual records from Statistics Canada.

After Section G is completed, all respondents are asked the "follow-up" question.

Chapter 5: Child Questionnaire Content

Content

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Introduction

The Child Questionnaire is used to interview the parents or guardians of children who were under 15 years of age on Census day, May 15, 2001.

This chapter presents a summary of the content of the questionnaire, with specific emphasis on the flow of questions in each section.

Important! For additional information on concepts and definitions of terms used throughout the questionnaire, please see Chapter 9.

Child Questionnaire -Who should respond

A parent or guardian must answer on behalf of a child under 15 years of age. If the parent or guardian of a mature child (13 or 14 years of age) insists that the child respond for himself/herself, it should be explained that a child could NOT answer the questions. This is because the questionnaire is about the parents' perception of the child's health and other aspects of his/her life. In addition, some questions relate to the family's economic situation, parents' work arrangements and social supports, which would be difficult for a child to answer.

If a parent or guardian is unable to respond because of a hearing limitation or difficulty speaking English or French, we accept the responses provided through an <u>interpreter</u>. Only as a last resort, once all other avenues have been exhausted, a proxy should be interviewed.

Providing comments

Comments are extremely important in assessing the information we receive. Mostly, we rely on you to record any information that could help explain an answer.

Please ensure that all comments are complete. As a general rule, **always** identify the question number (and response category identifier if applicable) to which the comment refers.

Child Questionnaire SECTIONS

The Child Questionnaire is divided into the following nine sections:

- ➤ **Section A Filter Question:** asks questions about whether the child is limited in his/her day-to-day activities because of a condition or health problem.
- ➤ Section B Activity Limitations: asks questions about the type and severity of activity limitations. It also identifies whether the child uses or needs aids, medication and health services.
- ➤ Section C Help with Everyday Activities: asks questions about the help received and needed by the child and his/her parents or guardians with everyday activities.
- Section D Child Care: asks questions about the child care arrangements.
- ➤ **Section E Education:** asks questions about the child's level of education, type of school and barriers to education.
- ➤ Section F Leisure and Recreation Activities: asks questions about the

child's recreational and leisure activities.

- ➤ Section G Home Accommodation: asks questions about the child's residence and any specialized features or aids that the child use and need.
- > Section H Transportation: asks questions about the type of transportation used for local travel.
- ➤ Section I Economic Characteristics: asks questions about insurance coverage for child's medical expenses and whether parents claimed certain tax credits. Information about the household income is also collected.

More detailed information about each section is provided in the following pages.

NOTE: If the child with a limitation is under 5 (DOB: After May 15, 1996) <u>skip</u> the following sections: E (*Education*), F (*Leisure and Recreation Activities*), G (*Home Accommodation*), and H (*Transportation*).

Section A – Filter questions

Filter Questions

A1 - A2C

Filter questions provide information on whether the child has difficulties with daily activities because of a physical condition, a mental condition or a health problem. These questions were included on the 2001 Census form.

(Age: 0-14)

NOTE: If respondents answer "Yes" to any of the questions included in this section, the interviewer should check the "General-Limitation" box on the <u>Profile Sheet</u>. For additional information about the Profile Sheet, please see Chapter 3 – Getting Started.

Section B – Activity limitations

Activity Limitations

B1 - B97

Section B identifies the type and severity of the child's long-term condition or health problem. We are only interested in limitations or difficulties that have lasted or are expected to last six months or longer.

At B62edit, all questions identifying activity limitations have been asked.

(Age 0-4: B1-B6, B11-B15, B51-B52, B59-B86)

At this point, if any limitation has been identified in Section A or in Section B (i.e. if any box is checked in the "Limitation" column on the "Profile Sheet"), then the interview continues.

(Age 5-14: B1 – B97 excluding B51 & B52)

Otherwise, this is the end of the interview, and the interviewer goes to the Follow-up Question on page 52 in the English version OR page 53 in the French version of the questionnaire.

If any limitation is reported in Section A or B, then parents are asked about the child's use and need of aids, such as a hearing aid, wheelchair, or crutches. Questions about the use and need of medication or health services are also asked.

Parents sometimes have "out-of-pocket" expenses as a result of their child's condition or health problem for which they are not completely reimbursed by any insurance or government program. Therefore, this section includes questions about out-of-pocket expenses related to the child's aids, medication, and services received from health professionals.

When asking about medication, "prescription medication" is one that a medical doctor has prescribed for the treatment of the child. "Non-prescription medication" is one that does not require a prescription, although it may be recommended by a physician (for example, aspirin for arthritis). Health products, such as vitamins, ointments, minerals or protein drinks which people use to prevent illness or to improve or maintain their health are not considered as prescription or non-prescription medication.

NOTE: If parents report that their child has an activity limitation and that he/she <u>uses</u> or <u>needs</u> specialized aids, the interviewer checks the corresponding boxes on the "Profile Sheet".

Types of activity limitations according to <u>age</u> group

As mentioned earlier, the questions included in Section B are intended to identify the types and severity of activity limitations. Children aged 5 to 14 (DOB: Before May 15, 1996) are asked questions about the following types of activity limitations or health conditions:

- 1) Hearing
- 2) Seeing
- 3) Communicating (including speaking and being understood)
- 4) Walking
- 5) Using hands and fingers
- 6) Learning (including dyslexia, hyperactivity or attention problems)
- 7) Developmental disability or disorder (including autism and Down syndrome)
- 8) Emotional, psychological or behavioral conditions
- 9) Chronic health conditions

Children aged 0 to 4 (DOB: After May 15, 1996) are only asked questions about:

- 1) Hearing
- 2) Seeing
- 3) Delay in physical or intellectual development
- 4) Chronic health conditions

In other words, activity limitations related to communicating, walking, using hands and fingers, learning and mental health conditions are not asked if the child's age is 0 to 4.

Parents, whose 5-14 year- old child has an activity limitation, are asked about the aids, specialized equipment and services that their child uses and needs. Questions on the use and need for aids are not asked if the child's age is 0 to 4 because the data collected may not be relevant to their age.

Important! In the Child Questionnaire, some Interviewer's Instructions are accompanied by a STOP sign. This is to remind the interviewer that the <u>skip</u> pattern followed by the questions varies depending on the age of the child. Therefore, the interviewer should carefully read the instruction on the age skip before continuing.

Hearing

B1 - B10

Age 0-4: B1-B5

Parents are first asked to identify whether their child uses a hearing aid. If the answer is "Yes", they are then asked to report whether their child has any difficulty hearing when he/she uses a hearing aid. If a difficulty is reported, the next question measures the degree of hearing difficulty.

If parents report that their child does NOT use a hearing aid, they are asked about their child's level of hearing. If a difficulty is reported, a follow-up question asks about the degree of the child's hearing difficulty.

Age 5–14: B1 – B10

When a hearing limitation is reported, the interviewer checks the "Hearing-Limitation" box on the "Profile Sheet". Then if the child's age is 5 to 14, questions about the use and need for aids or specialized services are asked (e.g. hearing aids, telephone with volume control).

If a hearing limitation is identified, **Question B10** asks whether the child has learned certain communication skills including Sign language to enable him/her to communicate with others.

Seeing

B11 -B20

A filter question first determines whether the child wears prescription glasses or contact lenses to see up close or at a distance. If the answer is "Yes", parents are asked whether the child experiences any difficulty seeing. If a difficulty is reported, then the next question is about the degree of seeing difficulty.

Age 0-4: B11 – B15

If it is reported that the child does NOT use prescription glasses or contact lenses, parents are asked whether their child has any difficulty with his/her eyesight. If a difficulty is reported, the next question measures the degree of difficulty for seeing.

Age 5-14: B11-B20

When a limitation is reported, the interviewer checks the "Seeing–Limitation" box on the "Profile Sheet". Then for children aged 5 to 14, questions about the use and need for aids are asked (e.g. magnifiers, closed circuit T.V)

Communicating

B21 - B30

(Age: 5-14)

Similar to the Adult Questionnaire, in order to assess whether the child has difficulty communicating, the following two elements of communication are considered:

- > Speaking
- Being understood

While these two elements are closely related, there are children who may have difficulty speaking, such as difficulty pronouncing the words clearly, but can be understood by others (for example, a child with a severe stutter). On the other hand, there are children who may pronounce words clearly, but due to a physical, mental or health condition experience difficulty formulating their sentences and therefore others may find it difficult to understand them.

If the child's age is 5 to 14, parents are asked whether their child has any difficulty speaking. If the answer is "Yes", then follow-up questions ask about the degree of speaking difficulty and how well the child can make himself/herself understood when speaking.

Once a limitation is reported, the interviewer checks the "Communicating–Limitation" box on the "Profile Sheet". Then questions about whether the child uses or needs aids are asked (e.g. a voice amplifier or a Blissboard)

If a limitation in speaking or being understood is identified, **Question B26** asks whether the child has learned certain communication skills, such as Sign language, to enable him/her to communicate with others.

Walking

B31 - B36

If the child's age is 5 to 14, parents are asked whether their child has any difficulty walking, even when using an aid or mechanical support, such as crutches or a walker. This means walking on a flat firm surface, such as a sidewalk or floor. If a difficulty is reported, parents are asked to report their child's level of walking difficulty.

(Age: 5-14)

Once a limitation is reported, the interviewer checks the "Walking–Limitation" box on the "Profile Sheet". Then questions about the use and need of aids are asked (e.g. wheelchair, lift devices).

Use of hands/fingers

B37 - B42

(Age: 5-14)

If the child's age is 5 to 14, questions about his/her ability to use his/her hands and fingers are included. Parents are specifically asked whether their child experiences any difficulty using his/her hands or fingers to grasp or hold small objects, such as a pencil or scissors. If a difficulty is reported, the next question asks about the child's level of difficulty using his/her hands or fingers.

If a limitation is reported, the interviewer checks the "Hands/Fingers—Limitation" box on the "Profile Sheet". Then the follow-up questions ask whether the child uses or needs aids designed to support, replace or assist in the use of his/her hands or fingers (e.g. a hand or arm brace; grasping tools or reach extenders).

Learning disabilities

(dyslexia, hyperactivity or attention problems)

B43 - B50

(Age: 5-14)

The process of getting a diagnosis to determine if a child has a learning disability can be quite long. Parents may believe that their child has a learning disability, even if no professional diagnosis has been made. Therefore, the first question asks parents if they think that their child has a learning disability. The second question asks parents whether a teacher or health professional told them that their child has a learning disability.

The questions about learning disabilities are asked only if the child is 5 to 14 years old. Once a learning disability is identified, the interviewer checks the "Learning–Limitation" box on the Profile Sheet. Then the follow-up question asks whether this condition reduces the amount or the kind of activities the child can do. Questions about the child's use or need for aids to help him/her with his/her learning difficulties are also asked.

Delay in physical or intellectual development

B51 - B52

(Age: 0-4)

If the child's age is under 5 (DOB: After May 15, 1996), parents are asked whether their child has a physical or intellectual delay in his/her development. This question may be considered very sensitive to some respondents. Be conscious of the parents' feelings and be prepared to reassure them about the confidentiality of the information and the fact that all respondents are asked these same questions.

If a limitation is reported, the interviewer checks the "Developmental – Limitation" box on the "Profile Sheet".

Developmental disability or disorder

B53 - B55

(Age: 5-14)

A developmental disability refers to a condition such as Down syndrome, or brain impairment due to a lack of oxygen at birth. A developmental disorder refers to brain disorders such as autism, Asperger syndrome and others. In the Child Questionnaire, questions related to developmental disability or disorder are asked only if the child's age is 5 to 14 (DOB: Before May 15, 1996).

Parents are asked whether a doctor, psychologist or other health professional told them that their child has a developmental disability or disorder. If the answer is "Yes", the interviewer checks the "Developmental-Limitation" box on the "Profile Sheet", then a follow-up question is asked to identify whether this condition limits the amount or the kind of activity the child can do.

Emotional / psychological or behavioral conditions

B56 - B58

(Age: 5-14)

Emotional, psychological or behavioral conditions will be assessed for children 5 years of age and over. Although the type of condition we are trying to get at here is fairly well understood by everyone, it is very important to note that we are ONLY interested in conditions that have lasted or are expected to last six months or more.

To identify the presence of a mental health condition, the first question asks parents whether their child has any long-term emotional, psychological or behavioral conditions. If "Yes" is reported, a follow-up question identifies whether this condition limits the amount or the kind of activity the child can do.

If the condition does limit the activities of the child, the interviewer checks the "Emotional/Psychological-Limitation" box on the "Profile Sheet".

Chronic health conditions

B59 - B61

Parents are asked to report whether their child has any chronic health conditions, which have been diagnosed by a health professional. Chronic conditions refer to conditions that have lasted or are expected to last six months or more. If the answer is "Yes", a follow-up question asks whether the condition limits the amount or the kind of activity the child can do.

(Age: 0-14)

If the condition does limit the child's activities, the interviewer checks the "Chronic-Limitation" box on the "Profile Sheet".

Section C – Help with everyday activities

Help with Everyday Activities

C1 - C24

Section C collects information about whether the child receives help with personal care and moving about inside his/her residence, because of a condition or health problem. It also identifies whether parents receive help or need additional help to take care of their child. Furthermore, the impact of the child's condition on the parents' work arrangements and financial situation is examined.

(Age 0-4: C12-C24)

(Age 5-14: C1-C24)

NOTE: If the child with limitations is under 5 (*DOB: After May 15, 1996*), skip questions C1-C11 and start from C12.

Section D - Child care

Child Care

D1 - D7

The purpose of this section is to find out about the childcare arrangements, while the parents are working or studying. In addition, it identifies whether a childcare program or service ever refused to take care of the child, because of his/her condition or health problem.

(Age: 0-14)

Section E - Education

Education

E1 - E38

(Age: 5-14)

This section identifies the effect of a long-term condition or health problem on the child's education and the difficulties that he/she may have experience in obtaining an education. Information is collected on the child's grade level, type of school, and whether the child enjoys school.

Parents are asked about their child's use of or need for special education services, assistive devices, and human support (e.g. notetakers and teacher's aides) at school. In addition, questions about parents' perception of the school environment and their own participation in the child's school activities are asked.

In this section, **Question E6** determines whether the child attends a "Special education school" or "Regular school". If parents answer "Private" or "Public" school, it is important to probe and find out whether the school is a "Regular" or "Special education school". A special education school is a school that is run only for students with an activity limitation or disability, such as a school for children who are blind or a school for children who are deaf or hearing impaired.

Question E13 asks about the province or territory where the child attended school in April 2001. If the child attended school in another country, check the response category of "Other".

Please note that in every province, a different name is used to describe the grade levels. For example, what we call "Kindergarten" in Ontario is called "Primary" in Nova Scotia. Therefore, **Questions E14-E19** include response categories to cover grade levels according to the province or territory where the child attended school in April 2001. When asking these questions, it is important that the Interviewer's Instructions be followed carefully and that interviewers avoid reading the response categories. This is because in some places people might have their own way of naming the grade levels, which <u>might not be exactly</u> as the ones used in the questionnaire.

Section F – Leisure and Recreation Activities

Section F – Leisure and Recreation Activities

F1 - F16

This section determines whether the child participates in physical and social activities <u>outside of school hours</u>. It also identifies the barriers and difficulties that may prevent the child from taking part in any social and physical leisure activities. Information on participation in summer camps is collected as well.

(Age: 5–14)

This section asks about how the child gets along with other children. It also identifies whether the child has access to a computer and the Internet at home, and if so, the frequency of Internet use and the type of activities are examined.

Please note that **Question F9** asks about how well the child gets along with other children. As an interviewer, when reading the response categories for respondents, make sure that you do NOT read the information provided in the brackets. That information will be provided only if respondents need more clarification.

Section G - Home Accommodation

Home Accommodation

G1 - G10

(Age: 5-14)

Section G identifies special features the child uses to enter or leave his/her residence and to get around inside it (e.g. an elevator or lift device, automatic or easy to open doors). It also asks about specialized features a child that may need inside his/her residence, but that he/she does not have. The reasons for not having access to the features are then identified.

Section H – Transportation

Transportation

H1 – H16

(Age: 5-14)

The purpose of this section is to identify transportation problems faced by a child who has a condition or health problem. Parents are asked about the means of transportation that the child uses for local travel on his/her own or with someone else (such as trips to the doctor, recreational events or any other local trips).

Information is collected on the need for and the availability of specialized bus service, the frequency of use of this service, and any difficulty experienced with the service. Questions about the use of taxi services and whether it is related to the child's condition and health problem are also asked.

In order to find out more about the parents' financial burden, they are asked whether they had any out-of-pocket expenses for the child's transportation, for example, travel to and from treatment, therapy or other medical or rehabilitation services.

Section I - Economic Characteristics

Economic characteristics

I1 - I10

(Age: 0-14)

This section identifies whether parents have any insurance coverage for the child's prescription medication, eyeglasses/contact lenses, and hospital charges for private or semi-private rooms. It also asks whether parents claimed specific types of tax credits for their child care expenses and medical expenses on their 2000 income tax return; and if so, whether they were received. Questions about claiming or receiving the Disability Tax Credit are included. The last questions are about the household income, which refers to the total income, before taxes and deductions, of all household members from all sources.

After Section \mathbf{I} is completed, all respondents are asked the **Follow-Up** question.

Chapter 6: Special Situations

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Introduction

This chapter provides instructions on how to deal with special situations. While it is impossible to anticipate every situation an interviewer might encounter, procedures have been developed for those that occur more frequently.

Dealing with deaf or hearing impaired respondents

Unexpected contacts with deaf or hearing impaired respondents In the introduction letter sent to respondents, we invite persons who are deaf or hearing impaired to contact us either by e-mail or on our TTY line.

Should you unexpectedly telephone or visit a person who is deaf or hearing impaired, please pass this case on to your supervisor who will make the necessary arrangements so that we may communicate with this respondent in a proper manner.

Telephone Answering Machine

What should you do?

If you reach a telephone answering machine, leave a message asking the respondent to return your call. Your supervisor will advise you about what message and telephone number you should leave.

Message for Adults Respondents

Hello, I'm...from Statistics Canada,

I would like to speak with ...(name of respondent)...

Could he/she call us back at...(region or census telephone number) and mention his/her case id...(# of case id.)

Our office hours are from Monday to Friday from...am to...pm. (mention your office schedule) and on Saturdays from...am to...pm. "Thank you".

Hello, I'm...from Statistics Canada,

Message for Children Respondents I would like to speak with the parent or guardian of......(name of respondent)

Could he/she call us back at...(region or census telephone number) and mention his/her case id...(# of case id.)

Our office hours are from Monday to Friday from...am to...pm. (mention your office schedule) and on Saturday from...am to...pm. "Thank you".

Duplicates

How does this happen?

You may find that you have two or more cases, which refer to the same respondent. This can happen if, by mistake, a duplicate record was generated for the same respondent.

Definition

A case is considered a **duplicate** when all the identification information is identical to another case except for the case ID number.

How will you know?

Generally, respondents will tell you when they have been recently contacted by an interviewer and completed a "questionnaire". This is probably the only way you will know that the case should be handled as a duplicate.

Ensure that the respondent is not referring to a different survey.

When you are certain the unit you have been assigned is a duplicate, select code "20 respondent altready interviewed for this survey" and hand it to your supervisor.

Requests for Mailed Questionnaire

Procedure

If a respondent refuses to answer the survey by telephone and requests a copy of the questionnaire by mail, explain that no questionnaires will be mailed out. Try to obtain the respondent's cooperation to complete it by telephone.

If the respondent still refuses, code the case as a refusal (code 50).. Inform your senior interviewer of the request.

Party Lines

Procedure

If the respondent states that the telephone line is a party line, you must determine if the respondent objects to being interviewed by telephone using this line. If not, continue with the interview.

If the respondent objects to a telephone interview, follow the procedure for refusal.

Refusals

Procedure

Follow this procedure in case of refusal:		
IF:	THEN:	
at the beginning of the interview, the respondent refuses to provide any information	 try to gain the respondent's cooperation by explaining the purpose of the survey; remind the respondent that all information is kept strictly confidential; 	
during the interview, the respondent refuses to provide any further information	Try to persuade the respondent to continue. Offer to reschedule if necessary.	
the respondent refuses to answer a specific question	Re-assure the respondent about the confidentiality of all information provided. Explain to the respondent the importance of full and accurate information.	

If the respondent still refuses, provide an explanation in Comments section (back page of questionnaire).

Example of refusal explanations

Examples of refusal explanations are:

- the respondent requests to be interviewed in person;
- the respondent refused to be interviewed by telephone because the telephone line is a party line;
- The respondent indicated having participated in other Statistics Canada surveys and does not want to participate in this test.

Chapter 7: Questions and Answers

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Introduction

Generally, if respondents are treated well, they respond well. Good respondent relations go beyond courtesy. It is important to realize that respondents should know, indeed, have a right to know, certain information pertaining to the survey.

The following questions and answers are designed to provide you with consistent and accurate answers to some of the questions commonly asked by respondents. It is important that you become familiar with all of the answers, so you can reply comfortably to similar questions asked while conducting the interview.

When You're Asked....

Why are you conducting this survey?	The 2001 Participation and Activity Limitation Survey will determine the number of Canadians with activity limitations, the type of limitations that they experience and most importantly, the barriers that they might face.
How do I know you're who you say you are?	You can call Statistics Canada at (number to be supplied by your regional office) to confirm that this is a legitimate survey and that I am an employee of Statistics Canada.
Why was I chosen for this survey?	You were chosen to represent other Canadians of your age and sex who may experience a limitation in their daily activities, because of a long term health problem or condition.
Where did you get my name?	Someone in your household completed two activity limitation questions on the Census questionnaire last May. These questions were designed to identify a sample of persons who could provide more detailed information on the nature of their limitations.
I thought the information I provided (on another survey) was confidential?	The information from the census is used to identify potential respondents who might otherwise be difficult to locate. The information you provide is combined with the information of other respondents and is published in a manner so that it is impossible to identify individuals. Your name, address and telephone number are never included with any published or released data.
Do you interview everyone who said they are limited in their daily activities?	No, we are interviewing only a sample of persons who indicated that they have an activity limitation. Because of this, it is very important that we have your support and that you agree to complete the interview.

I'm old; I'm not disabled! Why are you including me in your survey?

You were chosen for this survey to represent other Canadians of your age and sex. This survey includes questions about daily activities such as climbing stairs, walking a short distance, carrying an object, that you may have difficulty doing.

We need your answers to these questions to ensure that we are counting everyone who has any type of activity limitation.

What kinds of questions are you going to ask?

You will be asked questions about certain activities that are part of your daily routine such as climbing stairs, walking a short distance, standing or carrying an object. These questions will identify people who are limited in their day-to-day activities because of a condition or health problem expected to last six months or more.

Do I have to participate?

Your participation matters. The survey provides a comprehensive portrait of Canadians with activity limitations. Although participation in the survey is voluntary, your assistance is very important to ensure that the results are as complete and accurate as possible.

Do I have to answer all the questions?

Your answers for this survey will represent other Canadians of your age and sex who may experience a limitation in their daily activities because of a long-term health problem or condition.

All of the questions are important and we would therefore request that you answer them, even if they don't apply to your situation.

While participation in this survey is voluntary, we hope you will recognize the importance of this survey to all Canadians and participate willingly.

Why does the government spend money on a survey instead of providing better service to those who need it?	Government and private organizations need to know where are the people who need special services and what kind of services and programs they need. This survey will provide them with the information they need to develop relevant programs.
Who has access to my questionnaire?	Only Statistics Canada employees have access to your questionnaire and they are sworn in under the Statistics Act. They are subject to fines and/or imprisonment if they break the Oath of Secrecy.
Will participation in this survey affect my disability pension or any other monies I receive?	No, it will not. The purpose of this survey is to provide statistical information to researchers and government representatives in order to develop programs for persons with activity limitations. All answers are kept confidential and only Statistics Canada employees see the information that you provide.
Where can I get information about this survey and its results?	Information about this survey can be obtained from the statistical reference centers of the Statistics Canada regional offices. The results will be released in the spring of 2003.
I am a member of Are they aware of this survey?	While not every association may be aware of this survey, some are. (Refer to the list of associations in Appendix 4. Offer to give the name and telephone number of an appropriate association. Advise the respondent/caller

that he/she is responsible for any long distance charges.)

I am a person with a disability; what services are offered in my area?	(Refer to the list of "Selected Associations for Persons with Disabilities" and give the respondent the phone number of the contact for his/her province.)	
How much time will the interview take?	It will depend on how many questions apply specifically to you.	
I don't recall completing a questionnaire in May 2001.	Every Canadian had to fill in a census questionnaire. The person contacted at that time completed the census questionnaire on behalf of all household members.	
Why do you ask for the name, address and telephone number of a family member or friend?	As part of this survey, we may like to interview you again in a year or two. In case you move or there are difficulties reaching you, we need a contact we could call. We will only contact this person if we cannot reach you and then only to obtain your new address or telephone number.	
How do I know that the information I provide is kept confidential?	Statistics Canada recognizes the trust that respondents place in it to protect their data. That is why the Agency follows strict rules to ensure the confidentiality of your information. Under the Statistics Act, all Statistics Canada employees must take an oath of secrecy. Penalties for employees who breach the Act include both fines and imprisonment. Only employees who need to work directly with the	

any information that could identify you or your family.

questionnaires have access to them. When the survey data are released, your answers are combined with those of other respondents and we do not disclose

Why do pensioners and retired people have to answer income questions?

The questions cover all types of income, including from employment income, or from investments and pensions. This information from older persons is as important as from other groups in determining the economic well-being of Canadians.

Why doesn't
Statistics
Canada use the
income
information
from the Canada
Customs and
Revenue Agency
(formerly
Revenue

Canada)?

The income tax records do not cover all people and they do not provide important characteristics of persons with income. Through this survey, the income information can be combined with other factors such as education, occupation and age. The Canada Customs and Revenue Agency does not have access to individual records from Statistics Canada.

Chapter 8: Concepts and Definitions

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Common Concepts – Adults and Children

Activity limitation reference period In PALS the activity limitations we want to identify are of the long-term kind. In order to convey this in more concrete terms, we use a 6-month reference period. Thus, we always ask about **activity limitations or conditions that have lasted or are expected to last for six months or more.** The six months are measured from the time the limitation began. For example, if a respondent's mobility is limited because his leg has been in a cast for two months and is likely to remain so for another two or three weeks, this is <u>not</u> considered to be a "long-term" limitation.

Aids

Assistive devices

Specialized aids

These terms refer to special aids a person might use because of a condition or health problem which assist him or her to function, such as glasses, a hearing aid, a wheelchair, a cane or back brace, an artificial limb, a communications board, Braille reading material, etc.

Specialized equipment

Important!

Technical aids

There is no 6-month time reference for the use of aids, specialized equipment or assistive devices. These questions refer to the aids the respondent **currently** uses or needs.

Child care expenses

Child care expenses can be claimed if the respondent or their spouse paid for someone to look after their child, so they (or their spouse) could earn income, go to school, or conduct research in 2000. Please note there will be cases where this expense will not be applicable either because the respondent does not have children or even if they do, they are not eligible for the expense. "No" should be selected in these instances.

Disability Tax Credit

The Disability Tax Credit is available to an individual with a severe and prolonged mental or physical impairment that markedly restricts him or her in activities of daily living.

Medical Expenses Tax Credit

Medical Tax Credit applies to individuals who have sustained significant medical expenses for themselves or certain dependants.

Out-of-pocket expenses (costs)

Direct expenses (costs)

Out-of-pocket expenses are those expenses paid by the respondent (or family living with them in the case of help received or accommodation in the home) for whom there was no full reimbursement by any insurance, government program or service organization. It is important to identify and quantify the extra "out-of-pocket" expenses, which the respondent has incurred because of their condition.

Section B Activity Limitations (Adults)

Walking ½ km or ¼ mile

This measures the respondent's basic level of mobility. This means walking on a flat firm surface such as a sidewalk or floor using your legs (including artificial limbs).

Walking up and down a flight of stairs

Walking up and down a flight of stairs is intended to measure endurance and leg strength, both of which are requirements for independent living. By including "without resting", we are able to measure the respondent's level of stamina for each activity.

Carrying an object of 5 kg

This activity looks at carrying an object while walking across a flat firm surface. This activity incorporates function of the upper limbs as well as the

(or 10 lbs.) for 10 m (or 30 ft)

lower limbs, plus an element of strength.

Standing in line for 20 minutes

The activity of standing will measure the respondent's ability to stand without having to lean on something for support and retain his/her balance over a period of time. This means standing without leaning against a wall or using a chair, etc., for support (for example, standing in line for a movie or in a checkout line at the grocery store).

Moving from one room to another

Moving from one room to another means moving on a flat, firm surface from room to room. The method of movement is not important; therefore, if the respondent has no difficulty moving around when using a cane, crutches, a walker or a wheelchair, he/she is not limited in this activity.

In this activity, we are interested in the respondent's ability to get around the house and so the word "move" rather than "walk" has been used.

Bending down and picking up an object

Bending down and picking up an object means bending down, from a standing or sitting position, to pick up a small light object. The respondent may bend from the waist or bend the knees. This activity incorporates an element of flexibility with the function of grasping.

If the respondent informs you that he/she cannot pick up an object because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Dressing and undressing

The activity of dressing and undressing is included because it is considered to be one of the last activities an individual will give up before becoming dependent on others to perform daily activities. It incorporates general flexibility as well as specific functions such as the finger movements required to fasten and unfasten snaps, buttons and zippers.

Getting in and out of bed

If the respondent informs you that he/she does not have difficulty getting in and out of bed because it has been specifically modified, select "No" because the modified bed removes the difficulty.

Any bed that has been specifically modified to enable the respondent to get in and out of it is defined as an aid or specialized equipment.

Cutting toenails

Although cutting his/her own toenails may be seen as a rather odd question, the activity itself incorporates separate actions such as bending, and the strength and flexibility of fingers.

If the respondent informs you that he/she does not do this activity because he/she is missing legs or feet, apologize for asking the question and provide the following explanation:

This question is asked to find out if you have the ability to do this activity, but not whether you actually do it.

Select "No" in these cases.

Grasping or handling an object

Using his/her fingers to grasp or handle an object measures the flexibility and movement of the hands. No lifting is required.

If the respondent informs you that he/she cannot grasp or handle an object because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Reaching in any direction

Reaching measures the respondent's ability for full arm extension in every direction. There is no height or distance requirement for this action.

If the respondent informs you that he/she cannot reach in any direction because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Cutting food

Cutting food measures the respondent's ability to use cutlery such as a knife, fork and a spoon, to cut his/her own food. This includes cutting all types of food (e.g., meat, cheese, vegetables, and fruit).

If the respondent informs you that he/she cannot cut their food because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Section C - Help with everyday activities (Adults)

Preparing Meals

Many people <u>NEED to prepare meals</u> for themselves and/or their family but <u>because of a mental or physical condition</u>, they receive and/or need help accomplishing this everyday task.

If a respondent receives/needs help preparing meals <u>NOT</u> because of their <u>condition</u>, but because they do not want to cook or because someone else in the household always prepares meals, then the answer is No (they do not

receive/need help with preparing meals).

If a respondent <u>DOES NOT NEED</u> to prepare meals, for example, someone living in a nursing home or a teenager living with his parents, then the answer is No (regardless of their condition, they do not receive/need help with preparing meals).

Everyday Housework

Regular housekeeping includes tasks such as washing dishes, vacuuming, dusting, as well as any other regular task in the home.

Heavy household chores

It is possible that outdoor maintenance, such as mowing the lawn or shovelling snow, does not apply to respondents who live in an apartment or a condominium. In these cases, we are only interested in heavy indoor work such as spring-cleaning. The purpose of the questions related to this activity is to know the ability of the respondent to perform tasks requiring considerable effort.

Getting to appointments and running errands

The respondent is asked questions about the help he requires because of his condition. This help may include getting rides or having someone accompany them to help with the groceries.

Personal finances

Activities related to personal finances include getting to the bank and back, filling out forms, paying bills and administering the respondent's financial affairs (for example, using a power of attorney in the case of some persons with mental impairments).

Child care

Help with any work related to the care of a child under 15 can be included here.

Personal care

Help with personal care includes help with washing, dressing, or taking medication, as well as any other personal care activities.

Specialized nursing care or medical treatment

Does the respondent have a nurse visit the home to administer specialized care such as changing dressings or Ivs? As well this question asks about whether the respondent is in receipt of medical treatment at home such as injections, blood or urine testing, or catheter care.

Moving about inside residence

These questions deal with the help the respondent receives or needs to move around in his/her residence.

Difficulty making arrangements

Some questions identify the difficulties that some respondents have in finding help to perform daily activities. We are very interested in the reasons that explain why certain people do not get the help they need.

for help received

Cost of help received

A series of questions deal with the costs of the help received. They help to identify how much the condition of the respondent costs him/her directly or indirectly.

First, we want to identify 'who' pays for the help. If the respondent and his family pay for part or all of the help, we ask if they are reimbursed and from what source. We also ask about the out-of pocket costs they or their family have had in the past twelve months, for the help received (after reimbursements, tax credits, etc.)

Section D - Education (Adults)

Foreign education

If the respondent attended school in another country and finds it difficult to equate his/her education to the Canadian system, ask the respondent to provide an estimate of the equivalent grade.

Attending a school, college or university

Attending a school, college or university includes attendance on a full-time or part time basis, for example attending night courses part-time.

Kind of school

If the respondent currently attends more than one type of institution, indicate the one in which they are taking the most courses.

Special education school refers to a school that is run only for students who have a limitation, such as a school for persons who are blind or a school for the hearing impaired.

Grade

The answer category "non-graded" is to be marked when a person attends a school which does not have specific grade levels.

Certificate, diploma or degree

This question asks the respondent about the type of certificate, diploma or degree being sought. It does not refer to how much of the program has been completed by the respondent. Professional accreditation should be reported in the same category as the degree they completed, for example, chartered accountant (CA) should be reported as a bachelor degree.

High (secondary) school graduation certificate or

Mark this category for persons who have graduated from high school. Mark this category as well for persons who have enough credits for the equivalent of high school graduation in the province or territory in which they live, even if they obtained their education outside Canada.

equivalent

Trades certificate or diploma

Mark this category for persons who have received a certificate or diploma through in-school training in trades-level vocational and pre-vocational courses. Such courses are given at community colleges, institutes of technology and similar institutions. Persons who have a trade certificate or diploma may or may not also have apprenticeship or journeyman training. Include all training where the minimal entrance requirement was **less** than secondary or high school, junior or senior matriculation, or the equivalent.

Other nonuniversity certificate or diploma

Mark this category for persons who have received a certificate or diploma (other than a trades certificate or diploma) from a community college (both transfer and semi-professional career programs), CEGEP (both general and professional), institute of technology or any other non-degree-granting educational institution.

University certificate or diploma below bachelor level

Mark this category for persons who have a teaching certificate awarded by a provincial department of education at an approved institution such as a normal school or college of education. For persons who earned their teaching qualifications at an accredited university's faculty of education, mark **Bachelor's degree** (s).

For persons who have a diploma, certificate or licence from a professional association and whose course of study was conducted through a university, mark **University certificate or diploma below bachelor level** (provided that a bachelor's degree was not required to enrol in these programs).

Formal education

Formal education includes primary, secondary and post secondary schooling.

Section E – Employment Status (Adults)

Working for pay or in selfemployment

Working means persons who are paid employees; self-employed in their own business, profession, or in farming; or unpaid employees in a family business or farm.

Include any activity carried out by the respondent for pay or profit, including part-time work and "payment in kind" (payment in goods or services rather than money).

Work around the house or volunteer work such as for a church is not counted as working at a job or business.

Caring for own children

Caring for a child is one of the response options available to explain the respondent's absence from work or why the respondent works less than 30 hours per week.

Note: The respondent must be a parent (natural or adopted, but the child need not reside with the respondent).

Caring for elder relative

Providing care or assistance to an elderly relative includes relatives aged 60 or more. The elderly relative does not need to live in the same household as the respondent.

Other personal or family responsibilities

Other personal or family responsibilities include:

- caring for a younger relative (who is not the respondent's own child)
- any personal or family responsibilities that do not fall under any other selection
- changes in the family circumstances, marriage, death or serious family illness (other than the respondent's own child or an elderly relative).

Working less than 30 hours per week

A list of reasons for working less than 30 hours per week is provided. They include:

- own illness, condition or disability:
 - -any health related reason;
 - -the physical effort required (physically unable to continue in the job);
 - -being on sick leave from a job that the respondent will retire from as soon as all available sick leave expires (if the illness or disability actually prompted the retirement).
- caring for own children;
- caring for elder relative (60 years of age or older);
- other personal or family responsibilities;
- going to school;
- business conditions for example, not enough work, drop in orders, retooling, cutback in hours to save costs;
- could not find work with 30 or more hours per week.

If the main reason for working less than 30 hours per week is due to regulations restricting working hours (e.g. airline pilot), select "Other" from the list and specify the reason.

Name of employer

For persons aged 15 and over whose wages are paid by an agency that hires out their services, report the name of the agency.

For persons 15 and over who work as employees in someone's home (for example, nannies) report the name of the family worked for, then report private household.

Kind of business, industry or service

"Kind of business" refers to the product or service and the type of business the employer operates. Follow the general rules below:

Indicate both a general and a specific function of an employer's business. Describe the type of business in detail. For example:

Complete response	Insufficient response
copper mine	mining
automotive brake linings manufacturing	auto parts
retail household furniture and appliance store	furniture
secondary school	school
aluminium rolling and casting	aluminium
municipal police department	police
stuffed toys importing	importing
road construction	construction
shoe repair service	repair service
car insurance agency	insurance
interior decorating consultant	consultant

Kind of business, industry or service

- Distinguish between manufacturers, wholesalers and retailers. For example, retail bookstore, fountain pen manufacturer, wholesale grocery supplier, men's clothing manufacturer.
- In the case of government employees, enter the type of government;

whether it is federal, provincial, county, regional or municipal. If a person reports working for the Edmonton Parks and Recreations Department, the correct entry is "Edmonton municipal government".

• Some firms engage in more than one business or industrial activity. If the activities are carried out in separate locations, describe the activity at the respondent's place of work only. If the activities are carried out in the same location, describe the major activity of the firm. For example, a person working for "Western Bakeries" could be working in a factory making cakes or a factory making bread.

Kind of work

"Kind of work" refers to the duties or tasks performed by the respondent. The answer should provide more than just the job title.

Ask for specific descriptions of the work done. For example:

Complete response	Insufficient response
electrical equipment maintainer	maintenance
electrical motor repairman	repair work
typist, general office work	office work
industrial engineer	engineering
electronic equipment inspector	inspecting
aircraft assembly supervisor	supervising
health-care planning consultant	consulting

Main activities or duties

Report the main activities or duties this person does/did in his or her job. Be sure to indicate supervisory or management responsibilities if they apply.

For persons who are members of a religious order engaged in teaching or nursing, report these activities rather than the religious activities.

Class of worker (Question E13, E54, E80)

Select "working for wages, salary, tips or commission" for persons who worked:

- for wages, salary or tips;
- on commission as a salesperson for only one company and did not maintain an office or staff;
- for payment in kind (room, board) in a non-family enterprise (for example, as a member of a religious order);
- for piece-rates;
- as a member of the Armed Forces;
- an hour or more for pay in a job such as cleaning or babysitting (in another person's home);
- as a paid housekeeper or nanny.

Select "working without pay for your spouse or another relative in a family farm or business" for persons who worked without money wages at a task that contributed to the operation of a farm or business that belongs to a spouse or relative who is a member of this household.

Select "**self-employed alone or in partnership**" for persons who:

- operated their own business, farm or professional practice (alone or in partnership) even if no goods or services were sold;
- operated their own business, farm or professional practice (alone or in partnership) whether it made a profit or suffered a loss;
- operated a farm, whether they owned or rented the land;
- worked on a freelance or contract basis;
- provided meals and/or room or day care services in their own home for boarders, roomers or neighbours' children;
- operated a direct distributorship selling and delivering products such as cosmetics, newspapers, brushes or cleaning products.
- fished, trapped or hunted for profit or for the maintenance of the community, with their own or rented equipment or with equipment in which they had part ownership were setting up a business, farm or professional practice.

Union member

To be a union member, the respondent must have actually joined a union and signed a union card.

Many employees work in jobs covered by a union contract, but for one reason or another they have not joined the union and have not signed a union card, for example, due to personal or religious reasons. Under these circumstances, or if the respondent is unsure about his/her membership, but knows the job is covered by a union agreement, enter "No" for union member and "Yes" for covered by a union contract.

Collective agreement

The document the respondent's employer and labour representatives (or bargaining unit) have signed is called a Collective Agreement. It lays out the rights and responsibilities of both the employer (management) and the employee. It is crucial that the document cover not just one employee, but a group of employees (i.e. collective).

Number of persons employed

Sometimes the number of employees working for an employer varies significantly over time. In these circumstances, ask the respondent to report the **usual** number of employees at the location. **Location** refers to the specific building or complex where the respondent works. The same employer may operate at several locations, but the response should not include employees at these other locations.

Rate of pay or salary

We know it is sometimes difficult for a respondent to provide an exact wage amount. We also know that some people feel that wage ranges are easier for respondents to answer. Unfortunately, wage ranges do not provide enough information to calculate average weekly and hourly wage rates for particular groups of people. When an exact wage is not known, a reasonable estimate is acceptable.

Some respondents' earnings vary because of variability in work hours. Ask for the average earnings under normal circumstances. We are not interested in a particular wage, but rather in the average wages and the distribution of wages across groups of people.

If respondents hesitate, remind them that this information is kept confidential. Wage information, like all other information collected in this survey, is stripped of any identifying information before it is used.

Period reported for pay or salary

For respondents who choose to report their rate of pay or salary on a yearly basis, the earnings must correspond to an **entire** year. If the respondent has not worked for the full year (e.g., a respondent started at a job a few months ago), the amount entered should reflect what the respondent would normally earn, had he/she worked for a full year.

Some respondents may prefer to report an hourly rate of pay. The hourly rate of pay may be specified in a collective or individual agreement with the employer. If there is confusion about whether or not a respondent is an hourly worker, ask if he/she gets paid a pre-specified rate for all overtime hours and whether pay is deducted from his/her pay cheque for any absence from work. Either of these two conditions means the respondent is likely an hourly paid worker.

Tips or commissions

Obtain the estimate of usual tips or commissions for a period of time that is easy to calculate for the respondent. **Usually** refers to a typical pay period. Try to ensure that the respondent is reporting on his/her usual situation.

Employment term/duration

A **permanent** job is one that is expected to last as long as the employee wants it to and as long as business conditions permit. Sometimes permanent jobs are referred to as indeterminate since they have no pre-specified date of termination.

A job that is not permanent is one that has a predetermined date on which it will end or will end as soon as a specified project is completed. The employer has hired the employee on the understanding that the job will end at this specified time in the near future. Jobs, which are not permanent, are sometimes referred to as **term positions** since they exist only for a specified term, duration or project.

The intent of these questions is to measure the extent to which jobs are permanent or not rather than the extent to which the respondents' job-holding intentions are permanent or not. Some students may consider their job not to be permanent because they are only working temporarily and plan to return to school. Probe to find out if the job will be available to someone else after they leave. If this is the case, then the job is considered to be permanent.

Section G – Economic Characteristics (Adults)

Attendant care expenses	Attendant Care Expenses can be claimed by individuals who are entitled to claim the disability tax credit and who have incurred expenses for personal care that is necessary in order to enable them to work.
Caregiver amount	The Caregiver amount may be claimed if during the year, a person (alone or with another person) maintained a dwelling where the person and a dependant lived. There are several criteria including for example, that the dependant must have been 18 or over and been dependent due to "mental or physical infirmity". (Please note the latter term is that used by Revenue Canada.)
Tuition and education amounts	Generally, tuition fees can be claimed if the fees were for a course at a post-secondary school level or if one were 16 or older on December 31, 2000, and the fees were for a course one took to obtain or improve occupational skills.
	The education amount can be claimed if one was enrolled in a qualifying educational program at a designated educational institution.
Sources of income reference period	The reference period for the sources of income is from January 1 to December 31, 2000.
Definitions	
Accessible classrooms	These are classrooms that have special fixtures, furniture and arrangements in them which make them more accessible to people with activity limitations.
Accessible transportation	This is transportation that is easy to get to and make use of for people with activity limitations.
Accessible washrooms	These are washrooms that have easy to open doors and special fixtures in them that make them more accessible to people with activity limitations.
Agility	The ability to move and bend one's limbs easily and fluidly.
Alarms (Flashing / visual/	Devices that enable a deaf person to know that for example, the phone or the doorbell is ringing.

vibrating)

Amplifier (FM, acoustic, infrared)

Consists of a transmitter worn by the speaker and a receiver worn by the hearing-impaired person, which amplifies the sound either through his/her hearing aid or directly to the ear.

ASL

ASL is the acronym for American Sign Language. It is used as a means of communication amongst deaf people.

Asperger syndrome

Asperger syndrome is a life-long disorder characterized by a severe and sustained impairment in social interaction, and restricted and repetitive patterns of behaviour and interests. However, people with Asperger's do not have the significant delays in language, cognition, self-help skills or adaptive behaviour that are typical in autism.

Attention Deficit Disorder (ADD)

Attention Deficit Disorder is a biologically based condition causing a persistent pattern of difficulties resulting in one or more of the following behaviours:

Attention Deficit Hyperactivity Disorder (ADHD)

- Inattention: difficulty attending or focusing on a specific task
- Hyperactivity: difficulty inhibiting behaviour
- Impulsivity: difficulty controlling impulses

A person may be diagnosed with either ADHD or ADD depending on whether they are hyperactive or not.

Autism

Autism is a lifelong brain disorder, present from birth that typically appears during the first three years of life. The symptoms include:

- (1) Profound lack of affect or emotional contact with others.
- (2) Inconsistent pattern of sensory responses. Sometimes appear to be deaf and fail to respond; at other times, distressed by everyday noises.
- (3) Speech and language are absent or delayed while specific thinking capabilities might be present.
- (4) Fascination with manipulating objects

Bathroom aids

Devices such as bath and toilet grab bars, which help people getting in and out of the bath, or getting on and off a toilet seat.

Benefits from Canada or Quebec Pension Plan

These benefits include retirement pensions, survivors' benefits and orphans' benefits. Disability pensions should be recorded in response category (h), "Disability pension from the Canada or Quebec Pension Plan" (of Question G8).

Braces	Device used to support limbs.
Braille	Braille text is embossed characters that have been formed by raised dots in six-dot cells. Braille is intended for use by the visually impaired.
C.C.T.V.	A device consisting of a camera that magnifies anything placed in front, and a display allowing visually impaired people to read books, recipes, prescriptions, etc. It also allows them to see photographs and things far away.
Caption decoder	A device, which decodes a signal and displays it visually at the bottom of a television screen, enabling a person to read what is being said. People with hearing impairments often use a caption decoder.
Catheter	A catheter is a tube used to drain or inject fluid, apply pressure to a vessel, unblock or widen obstructed blood vessels, or control bleeding. Commonly used to drain urine from the bladder.
Chiropractor	A chiropractor diagnoses and treats patients' disorders of the spine and other body joints by adjusting the spinal column or through other corrective manipulation.
Closed caption T.V.	A television that displays the dialogs and sounds at the bottom of screen, enabling a person to read what is being said.
Closed circuit TV	A device consisting of a camera that magnifies anything placed in front, and a display allowing visually impaired people to read books, recipes, prescriptions, etc. It also allows them to see photographs and things far away.
Commissions	Commissions are a percentage paid to the agent or sales representative from the profits of goods sold or a business obtained.
Communications board such as "Bliss"	A touch screen used as an alternative method of communication for those who are unable to communicate verbally. Each "button" or "key" on the pad represents a word or concept that the user may wish to communicate. The units may be wheelchair mounted or portable for people who can walk.
Complex medical care needs	Persons with complex medical care needs require technology, specific services, or some form of ongoing medical support for survival. This definition includes persons with severe chronic and progressive illnesses and severe disabilities.

Developmental disability

Refers to substantial limitation in functioning, characterized by significant sub-average intellectual functioning, as well as limitations in adaptive skill areas, such as communication, self-care, home living, social skills, self-direction, functional academics, etc. Developmental disability is a permanent condition that manifests itself before age 18.

Developmental disorder

A <u>developmental disorder</u> refers to brain disorders such as autism, Asperger syndrome and others.

Down syndrome

Down syndrome is the most common and readily identifiable chromosomal condition associated with developmental disability. It is caused by a chromosomal abnormality when for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes.

Some common characteristics are poor muscle tone, slanting eyes with folds of skin at the inner corners, excessive ability to extend the joints and broad feet with short toes. Physical as well as intellectual development is slower than their non-disabled peers.

Dyslexia

A disorder most commonly known as a reading and writing disorder, where a person might confuse reversible letters, i.e. "b" and "d"; transpose letters in syllables, syllables in words or words in phrases; read words backwards; have trouble recognizing whole words or groups of letters; or have trouble linking the spoken word with the written word.

E-Commerce

Shopping or conducting some other business transaction on the internet.

Electronic chat Groups

These are special areas usually on a web site where people can log on and communicate in real time, by typing with keyboards or other input devices, with one or many other people about similar interests.

Electronic news groups

This is a virtual message board that people interested a specific topic log onto to ask questions, provide answers or just discuss various aspects of the topic of interest.

Employment Insurance

Employment Insurance includes benefits received for:

- unemployment
- sickness
- maternity, paternity or adoption
- work sharing or training

Fetal alcohol syndrome (FAS)

Fetal Alcohol Syndrome (FAS) is a medical diagnosis given to individuals who have a birth defect caused by the maternal ingestion of alcohol. To be given this diagnosis an individual must have the following symptoms:

- a) growth deficiency (either height or weight) and
- b) a specific pattern of facial and physical abnormalities and
- c) central nervous dysfunction (including microcephaly, intellectual impairment, learning disabilities, attention deficit and hyperactivity).

FM systems

Communication systems, which enable people who are hard of hearing to better, comprehend speech or enjoy listening to music. They use frequency modulated (FM) radio waves to transmit the signal from a transmitter (microphone, audio feed) to a receiver. The receiver converts the radio waves back into sound and then amplifies the sound.

Grab bars Grasping tools

Devices that provide support in bathtubs, showers, and around toilets.

Tools specifically designed to help people with a flexibility limitation. It provides them a way to seize objects that otherwise would be out of reach.

Guaranteed Income Supplement or Spouse's Allowance

Refers to Guaranteed Income Supplements paid to persons 65 years of age and over, and Spouse's Allowance paid to 60 to 64-year-old spouses of Old Age Security Pension recipients and 60 to 64-year-old widow(er)s.

Home care

Care provided in the home to persons who are ill, who are incapacitated or who are otherwise limited in their activities. This can be nursing care, home housekeeping services, meals on wheels and other services.

Household income

Refers to the total income, before taxes and deductions, of all household members from all sources.

Human support

Human support can include a reader, job coach, personal assistant, note taker, subject area tutor, therapists, psychologist for assessments, career counselors for vocational assessment, learning disabilities specialists etc.

Hyperactivity

Hyperactivity is more easily observed in children but it also applies to adults. Someone who is hyperactive displays the following types of behavior: fidgets with hands and feet; squirms in their seat; talks excessively; runs about or climbs excessively in situations where it is inappropriate to do so (in adults, this may be limited to feelings of restlessness); is often "on the go" or acts as

if	"driven	by a	motor"	,
11	ariven	by a	HOLOI	

Income from selfemployment

Self-employment income includes net farm income and net non-farm income. Persons who operated an agricultural operation in 2000 should report net farm income. Persons who owned and operated a non-farm, unincorporated business or professional practice in 2000, alone or in partnership, would report net non-farm income.

Informal help

Informal help that may come from various non-institutional, non-governmental sources, such as citizens groups, community or neighborhood associations and even assistance from one's circle of family, friends or neighbors.

Infrared system

System whereby headphones connect to the output of a TV, VCR or compatible audio source to provide the hearing impaired person a high quality sound on a high frequency wavelength. The system can also be adapted for small and large areas allowing the person to hear in places such as churches, theatres and cinemas.

Inhaler

Device used by people suffering from asthma that sprays medication which helps to ease breathing.

Internet connection

A connection from your computer to the Internet. Usually via modem or direct connection to a special cable modem or local area network. In most cases this requires the services of an Internet Service Provider (ISP).

Job Coach

A job coach is someone who provides on-the-job training and support for the person with a developmental disability. (Government-funded non-profit agencies provide this service.) As the new employee becomes more proficient and confident, the job coach gradually reduces the amount of time he or she spends at the workplace. Eventually the employee is working independently under the supervision of the employer.

Job redesign

Refers to the process of adapting a worker's tasks and/or workplace in order to enable the person who has become limited in their activities to work or to be reinstated in their former position.

Learning disability

A generic term that refers to a group of disorders due to identifiable or inferred central nervous system dysfunction. Symptoms include difficulties in any of the following areas: attention, memory, reasoning, coordination, communicating, reading, writing, spelling, calculation, social competence and emotional maturation. A person with a learning disability usually has average or above average intelligence.

Legally blind	A person is considered legally blind if visual acuteness in both eyes with corrective lens is 20/200 (6/60) or less (with Snellen's chart or the equivalent), or if the greatest diameter of the field of vision in both eyes is less than 20 degrees.
Lifts / Lift type devices	Devices used to help people getting in or out of bed and getting up from a sitting position. For example, a bed rail, a bed rope ladder, grab bars, etc
LSQ	LSQ is the acronym for Langage des sourds du Québec, Sign language used in Quebec. It is often used by deaf people to communicate.
Maternity or Parental Leave	Maternity (or pregnancy) leave is a certain number of weeks (usually up to 17) which a pregnant woman can take off from work. Parental leave is a right which new parents (mothers, fathers and adopting parents) have to take time off work when a baby or child first comes into their care (usually up to 35 weeks). A birth mother can take both pregnancy leave and maternity leave.
	Maternity and parental benefits are also available from the federal Employment Insurance Program. The program provides 15 weeks of maternity benefits for biological mothers and 35 weeks of parental benefits for both biological and adoptive parents.
Medical treatment	Medical treatment given in the home to people with an illness or condition for which they need care.
Message relay system	A service offered by a telephone company to assist you in communicating with a deaf person.
Mobility	The ability to move oneself from one location to another with or without a specialized aid.
Modified workstations	Workstations can be modified to be more accessible to people with activity limitations.
Nursery school	Nursery school incorporates an early childhood education approach into the day to day care of young children. A nursery school runs somewhat like a preschool with a fair amount of structure and order.
Orthopedic footwear	Refers to any shoes, boots, etc. that were specially prescribed by a doctor for the respondent.

Other income For Question G8 (1) in the Adults Questionnaire, this can include: provincial or territorial income supplements to Old Age Security pension recipients provincial or territorial payments for rent or lodging for senior citizens Goods And Services Tax (GST) or Harmonized Sales Tax (HST) refunds refundable provincial or territorial tax credits payments received from training programs sponsored by the federal, provincial or territorial governments retirement pensions, superannuation and annuities, including those from RRSPs and RRIFs dividends, interest on bonds, deposits and savings certificates, and other investment income alimony and child support non-refundable scholarships, bursaries, fellowships and research grants severance pay and retirement allowances royalties - non-investment income from outside Canada Pain Pain management aids are those aids used by the respondent specifically for the alleviation of chronic pain. management aids **Parental Leave** See "Maternity or Parental Leave". Personal care washing, bathing, oral hygiene, feeding, taking medication, and toileting.

management aids Parental Leave See "Maternity or Parental Leave". Personal care Any type of care that involves day to day hygiene or toiletry. For example, washing, bathing, oral hygiene, feeding, taking medication, and toileting. Personal Refers to the total income of the individual (the respondent), before taxes and deductions. Personal Courses taken by the respondent specifically for their own interest and not for other reasons such as career development etc. Pocket Electronic device used by people to keep track of things they have to do and remember.

Portable note- takers	Braille or speech note takers are devices used by visually impaired people for note taking using a Braille keyboard for input and either Braille or speech output.
Proxy interview	An interview answered by someone other than the respondent on his/her behalf because the respondent does not speak English or French and there is no interpreter available; or the respondent is unable to respond because of his/her condition; or the respondent is away for the duration of the survey.
Puffers	Common name of inhalers for persons suffering from asthma.
Reach extender	Adaptive device used to increase the reach up to 27 inches. It's also used for grasping objects and picking up small metallic objects.
Scanner	The scanner is often coupled with OCR (optical character recognition) software to comprise a suite of electronic aids used for capturing a hard copy text or hand written information electronically.
Social service	A service provided by the government for the community. For example, public housing, health and wellness programs, and social workers.
Special education classes	Refers to classes given in a regular school to students with a condition or health problem, (for example, students who have a developmental disability). These classes may be given in addition to, or instead of, the regular school curriculum.
Special education school	Refers to a school that is run only for students with a limitation or disability, such as a school for persons who are blind or deaf.
Specialized bus services	A bus service that has busses or vans with large amounts of floor space, special anchors, ramps or lifts, and special seats that meet the needs of persons in wheelchairs and persons with other mobility limitations.
Specialized nursing care	Any type of health related care that a visiting or attending nurse is responsible for. Examples of this could be changing dressings, therapy, and changing Ivs.
Speech read or lip read	A lip reader is a person who is able to interpret the lip movements another person makes when they are talking. Speech reading involves reading many other cues such as facial expressions, gestures, contextual cues, and body language.
Spina bifida	Spina Bifida means cleft spine, which is an incomplete closure in the spinal column. In the most severe form of spina bifida, a portion of the spinal cord itself protrudes through the back.

Talking books	Currently, talking books for the visually impaired are distributed on audiocassettes. The next-generation technology for this application will be digitally based, bringing many improvements in sound quality, document navigation, and searching.
TENS machine	TENS (Transcutaneous Electrical Nerve Stimulation) is a device used for relief of pain from various causes. The mild electric current blocks pain signals from the nerve and thus prevents their recognition by the brain.
Tips	Tips are a small sum of money given in appreciation of a service given.
TTY or TDD	Attached to the telephone, this device includes a typewriter keyboard, a screen and sometimes a printer. It enables a person who is deaf or hearing impaired to communicate visually.
Voice recognition software	Voice activated or voice sensitive computer software that makes use of a soundcard interface on your computer to convert your voice into digital signals, which it then converts to text. People with learning disabilities or limited mobility often use this software.
Volume control telephone	A telephone device that amplifies and improves the quality of the sound to the listener. It is often used by persons with a hearing impairment.
Voluntary organizations or agencies	All organizations that offer free services, such as social clubs, community groups, religious organizations, etc.
Wages and salaries (for Source of income in Question G8 - Adults)	Wages and salaries include wages and salaries from all jobs before deductions for income tax, pensions, etc. They can also include:
	- commissions, tips, cash bonuses and casual earnings
	- military pay and allowances
	- benefits from wage-loss replacement plans or income-maintenance insurance plans
Walker TENS machine	- employer or union supplementary unemployment benefits
	Usually a light metal frames, standing about waist-high to the user. It is used as a support in order to get around.
	TENS (Transcutaneous Electrical Nerve Stimulation) is a device used for relief of pain from various causes. The mild electric current block pain signals from the nerve and thus prevents their recognition by the brain.

Tips	Tips are a small sum of money given in appreciation of a service given.	
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Voice recognition software	Voice activated or voices sensitive computer software that makes use of a soundcard interface on your computer to convert your voice into digital signals, which it then converts to text. People with learning disabilities or limited mobility often use this software.	
Volume control telephone	A telephone device that amplifies and improves the quality of the sound to the listener. Persons with a hearing impairment often use it.	
Voluntary organizations or agencies	All organizations that offer free services, such as social clubs, community groups, religious organizations, etc.	
Walker	Usually a light metal frames, standing about waist-high to the user. It is used as a support in order to get around.	
	• •	

Activity Limitations

Walking ½ km or ¼ mile	This measures the respondent's basic level of mobility. This means walking on a flat firm surface such as a sidewalk or floor using your legs (including artificial limbs).
Walking up and down a flight of stairs	Walking up and down a flight of stairs is intended to measure endurance and leg strength, both of which are requirements for independent living. By including "without resting", we are able to measure the respondent's level of stamina for each activity.
Carrying an object of 5kg or 10 lbs for 10 m or 30ft	This activity looks at carrying an object while walking across a flat firm surface. This activity incorporates function of the upper limbs as well as the lower limbs, plus an element of strength.
Standing in line for 20 minutes	The activity of standing will measure the respondent's ability to stand without having to lean on something for support and retain his/her balance over a period of time. This means standing without leaning against a wall or using a chair, etc., for support (for example, standing in line for a movie or in a checkout line at the grocery store).

Moving from one room to another

Moving from one room to another means moving on a flat, firm surface from room to room. The method of movement is not important; therefore, if the respondent has no difficulty moving around when using a cane, crutches, a walker or a wheelchair.

In this activity, we are interested in the respondent's ability to get around the house and so the word "move" rather than walk has been used.

Bending down and picking up an object

Bending down and picking up an object means bending down, from a standing or sitting position, to pick up a small light object. The respondent may bend from the waist or bend the knees. This activity incorporates an element of flexibility with the function of grasping.

If the respondent informs you that he/she cannot pick up an object because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Dressing and undressing

The activity of dressing and undressing is included because it is considered to be one of the last activities an individual will give up before becoming dependent on others to perform daily activities. It incorporates general flexibility as well as specific functions such as the finger movements required to fasten and unfasten snaps, buttons and zippers.

Getting in and out of bed

If the respondent informs you that he/she does not have difficulty getting in and out of bed because it has been specifically modified, select "No difficulty" because the modified bed removes the difficulty.

Any bed that has been specifically modified to enable the respondent to get in and out of it is defined as an aid or specialized equipment.

Cutting toenails

Although cutting his/her own toenails may be seen as a rather odd question, the activity itself incorporates separate actions such as bending, and the strength and flexibility of fingers.

If the respondent informs you that he/she does not do this activity because he/she is missing legs or feet, apologize for asking the question and provide the following explanation:

This question is asked to find out if you have the ability to do this activity, but not whether you actually do it.

Select "No difficulty" in these cases.

Grasping or handling an object

Using his/her fingers to grasp or handle an object measures the flexibility and movement of the hands. No lifting is required.

If the respondent informs you that he/she cannot grasp or handle an object because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Reaching in any direction

Reaching measures the respondent's ability for full arm extension in every direction. There is no height or distance requirement for this action.

If the respondent informs you that he/she cannot reach in any direction because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Cutting food

Cutting food measures the respondent's ability to use cutlery such as a knife, fork and a spoon, to cut his/her own food. This includes cutting all types of food (e.g., meat, cheese, vegetables, and fruit).

If the respondent informs you that he/she cannot cut their food because they have no arms or hands, probe further about the use of aids or specialized equipment; if aids are used, ask the question again, with the preamble "With these aids..."

Help with everyday activities

Preparing Meals

This question asks if the respondent ever receives help preparing meals **because of their condition,** not because they can't cook or don't want to cook.

Everyday Housework

Regular housekeeping includes tasks such as washing dishes, vacuuming, dusting, as well as any other regular task in the home.

Heavy household chores

It is possible that outdoor maintenance, such as mowing the lawn or shoveling snow, does not apply to respondents who live in an apartment or a condominium. In these cases, we are only interested in heavy indoor work such as spring-cleaning. The purpose of the questions related to this activity is to know the ability of the respondent to perform tasks that require considerable effort.

Getting to		
appoint ments		
and running		
errands		

The respondent is asked questions about help getting to appointments and running errands because of their condition. This might include getting rides or having an assistant help with the groceries.

Personal finances

These questions ask about any help the respondent might receive or need in doing their personal finances or budgeting or paying bills etc.

Child care

Help with any work related to the care of a child under 15 can be included here.

Personal care

Help with personal care includes help with washing, dressing, or taking medication, as well as any other personal care activities.

Specialized nursing care or medical treatment

Does the respondent have a nurse visit the home to administer specialized care such as changing dressings or IVs? As well this question asks about whether the respondent is in receipt of medical treatment at home such as injections, blood or urine testing, or catheter care.

Moving about inside residence

These questions deal with the help the respondent receives or needs to move around in his/her residence.

Difficulty making arrangements for help finding help

Some general questions identify the difficulties that some respondents have in finding help to perform daily activities. We are very interested in the reasons that explain why certain people do not get the help they need.

Cost of help received

A series of questions deal with the costs of the help received. They help to identify how much the condition of the respondent costs him/her directly or indirectly.

First, we want to identify 'who' pays for the help. If the respondent and his family pay for part or all of the help, we ask if they are reimbursed and from what source. We also ask about the out-of pocket costs that they have had in the past twelve months, for the help received (after reimbursements, tax credits, etc.)

Education

Foreign education

If the respondent attended school in another country and finds it difficult to equate his/her education to the Canadian system, ask the respondent to provide an estimate of the equivalent grade.

Attending a		
school, college or		
university		

Attending a school, college or university includes attendance on a full-time or part time basis, for example attending night courses part-time.

Kind of school

If the respondent currently attends more than one type of institution, indicate the one in which they are taking the most courses.

Special education school refers to a school that is run only for students who have a limitation, such as a school for persons who are blind or a school for the hearing impaired.

Grade

The answer category "non-graded" is to be marked when a person attends a school, which does not have specific grade levels.

Certificate, diploma or degree

This question asks the respondent about the type of certificate, diploma or degree being sought. It does not refer to how much of the program has been completed by the respondent. Professional accreditation should be reported in the same category as the degree they completed, for example, chartered accountant (CA) should be reported as a bachelor degree.

Formal education

Formal education includes primary, secondary and post secondary schooling.

Employment

Working for pay or in selfemployment

Working means persons who are paid employees; self-employed in their own business, profession, or in farming; or unpaid employees in a family business or farm.

Include any activity carried out by the respondent for pay or profit, including part-time work and "payment in kind" (payment in goods or services rather than money).

Work around the house or volunteer work; such as for a church is not counted as working at a job or business.

Caring for own children

Caring for a child is one of the response options available to explain the respondent's absence from work or why the respondent works less than 30 hours per week.

Note: The respondent must be a parent (natural or adopted, but the child need not reside with the respondent).

Caring for elder relative

Providing care or assistance to an elderly relative includes relatives aged 60 or more. The elderly relative does not need to live in the same household as the respondent.

Other personal or family responsibilities

Other personal or family responsibilities include:

- caring for a younger relative (who is not the respondent's own child)
- any personal or family responsibilities that do not fall under any other selection
- changes in the family circumstances, marriage, death or serious family illness (other than the respondent's own child or an elderly relative).

Working less than 30 hours per week

A list of reasons for working less than 30 hours per week is provided. They include:

- own illness, condition or disability:
 - -any health related reason;
 - -the physical effort required (physically unable to continue in the job);
 - -being on sick leave from a job that the respondent will retire from as soon as all available sick leave expires (if the illness or disability actually prompted the retirement).
- caring for own children;
- caring for elder relative (60 years of age or older);
- other personal or family responsibilities;
- going to school;
- business conditions for example, not enough work, drop in orders, retooling, cutback in hours to save costs;
- could not find work with 30 or more hours per week.
- If the main reason for working less than 30 hours per week is due to regulations restricting working hours (e.g. airline pilot), select "Other" from the list and specify the reason.

Name of employer

For persons aged 15 and over whose wages are paid by an agency that hires out their services, report the name of the agency.

For persons 15 and over who work as employees in someone's home (for example, nannies). Report the name of the family worked for, then report private household.

Kind of business, industry or service "Kind of business" refers to the product or service and the type of business the employer operates. Follow the general rules below:

Indicate both a general and a specific function of an employer's business. Describe the type of business in detail. For example:

Complete response	Insufficient response
copper mine	mining
automotive brake linings manufacturing	auto parts
retail household furniture and appliance store	furniture
secondary school	school
aluminum rolling and casting	aluminum
municipal police department	police
stuffed toys importing	importing
road construction	construction
shoe repair service	repair service
car insurance agency	insurance
interior decorating consultant	consultant

Kind of business, industry or service

- Distinguish between manufacturers, wholesalers and retailers. For example, retail bookstore, fountain pen manufacturer, wholesale grocery supplier, men's clothing manufacturer.
- In the case of government employees, enter the type of government; whether it is federal, provincial, county, regional or municipal. If a person reports working for the Edmonton Parks and Recreations Department, the correct entry is "Edmonton municipal government".
- Some firms engage in more than one business or industrial activity. If the
 activities are carried out in separate locations, describe the activity at the
 respondent's place of work. If the activities are carried out in the same
 location, describe the major activity of the firm. For example, a person
 working for "Western Bakeries" could be working in a factory making
 cakes or a factory making bread.

Kind of work

"Kind of work" refers to the duties or tasks performed by the respondent. The answer should provide more than just the job title.

Ask for specific descriptions of the work done. For example:

Complete response	Insufficient response
electrical equipment maintainer	maintenance
electrical motor repairman	repair work
typist, general office work	office work
industrial engineer	engineering
electronic equipment inspector	inspecting
aircraft assembly supervisor	supervising
health-care planning consultant	consulting

Most important activities or duties

Report the main activities or duties this person does/did in his or her job. Be sure to indicate supervisory or management responsibilities if they apply.

For persons who are members of a religious order engaged in teaching or nursing, report these activities rather than the religious activities.

Class of work

Select working for **wages**, **salary**, **tips or commission** for persons who worked:

- for wages, salary or tips;
- on commission as a salesperson for only one company and did not maintain an office or staff;
- for payment in kind (room, board) in a non-family enterprise (for example, as a member of a religious order);
- for piece-rates;
- as a member of the Armed Forces;
- an hour or more for pay in a job such as cleaning or babysitting (in another person's home);
- as a paid housekeeper or nanny.

Select working without pay for your spouse or another relative in a family farm or business for persons who worked without money wages at a task that contributed to the operation of a farm or business that belongs to a spouse or relative who is a member of this household.

Select **self-employed alone or in partnership** for persons who:

- operated their own business, farm or professional practice (alone or in partnership) even if no goods or services were sold;
- operated their own business, farm or professional practice (alone or in partnership) whether it made a profit or suffered a loss;
- operated a farm, whether they owned or rented the land;
- worked on a freelance or contract basis;
- provided meals and/or room or day care services in their own home for boarders, roomers or neighbors' children;
- operated a direct distributorship selling and delivering products such as cosmetics, newspapers, brushes or cleaning products.
- fished, trapped or hunted for profit or for the maintenance of the community, with their own or rented equipment or with equipment in which they had part ownership were setting up a business, farm or professional practice.

Union member

To be a union member, the respondent must have actually joined a union and signed a union card.

Many employees work in jobs covered by a union contract, but for one reason or another they have not joined the union and have not signed a union card, for example, due to personal or religious reasons. Under these circumstances, or if the respondent is unsure about his/her membership, but knows the job is covered by a union agreement, enter "No" for union member and "Yes" for covered by a union contract.

Collective agreement

The document the respondent's employer and labor representatives (or bargaining unit) have signed is called a Collective Agreement. It lays out the rights and responsibilities of both the employer (management) and the employee. It is crucial that the document cover not just one employee, but a group of employees (i.e. collective).

Number of persons employed

Sometimes the number of employees working for an employer varies significantly over time. In these circumstances, ask the respondent to report the **usual** number of employees at the location. **Location** refers to the specific building or complex where the respondent works. The same employer may operate at several locations, but the response should not include employees at these other locations.

Rate of pay or salary

We know it is sometimes difficult for a respondent to provide an exact wage amount. We also know that some people feel that wage ranges are easier for respondents to answer. Unfortunately, wage ranges do not provide enough information to calculate average weekly and hourly wage rates for particular groups of people. When an exact wage is not known, a reasonable estimate is acceptable.

Some respondents' earnings vary because of variability in work hours. Ask for the average earnings under normal circumstances. We are not interested in a particular wage, but rather in the average wages and the distribution of wages across groups of people.

If respondents hesitate, remind them that this information is kept confidential. Wage information, like all other information collected in this survey, is stripped of any identifying information before it is used.

Period reported for pay or salary

For respondents who choose to report their rate of pay or salary on a yearly basis, the earnings must correspond to an **entire** year. If the respondent has not worked for the full year (e.g., a respondent started at a job a few months ago), the amount entered should reflect what the respondent would normally earn, had he/she worked for a full year.

Some respondents may prefer to report an hourly rate of pay. The hourly rate of pay may be specified in a collective or individual agreement with the employer. If there is confusion about whether or not a respondent is an hourly worker, ask if he/she gets paid a pre-specified rate for all overtime hours and whether pay is deducted from his/her pay check for any absence from work. Either of these two conditions means the respondent is likely an hourly paid worker.

Tips or commissions

Obtain the estimate of usual tips or commissions for a period of time that is easy to calculate for the respondent. **Usually** refers to a typical pay period. Try to ensure that the respondent is reporting on his/her usual situation.

Employment term/duration

A **permanent** job is one that is expected to last as long as the employee wants it to and as long as business conditions permit. Sometimes permanent jobs are referred to as indeterminate since they have no pre-specified date of termination.

A job that is not permanent is one that has a predetermined date on which it will end or will end as soon as a specified project is completed. The employer has hired the employee on the understanding that the job will end at this specified time in the near future. Jobs, which are not permanent, are sometimes referred to as **term positions** since they exist only for a specified term, duration or project.

The intent of these questions is to measure the extent to which jobs are permanent or not rather than the extent to which the respondents' job-holding intentions are permanent or not. Some students may consider their job not to be permanent because they are only working temporarily and plan to return to school. Probe to find out if the job will be available to someone else after they leave. If this is the case, then the job is considered to be permanent.

Economic Characteristics

Medical Tax Credit	Medical Tax Credit applies to individuals who have sustained significant medical expenses for themselves or certain dependants.
Disability Tax Credit	The Disability Tax Credit is available to an individual with a severe and prolonged mental or physical impairment that markedly restricts him or her in activities of daily living.
Attendant care expense deduction	The Attendant Care Expense deduction is available to individuals who are entitled to claim the disability tax credit and who have incurred expenses for personal care that is necessary in order to enable them to work.
Caregiver deductions	The Caregiver amount may be claimed if during the year, a person (alone or with another person) maintained a dwelling where the person and a dependant lived. There are several criteria including for example, that the dependant must have been 18 or over and been dependent due to "mental or physical infirmity". (Please note the latter term is that used by Revenue Canada.)
Tuition and education amounts	Generally, tuition fees can be claimed if the fees were for a course at a post-secondary school level or if one were 16 or older on December 31, 2000, and the fees were for a course one took to obtain or improve occupational skills.
	The education amount can be claimed if one was enrolled in a qualifying educational program at a designated educational institution.
Child care expenses	Child care expenses can be claimed if the respondent or their spouse paid for someone to look after their child, so they (or their spouse) could earn income, go to school, or conduct research in 2000. Please note there will be cases where this expense will not be applicable either because the respondent does not have children or even if they do, they are not eligible for the expense. "No" should be selected in these instances.
Sources of income reference period	The reference period for the sources of income is from January 1 to December 31, 2000.

Chapter 9: Keys to Effective Interviewing

Content

Keys To Effective Interviewing	
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Purpose

This chapter offers guidelines for more effective interviewing to assist in bettering respondent relations.

Introductory Techniques

Guidelines

Your first step in the interview process is to set up a friendly relationship with the respondent and secure his or her co-operation.

- Make a good first impression. The first impression you make greatly influences the interview's outcome. To create the best impression, it is vital to project a professional image that portrays the seriousness of your intentions. Your tone of voice and attitude should invite co-operation.
- Avoid questions that can be answered "no". Asking permission to conduct the interview sets you up for refusals. You may find it easier to replace your questions with positive statements. For example, instead of asking: "May I talk with you now?" or "Is this a convenient time to do the interview?", try saying, "I'd like to do the interview with you now."
- Approach each interview as though it will take place immediately. Never assume a respondent is too busy. Make arrangements to call at a more convenient time <u>only if the respondent suggests this.</u> When you must make an appointment, do not ask for a convenient time. Begin by suggesting alternate days and times.
- When respondents are reluctant or hesitant, listen closely in order to focus on their main concern. It is important to listen to respondents and address only what concerns the respondent. Unsolicited information may bore the respondent, may be misunderstood, or may even be interpreted as "justifying" your request.
- When a respondent does not want to continue the interview, either because he thinks its too long or something or someone is disturbing him, try rescheduling with an appointment.

Listening Skills

Guidelines

- You should develop and practice good listening skills.
- Wait for the respondent to stop speaking before you stop listening.
- If you allow a short pause after each question, this ensures that the respondent has finished speaking. Pauses in the interview also communicate a mood. No pauses indicate that you are anxious and insecure, which tends to make the respondent feel the same.
- Indicate that you are listening.
- An occasional "Yes, I see," shows that you are still interested in what the respondent is saying.
- Ask questions if you do not understand something or feel you have missed a point.
- Neglecting to do so could cause confusion later in the interview and the respondent may feel you are not really listening.
- Do not make assumptions about what the respondent is going to say.
- Do not record an entry until the respondent has given you a complete answer.

Speech

Guidelines

Vocal expression, through language, grammar, voice quality, rate of speech and proper enunciation, is key to a positive image. Keep these points in mind:

Clarity: Speak directly into the telephone mouthpiece with your mouth about one inch away.

Enunciation: Clear enunciation will help prevent misunderstanding and the need to repeat yourself.

Rate of speech: Use pauses for emphasis and for regulating the pace of the interview. If you speak too quickly, people start listening to your rate of speech, not to what you are saying. But speaking too slowly may irritate listeners: it keeps them hanging on every word. When you speak too slowly, respondents tend to anticipate what you are about to say.

Pitch: Speech experts say low pitch is desirable because it projects and carries better. It is also more pleasing to the ear. Do not let your voice become high-pitched. Try lowering your head, which lowers your voice pitch.

Inflection: Use the full range of your voice to make the interview interesting. Do not talk in a monotone.

Conducting the Interview

Guidelines

Because researchers need to combine the data collected from all interviews, they must be collected in a uniform manner. This means that all people in the sample must be asked the same questions in the same way.

You should remember to:

- Ask questions exactly as worded. Research has shown that even inadvertent or very slight word changes can change the response obtained.
- Ask every question specified. Sometimes the respondent, in answering one question, also answers another question that appears later in the interview. However, it is important to ask every question. In this situation, you might say, "You've already told me something about this, but the next question asks..." This indicates that you are aware of the earlier response and you are asking for the respondent's co-operation to answer the question again.
- Ask questions in a positive manner. Some interviewers feel uncomfortable when asking certain types of questions and adopt an apologetic attitude. For example: "You might not want to answer this question, but...." or "This question probably won't make much sense to you..." Such statements negatively affect the flow of the interview and have a tendency to change the respondent's answers. Such statements also put the value of the survey into question and can lead to refusal situations.
- Explain delays between questions. Some answers will take longer to record than others. You can explain this to the respondent by saying, "Please excuse the delay, I'm entering the information you gave me."
- Repeat and clarify questions that are misunderstood or misinterpreted. Occasionally a respondent may misunderstand or misinterpret a question, particularly when the question involves numbers. When this happens, REPEAT THE QUESTION AS IT IS WRITTEN. If you still do not get an appropriate response, you may have to probe.

Awkward moments

• Sometimes people are tempted to relieve feelings of awkwardness or tension by laughing or making light of a question. As an interviewer, be aware of this and realize that respondents may interpret it as laughter at their responses or that their response is not considered acceptable. If the respondent laughs at him or herself, it is advisable not to join in.

Probing Techniques

Types of probes

Any probe must be controlled and neutral. There are five basic types of probes:

Rereading the question. Sometimes a respondent will not understand a question, will get off the subject or will give you an answer that does not fit the question. When this happens, reread the question, emphasizing the most important words.

Rephrasing the question. When repeating the question does not work, probe further by asking neutral questions. Your probe has to control the respondent's train of thought as well as elicit more information. Probing has to be done carefully: you must never introduce bias by suggesting answers. For example, "So, would you say...." This is a biased probe. It leads the respondent to simply accept the suggested answer.

The pause. Simply waiting expectantly can be the most effective controlled and neutral probe. Pausing lets the respondent know that he or she has not answered the question satisfactorily and that you are waiting for an appropriate answer. Be careful, however, not to pause too long.

Asking for more information. Respondents may not always know how much or what kind of information is required. They need you to let them know how detailed their answers should be. Sometimes, you can just ask for more information using questions like, "Can you tell me a little more about that?" or "Anything else?" or "I'm not sure I understand."

For questions requiring specific information (for example, days, hours), it is important to get the respondent to convert answers into the appropriate units. Do not assume that an answer of "about half an hour" means 30 minutes. If you need the response in minutes, probe by asking, "How many minutes did...

Zeroing-in. Respondents may feel uneasy at times when they cannot give you the most precise or exact information possible. In most cases, their opinion or best recollection is better than no information at all.

Probing is an art

You should probe without making respondents feel that their judgement is being questioned. Respondents must not get the impression that the interview is a quiz or a cross-examination. Respondents must not feel some answers are more "acceptable" than others are.

In general, let nothing in your words or manners imply criticism, approval or disapproval, agreement or disagreement with an answer. Do not suggest responses either. Respondents will often simply accept your prompt, thinking that the answer you have suggested is the one you want.

Appendix 1

Equivalency Quebec School

Codes to be used in Question D7 (Adults) for Quebec School Level		
Quebec School Level	Codes for Question DT (Adults)	
primary		
1	1	
2	2	
3	3	
4	4	
5	5	
6	6	
secondary		
1	7	
2	8	
3	9	
4	10	
5	11	

Appendix 2 - Sensitivity Issues

The following are some tips and suggestions which will assist you in interviewing persons who may have activity limitations. The first section contains general courtesies, as well as tips which apply to both telephone and personal interviews. The second section is more pertinent to personal interviews. Please ensure, however, that you review both sections.

I - General (Telephone and Personal Interviews)

- Persons with activity limitations are people first. React to the person, not to his/her activity limitation.
- Do not make assumptions concerning an individual's abilities or capacities based on the appearance of the activity limitation. Each type of limitation has a wide range of severity and individuals with the same type of limitation are never exactly alike in terms of what they can or cannot do.
- Do not patronize persons with activity limitations or tell them that you admire their courage and strength.
- Persons with an activity limitation are not necessarily ill or sick. In addition, don't assume they are more fragile or sensitive.
- Use a normal tone of voice. Never speak to a person with an activity limitation in a different tone of voice, which might suggest that one assume a difference based on the limitation.
- For respondents with speech difficulties, maximize the communication by allowing the person to speak at his/her own pace. Ask the respondents to repeat themselves if you do not understand what they are saying or rephrase what you have understood so that they can confirm or correct as necessary. Do not assume that the speech impairment indicates a developmental delay or any form of intellectual impairment.
- Allow someone on a ventilator plenty of time to speak.
- People with a learning disability or development disability may take time to understand what is being asked. Do not rush. Make sure the person clearly understands what is being asked.

II - Personal Interview Tips

1 - General:

Speak directly to the respondent even if they are accompanied by an attendant or a Sign language interpreter.

2 - For respondents who may be <u>blind or visually</u> impaired:

If applicable, upon entering the room where you will interview the respondent, announce your presence and identify yourself. When you are leaving the room, let the respondent know that you are doing so.

When a guide dog is being used, do not distract the dog without the owner's permission.

Be careful not to raise your voice when speaking to a respondent who is blind or visually impaired.

3 - For respondents who may be <u>deaf or hearing</u> impaired:

Do not assume that persons with a hearing impairment are non-verbal. Some choose not to use their voices if they think they are difficult to understand or have an inappropriate pitch or volume.

If the respondent can lip-read (not all persons who have difficulty hearing can lip-read), be conscious of the following in order to facilitate ease of communication:

- the interviewer should face the respondent.
- the interviewer should face the light source.
- use a normal tone of voice. Speak slowly and clearly. Do not exaggerate lip movements, which make lip-reading more difficult.
- Avoid putting your hands in front of your face.
- Do not gesture too much.

Do not shout at a person who is hearing impaired. Just speak in a normal tone of voice. The person will ask you to speak louder or slower if this is what is needed.

Do face the hearing impaired respondent, not the interpreter.

4.- For respondents who may have a mobility limitation:

For a respondent in a wheelchair, seat yourself so that you are both at the same eye level. It can be strenuous for the person to continue looking up for a long period of time.

Appendix 3

DEALING WITH STRESS IN YOUR JOB

Prepared for Statistics Canada by:

Dr. Santosh Bhalla

If you need assistance please contact your Employee Assistance Program

In the region: 1-800-268-7708

In Ottawa: 951-8427

Main Building, Room 1001

Handling Difficult Respondents

You are likely to get respondents who may not want to talk to you about some particular topics. Some of the reasons why this might happen are as follows:

- You are representing the Government and people may not trust you. Trust will be an even bigger issue when you start asking financial questions.
- They are afraid that the information will not stay confidential
- They are not comfortable talking over the phone
- Timing is not good for them
- Some of the questions are too personal
- They get very upset about the length and details of the questionnaire.

What are appropriate and inappropriate things to say if a respondent starts get angry with you or upset and does not want to continue with the interview because of the sensitive nature of the questions?

Appropriate statements/behaviors:

"I see that you find it difficult to talk about this subject, but it is only by hearing from people that we can understand the extent and nature of health and activity limitations in Canada.

"I want to assure you once again that all information will be kept confidential".

"If this is not a good time, I will call you back at _____".

"I realize you are finding the survey very detailed but it is necessary to enter a response for each question".

You (the interviewer) stay calm and patient.

You continue with the interview even if you have to repeat any of the above statements unless the person cannot go through because they are too upset. Make an appointment to continue later.

Inappropriate comments/behaviors:

(We are sure none of the interviewers will make the following statements or engage in the behaviors. But sometimes respondents can really get very difficult and try an interviewer's patience. In times like these, the following will be a good reminder to keep their perspective).

"Don't get upset with me, I am only doing my job".

"I have nothing to do with how long or detailed the survey is".

"I have no idea why Statistics Canada needs this information".

"Well, it is the Government, what else do you expect?"

Getting angry at the respondent.

Lose patience and hurry through the questionnaire,

Appropriate And Inappropriate Roles

Support Vs. Counseling

You will be talking with many respondents who have lived with or are still living with daily activity limitation(s). It is very natural to get upset when listening to someone about such experiences. It is also a natural feeling to try to help this person by offering advice, suggestions regarding what they should do. However, you are not in a position to do that in these circumstances. You can, as an interviewer, provide support as discussed below but should not get into a counseling role. The most important reason for this is that it requires extensive training in both the subject matter and the skills involved in offering meaningful help to people dealing with these serious problems. It will also distract you from your objective of collecting information.

The only thing you can offer a respondent is the phone number of a support service. List provided at training).

Empathy Vs. Sympathy

When other people are going through difficult times, we feel very bad for them.

One of our natural tendencies is to feel sympathy for them and even feel pity for them. Often times, their dignity has been affected and their self-esteem has, in many cases, suffered because of the limitations. You need to be careful in what and how you express your own feelings.

Some of the statements to avoid are:

- Poor you!
- It must be horrible what you are going through.
- I wish I could do something for you.
- I feel so bad for you.
- It is too much for me to handle. I need to take a break.
- You should get immediate help.

Some of the behaviors to avoid are:

- Start crying.
- Over identifying with the respondent.
- Avoid making assumptions.
- Becoming impatient with respondents. Some of them may be slow in giving answers.

Some of the appropriate empathetic statements/behavi ours are:

- Listening, really carefully, with a great deal of attention to the tone of voice, any changes in the voice, acknowledging responses with statements like 'I am listening, please go on, etc.
- Watching your own tone of voice, so as not to appear uncomfortable, hurried, upset.

Potential stressors and their effects on the interviewers doing this type of work

A partial list of changes (stressors and symptoms) <u>you</u> may experience following difficult interviews, includes:

May find it difficult to go to sleep (can't get a particular interview out of your mind, shift work)

Increased anxiety (about doing a good job, not saying the wrong thing, being able to get through the questionnaire, etc.)

Hyper-vigilance (one's own and family's health)

Becoming more sensitive about certain types of comments, jokes

A particular respondent may trigger some memories from your personal life and this causes strong emotional reactions Feelings of powerlessness and helplessness for not being able to do more for the respondents

Increase in general irritability and even anger

Increased emotional fatigue

Avoidance of certain people, programs on television

More time on reflection about your own life, society in general

Frustration and boredom about having to repeat the same questions many times during a day

Wondering what and if the information you collect will be used meaningfully

Loss of idealism, increase in general negativity

How can you best take care of yourself

There is no doubt this work will put some extra demands on your coping abilities. Most of the coping abilities you use in general to manage your daily life and crises in your life will all be useful at this time.

The following strategies may help you deal with stress in general:

Importance of good nutrition in stress management

Importance of taking healthy 'breaks'

Physical exercise

Mental Relaxation

Good and regular sleep habits

Support seeking

- Peers
- supervisor or senior interviewer
- professional resource.
- Employee Assistance Program counselor

Positive factors in this type of work; how to minimize stress, maximize benefits

What do you see as the positive factors for you in this work? Learning about own strengths, vulnerabilities

Recognize the strength of people who have been/are in difficult situations

Make an important contribution to one of society's problems

Learn about an important social problem

Examine own situation, relationships.

What can you do individually and as a group to minimize stress and maximize positive benefits?

Support coworkers

Seek support for self from peers, professional resources

Detach and maintain separation from work, taking time out for self

Set limits about what can you realistically accomplish (in your personal life

while you are on this project).

Focusing on small changes your work can make (gathering reliable

information is a very important activity).

Stay connected to friends

Healthy play

Regular exercise

Recognize that you might occasionally make mistakes learn from them.

Pay attention to nutrition, rest and sleep.

Organizational support available to interviewers

Your Employee Assistance Program counselors

Availability of a professional psychologist/counselor via telephone throughout the duration of the interviewing phase, to discuss any personal questions, concerns, in a completely confidential manner.

Speak to your immediate supervisor if you feel you have the need for such counseling and a telephone appointment will be scheduled for you.

Appendix 4

SELECTED ASSOCIATIONS FOR PERSONS WITH DISABILITIES

Canada

Canadian Abilities Foundation,

489 College St., Ste. 501,

Toronto, Ontario

M6G 1A5

Tel: 416-923-1885 Fax: 416-923-9829

E-mail: able@abilities.ca Web site: www.abilities.ca

Council of Canadians with Disabilities (CCD),

926-294 Portage Ave., Winnipeg, Manitoba

R3C 0B9

Tel: 204-947-0303 TTY: 204-947-0303

Web site: www.pcs.mb.ca/~ccd/

Canadian National Institute for the Blind,

National Office 1931 Bayview Ave., Toronto, Ontario M4G 4C8

Tel: 416-480-7580 Web site: www.cnib.ca

Learning Disabilities Association of Canada,

200-323 Chapel St., Ottawa, Ontario

K1N 7Z2

Tel: 613-238-5721 Fax: 613-235-5391

Canadian Mental Health Association,

National Office, 2160 Yonge St., 3rd Floor, Toronto, Ontario M4S 2Z3

Tel: 416-484-7750

Web site: www.cmha.ca

Canadian Association of the Deaf,

Head Office, Suite 203, 251 Bank St.,

Ottawa, Ontario Tel: 613-565-2882 TTY: 613-565-8882 Web site: www.cad.ca

Canadian Association for Community Living,

c/o York University, Kinsmen Building, 4700 Keele St., North York, Ontario

M3J 1P3

Tel: 416-661-9611 Fax: 416-661-2023 Toll:1-800-856-2207 TTY: 416-661-2023 E-mail: info@cacl.ca Web site: www.cacl.ca

Canadian Association of Independent Living Centres,

National Office, 1004-350 Sparks St., Ottawa, Ontario

K1R 7S8

Tel: 613-563-2581 Fax: 613-235-4497 TTY: 613-563-2581 E-mail: caicl@magma.ca Web site: www.cailc.ca

Québec

Office des personnes handicapées du Québec,

309 rue Brock,

Drummondville, Québec

J2B 1C5

Tel: 819-475-8585 Fax: 819-475-8753 Toll: 1-800-567-1465 TTY: 1-800-567-1477

E-mail: publication@ophq.gouv.qc.ca Web site: www.ophq.gouv.qc.ca

Institut national canadien pour les aveugles,

1010 rue Ste-Catherine Est,

Bureau P100,

Montréal, Québec

H2L 4Z8

Tel: 514-934-4622 Toll: 1 800 465-4622 E-mail: inca_qc@cam.org Web site: www.cnib.ca

Association des devenus sourds et des malentendants du Québec,

7400 St-Laurent Blvd.,

Suite36.

Montréal, Québec

H2R 2Y1

Tel: 514-278-9633 Fax: 514-278-9075 ATS: 514-278-9636

E-mail: adsmq@sympatico.ca

Web site: www. sympatico.ca/ adsmq

Association du Québec pour l'intégration sociale,

3958 Dandurand, Montréal, Québec

H1X 1P7

Tel: 514-725-7245 Fax: 514-725-2796

E-mail: aqisiqdi@total.net

Web site: www. Total.net/aqisiqdi/

Quiz for Interviewers

2001 PALS - Child and Adult Questionnaires

I) General
Important! Please note that the first five questions below apply to both the Adult and Child questionnaires.
1 - You contact a respondent whose DOB on the questionnaire label is 1986 01 06 (1986 January 06). When confirming the label information, he reports that he was born on July 06 1986. How do you proceed?
ANSWER: Chapter 3
2 - Who is asked the follow-up question?
ANSWER: Chapter 3
3 - What is the Profile Sheet used for? Why is it important that it be filled out accurately?
ANSWER: Chapter 3

4 - When asking questions about medications, would you consider vitamins as medication? Prescription or non-prescription medication?
ANSWER: Chapter 5
5 - If a respondent answers 5 2 hours for Question F5(a) in the Adults Questionnaire, how would you record the response? If they say 4 1/4 hours for F5(b), what would you put?
ANSWER: Chapter 3
II) Adult Questionnaire 1 - Can an adult respondent with a severe developmental disability, who doesn't use Sign
language, have an interpreter? ANSWER: Chapter 3
2 - The intended adult respondent is unable to speak English or French and an older child aged 17 agrees to interpret for him. The child interprets for all of Sections A and B, but then starts to get extremely tired and agitated. At Question C2, the child begins to answer for the respondent, no longer translating the questions and answers back and forth. How
would you code the information source? ANSWER: Chapter 3

3 - For <u>Question B47</u> : Do you (Does) have any difficulty standing in line for more than 2 minutes? If the respondent answers AYES, always! I am very hyper and I cannot stay i
one place that long, how do you record the response?
ANSWER: Chapter 8
4 - For <u>Question B59:</u> Do you (Does) have any difficulty getting into and out of bed? It the respondent answers "My bed was modified with a special lift mechanism to help me go in and out of bed", how do you record the response?
ANSWER: Chapter 8
5 - For <u>Question B85</u> : Do you (Does) FREQUENTLY have periods of confusion of difficulty remembering things? These difficulties are often associated with diseases such at Alsheimer's or may be the result of a brain injury? If the respondent answers Oh yes, I've always had difficulty remembering things or Hey I'm 85. Of course, I have difficult remembering things. Wait till you're my age, you will too., how do you record the answer?
ANSWER: Chapter 4

6 - For Question C2: Because of your (his / her) condition, do you (does) usually RECEIVE help with heavy household chores, such as spring cleaning or yard work? If the respondent answers, I have never prepared my meals. My wife has always prepared them		
for me, how do record the answer?		
ANSWER: Chapter 8		
7 - If the respondent answers to <u>Question C45h (</u> Another reason):		
"Now, I would like you () to think about all the help you NEED (NEEDS) but do (does) not have. Why do you (does) not receive the help you NEED (he / she NEEDS)? I will read you a list of possible reasons. Please answer yes or no to each."		
by saying, Yes, Meals on Wheels doesn't service us way out here and my kids are busy a work and they can't help me as often as I need it, how do you record it?		
ANSWER: Chapter 3		
8 - For <u>Question B12,</u>		
Which aids do you (does) NEED but do (does) not have?		
If the respondent answers Alerting alarms, how do you record this on the questionnaire?		
ANSWER: Chapter 3		
9 - A respondent reports that he has constant pain, but this pain does not limit his activities. Is he considered to have a pain limitation and do you check the Pain-Limitation box on the Profile Sheet?		
ANSWER: Chapter 4		

10 - If a respondent reports in <u>Question A1</u> that Yes, sometimes, he has difficulty hearing seeing, remembering etc, but in the rest of Section A and all of Section B he indicates no limitations, do you ask him the questions in Sections C to G?
ANSWER: Chapter 4
11 - If a respondent reports no limitations in Section A or B, at what point (item number do you end the interview?
ANSWER: Chapter 4
12 - A respondent thinks he has a condition that makes it difficult for him to learn, but he has never been told that he had a learning disability and he reports that this condition does NOT limit his activities. Is he considered to have a learning limitation and do you check the Learning - Limitation box on the Profile Sheet?
ANSWER: Chapter 4

${\bf 13}$ - What is the purpose of the Stop sign at the beginning of Sections D and E in the Adults Questionnaire?
ANSWER: Chapter 3 and/or 4
14 - A respondent reports that they worked 90 hours last week. What do you do if, when you confirm that, they now say 60 hours?
ANSWER: Chapter 3
15 - Why do we ask Question G11, Is this a one-person household? ?
ANSWER: Chapter 4
III - Child Questionnaire
1 - What would be your answer if a parent or guardian insists that his/her child answers the Child Questionnaire?
ANSWER: Chapter 5

2 - What types of activity limitations are asked about if the child is born AFTER May 15, 1996 (age is 0 to 4)?
ANSWER: Chapter 5
3 - If child is born AFTER May 15, 1996 (age is 0 to 4) and he/she has an activity limitation, which sections of the questionnaire should be skipped?
ANSWER: Chapter 5
4 - If child is born AFTER May 15, 1996 (age is 0 to 4), should you ask the questions about the use and need of aids or specialized equipment?
ANSWER: Chapter 5
5 - When answering Question E6,
In APRIL 2001, what type of school was attending?
if parents tell you that their child attended a Public or Private school in April 2001, how would you fill out the response?
ANSWER: Chapter 5

Operational questions

1 -The respondent says, "this interview is taking forever. I don't know if I want to finish it!" What do you say?
ANSWER: Chapter 7
2 – When the respondent ask: "Where did you get my name?" What do you answer? ANSWER: Chapter 7
3 – The respondent says: "I am a person with a disability; what services are offered in my area?" What is your answer?
ANSWER: Chapter 7
4 – The respondent asks: "How much time will the interview take?" What is your answer?
ANSWER: Chapter 7

5 – When the respondent wonders what kind of questions are you going to ask? What do you answer?
ANSWER: Chapter 7
6 - The respondent comments « What did you say » after you've read the question.
Does he understand the question or not? What should you do?
ANSWER: Chapter 9
7 - You have started an interview and after a few questions, you find that your respondent is not a child but an adult. What do you do?
ANSWER: Chapter 3

8 - You call a respondent and he tells you he doesn't want to do the interview over the telephone. What do you do?
ANSWER: Chapter 3
9 - The respondent you have just reached is very weak and tells you he cannot stay on the phone for a long period of time. What will you do?
ANSWER: Chapter 3