

# INCLUSIVE RESEARCH NETWORK

- ✓ **Share your ideas with other researchers.** 
- ✓ **Plan your own research.** 
- ✓ **Have an 'expert research buddy'** 
- ✓ **Get the support you need.**

## CO-RESEARCHER HANDBOOK

## WHERE WE LIVE SURVEY

# Steps to do this research

## Step 1

### Work with the person who will support you

#### WHERE WE LIVE SURVEY INFORMATION FORM FOR SERVICE PROVIDERS, FAMILY MEMBERS, AND SUPPORT PEOPLE

Researchers: Edurne Garcia, National Institute for Intellectual Disability (NIID), Edel Tierney, National Federation of Volunteer Bodies, Patricia O'Brien (NIID), Roy MacConkey (NIID), and Stephen Curtis, Inclusive Research Network.

Give the **information sheet** to the person who is going to support you

#### ALL WE WANT TO SAY, LIVING OPTIONS CONSENT FORM FOR SUPPORT PERSONS

Researchers: Edurne Garcia, National Institute for Intellectual Disability (NIID), Edel Tierney, National Federation of Volunteer Bodies, Patricia O'Brien (NIID), Roy MacConkey (NIID), and Stephen Curtis, Inclusive Research Network.

Get **consent** from the person who is going to support you

Ask your support person to:



- Help you go through the next steps
- Practice with the support person

## Step 2

### Try to find some people with disabilities



Some men and some women



Some people in their 20s, 30s, 40s, 50s and 60s



Give the information sheet to:

- The person who you want to talk to
- The person's family members
- The boss of the staff



Sit down and talk to them, one at a time, about the project.

You can use the information sheet.

## Step 3

### Consent

**CONFIDENTIAL**

I would be happy to talk to another person if I have any reasons

I agree to take part in this project

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

Ask them the questions to see if they understand what the study is about.



If they understand what the study is about and what they will have to do, ask them to sign the consent form

## Step 4 Interview



Take your time when interviewing the person

Give the person time to respond



Let the person see the questions and pictures in the question booklet to help them understand.



Let the support person record the interviewee's answers in the answer booklet while you ask the questions in the question booklet.



When you have finished asking the questions ask the person if there anything else they would like to add.



Say Thank You for their time.

# STEP 1

## Work with the person who will support you

### WHERE WE LIVE SURVEY INFORMATION FORM FOR SERVICE PROVIDERS, FAMILY MEMBERS, AND SUPPORT PEOPLE

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Give the **information sheet** to the person who is going to support you

### ALL WE WANT TO SAY: LIVING OPTIONS CONSENT FORM FOR SUPPORT PERSONS

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## **WHERE WE LIVE SURVEY**

### **INFORMATION FORM FOR SERVICE PROVIDERS, FAMILY MEMBERS, AND SUPPORT PEOPLE**

Researchers: Edurne Garcia, National Institute for Intellectual Disability (NIID), Edel Tierney, National Federation of Volunteer Bodies, Patricia O'Brien (NIID), Roy MacConkey (NIID), and Stephen Curtis, Inclusive Research Network.

The proposed research plans to administer a questionnaire to people with intellectual disabilities about living options. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about how they like where they live. This research aims at answering three questions: "Where they live?", "Who they live with?", "What they like about where they live?", and "What do they not like about where they live?"

Administering the questionnaire will last from 30 minutes to 1 hour. People with intellectual disabilities who have been trained as researchers will administer the questionnaire. Research interns at the National Institute for Intellectual Disability and the National Federation of Voluntary Bodies will record the answers in a booklet. Information forms about the research will be distributed to service agencies and advocacy agencies as well as group homes, residential facilities, and independent living centres. Researchers will be trained on how to select the sample and will identify the sample they want to survey.

If we hear from any of the research participants anything that would suggest he or she is unsafe, the necessary authorities may need to be contacted after the person has had the opportunity to discuss the issues with a third party.

When the research is completed, the results will be presented at the National Disability Authority Annual Conference in October. A major purpose of this

research is to hear the voice of intellectually disabled citizens so that their needs and wishes regarding living options can be identified.

If you have any questions about this research please contact Edel Tierney at 00 353 91 792316 or Edurne Garcia at 01896220. Thank you!

**ALL WE WANT TO SAY: LIVING OPTIONS  
CONSENT FORM FOR SUPPORT PERSONS**

**Researchers:** Edurne Garcia, National Institute for Intellectual Disability (NIID), Edel Tierney, National Federation of Volunteer Bodies, Patricia O'Brien (NIID), Roy MacConkey (NIID), and Stephen Curtis, Inclusive Research Network.

I have had this research explained to me

I have been able to ask questions and have them answered

I understand what is expected of me as a support person

I will support the researcher to do this survey

I will not speak for the researcher unless invited to do so by them

I will not talk about what goes on in the meeting to other people

I agree to take part in this project

I will not speak for the person being interviewed

Signed: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_



Ask your support person to:

- Help you go through the next steps
- Practice with the support person

## STEP 2

### Try to find some people with disabilities



Some men and some women



Some people in their 20s, 30s, 40s, 50s and 60s



Give the information sheet to:

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Sit down and talk to them, one at a time, about the project.

You can use the information sheet.

# Where We Live Survey

## Participant Information Form

Hello my name is .....



I am a member of the Inclusive Research Network which is looking at how people with disabilities can do research about issues that are important to them.

We have decided to do some research about Living Options and we are asking you to take part because your ideas are important to us.



This means we would like to ask you some questions about:

- Where you live?
- Who you live with?
- What you like about where you live?
- What you do not like about where you live?



## **CONFIDENTIAL AND PRIVATE**

Your answers will be kept confidential and private and I will not use your name when I am recording your answers or reporting what I have found out.

The research will not change the place where you live now but will help us know more about what people like and don't like about where they live and how to help people live in a place of their choice.



We will present the findings on October 6<sup>th</sup> at the National Disability Authority Conference.



Please think if you want to take part in this research and ask me any questions you have about it.

If you don't want to take part in the research, that's fine.



If you decide to participate in this research, I will ask you to sign the consent form.



If you decide to take part in this research, you can stop at any time without any consequences.

If we hear some things that make us think that people are unsafe then we would ask you to meet with another person to talk to them about what has happened and to support you to decide what to do next.



If you have any questions later on, please contact Edel Tierney at 00 353 91 792316 or Edurne Garcia at 01896220. Thank you!

## **WHERE WE LIVE SURVEY**

### **INFORMATION FORM FOR SERVICE PROVIDERS, FAMILY MEMBERS, AND SUPPORT PEOPLE**

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If you have any questions about this research please contact Edel Tierney at 00 353 91 792316 or Eburne Garcia at 01896220. Thank you!

# STEP 3



## Consent

**CONFIDENTIAL**

I would be happy to talk to another person if I have any concerns



I agree to take part in this project



Signature: \_\_\_\_\_  
Printed name: \_\_\_\_\_  
Date: \_\_\_\_\_

Ask them the questions to see if they understand what the study is about.



If they understand what the study is about and what they will have to do, ask them to sign the consent form



Now check that the person you are going to interview understands:

- what she or he is going to do and
- what the survey is about.

You can say:

I am going to ask you four questions to see if I explained everything well to you.

1. If you decide to take part in this research, what are we going to talk about? (Please pick one of these two options)

- ... about where you live?



OR

- ... about your health?



2. If you decide to take part in this research, what will you be doing? (Please pick one)

- Answering the questions



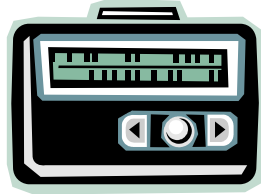
OR

- Going shopping



### 3. If you take part in this survey...

- Anyone can find out what you are telling me



- Your answers will be kept confidential and private

**CONFIDENTIAL AND PRIVATE**

### 4. If you don't want to keep answering the questions...

- You can stop answering the questions at any time



- You have to keep answering the questions until we finish



**You have answered all the questions and now I will fill in a consent form with you.**

# WHERE WE LIVE SURVEY

## CONSENT FORM FOR RESEARCH PARTICIPANTS

The researcher has explained the research to me



I have been able to ask questions about the research



I understand that I will answer questions about where I live for about 20 minutes to complete this survey



I can stop being involved at any time on this project



My responses will be kept confidential and private

**CONFIDENTIAL AND PRIVATE**

I would be happy to talk to another person if I am unhappy about anything in this survey



I agree to take part in this project



Signed: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of witness: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

# STEP 4



## Interview



Take your time when interviewing the person.

Give the person time to respond.



Let the person see the questions and pictures in the question booklet to help them understand.



Let the support person record the interviewee's answers while you ask the questions.

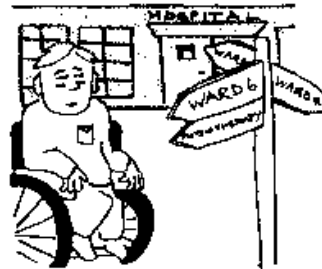
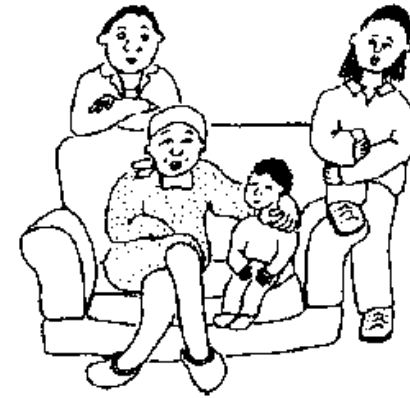
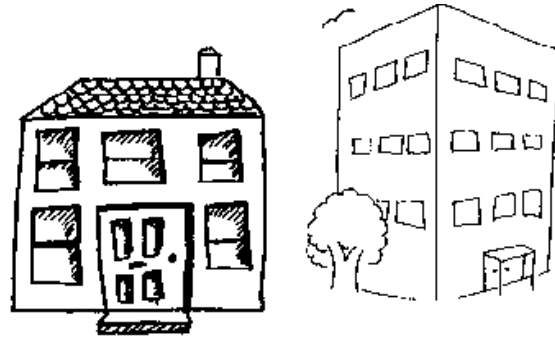


When you have finished asking the questions ask the person if there anything else they would like to add.



Say Thank You for their time.

I am going to ask you questions about where you live and who you live with...



What age are you? (You don't have to say if you don't want to)



Tell me about where you live



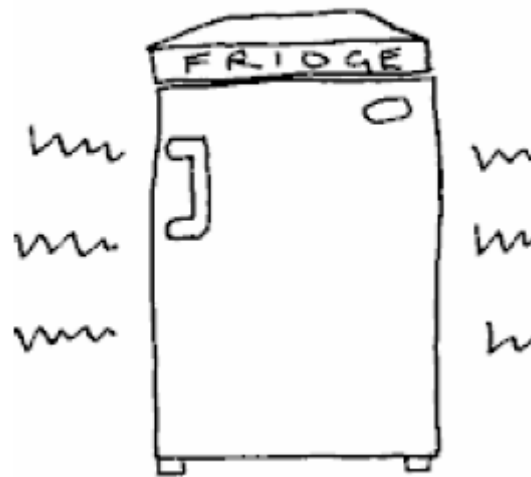
How many people live with you in your home?



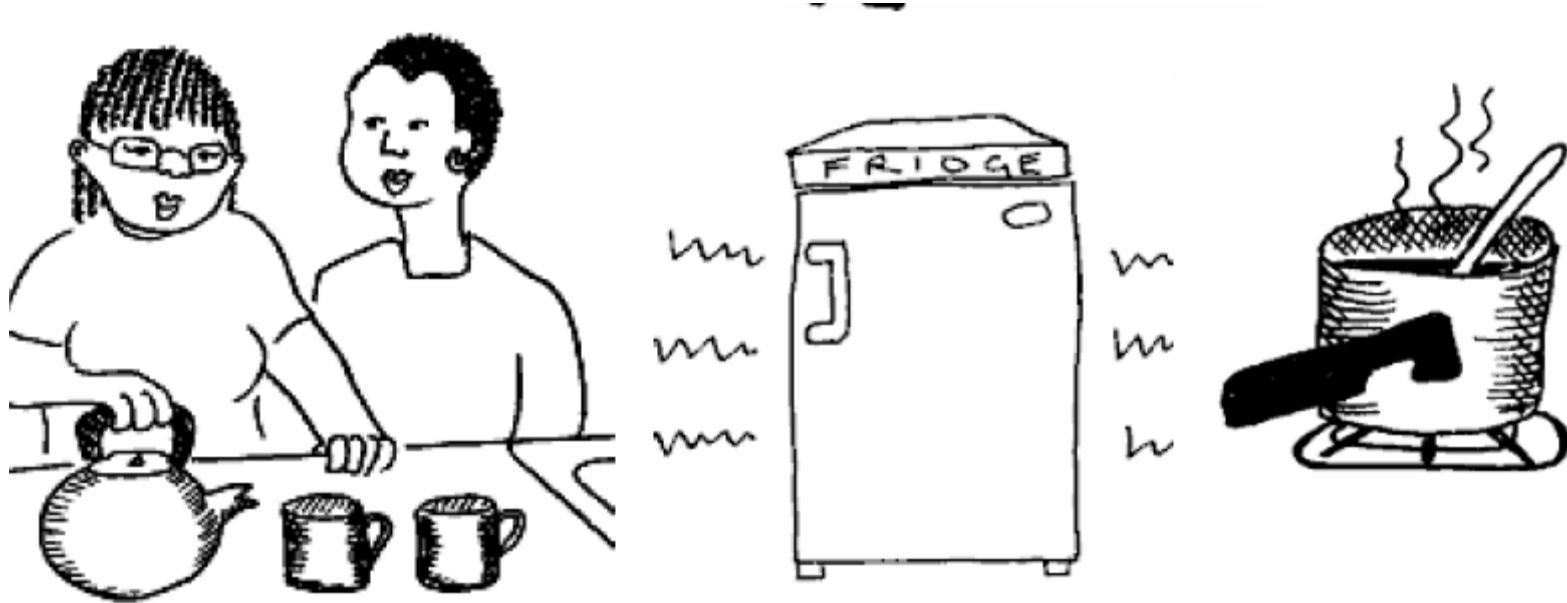
How long have you lived there?



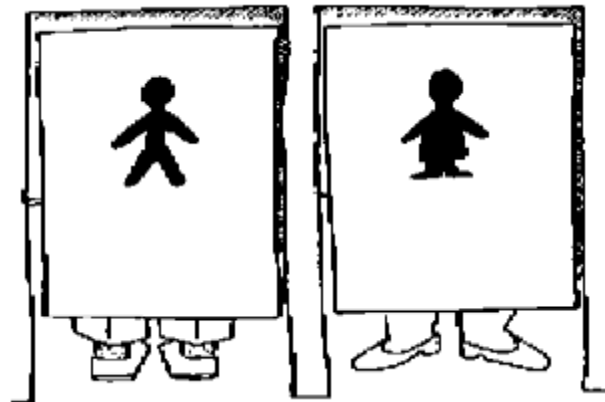
Do you share your kitchen with other people?



Are you able to use the kitchen when you want?



Do you share your bathroom with other people?



Do you share your bedroom with other people?

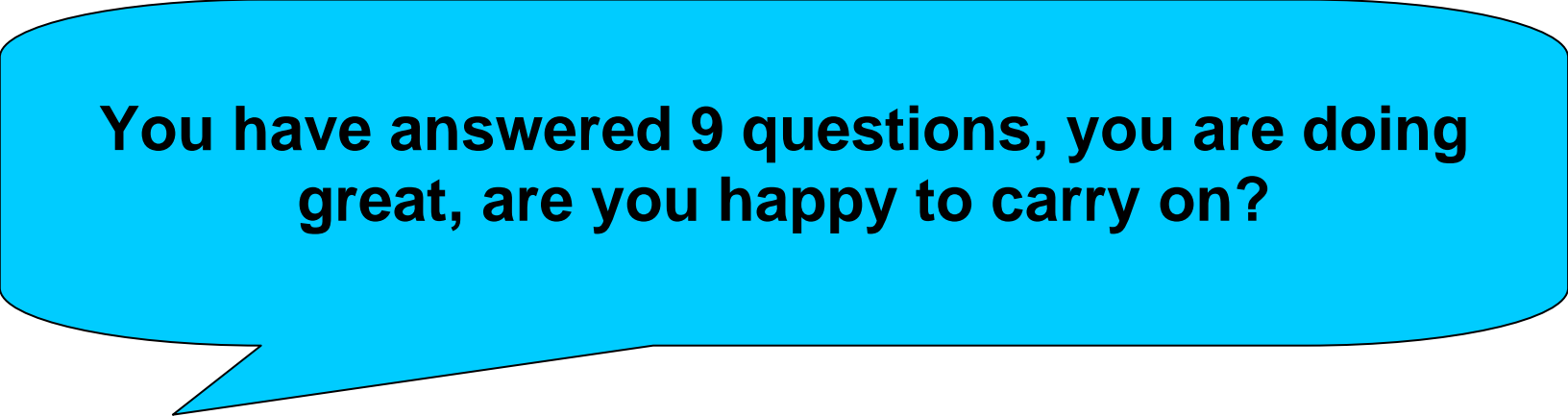


Do you have a key to your bedroom?



Does anybody come into your bedroom when you are not there?





**You have answered 9 questions, you are doing great, are you happy to carry on?**

In this part, I'm going to ask you questions about getting around



## Where do you live?

- In a city



- In a town



- In the countryside



- Other \_\_\_\_\_

You said you live in:



A city, what distance are you from the city centre?



A town, what distance are you from the centre?



The countryside, what distance are you from the nearest town?



Where you live, do you have access to these?

Train



Bus



Taxi



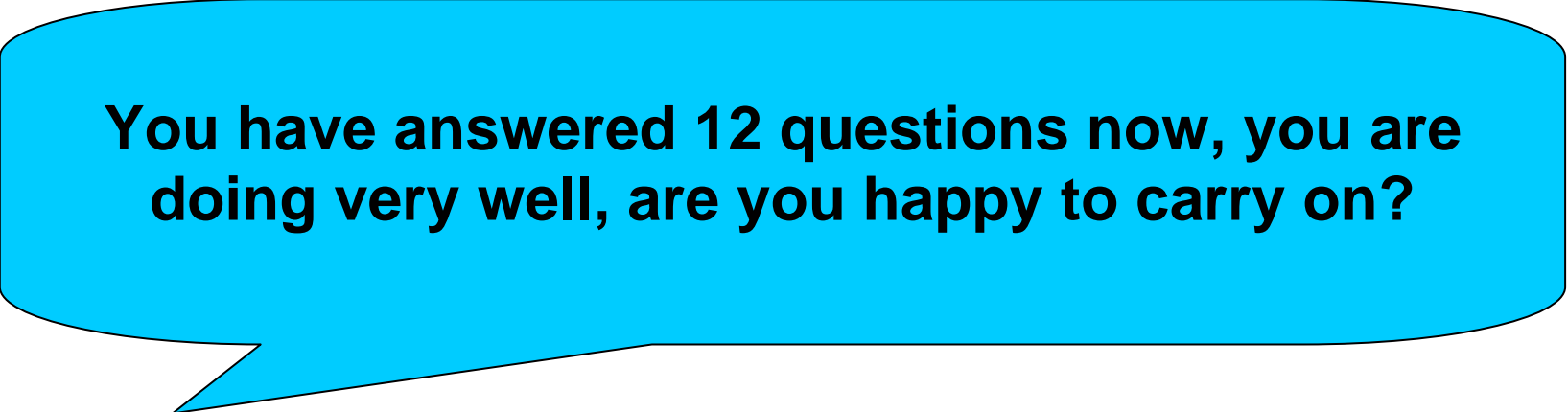
Airplane



Tram



Other \_\_\_\_\_



**You have answered 12 questions now, you are doing very well, are you happy to carry on?**

Do you like where you live?



Yes I like it



No I don't like it

You said:

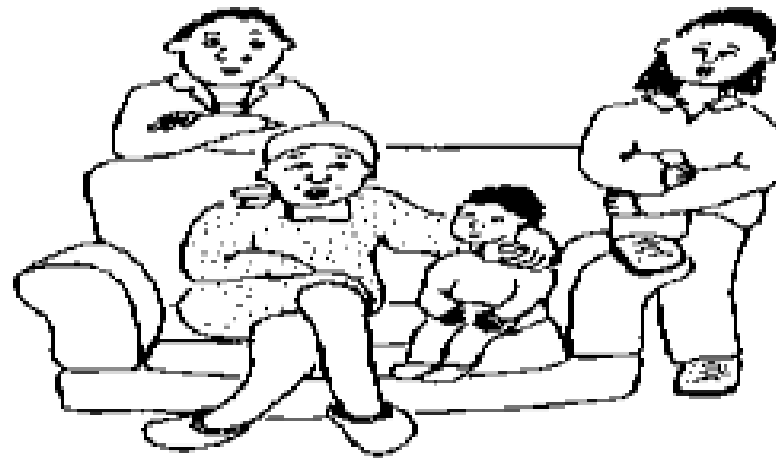


You like it, why?

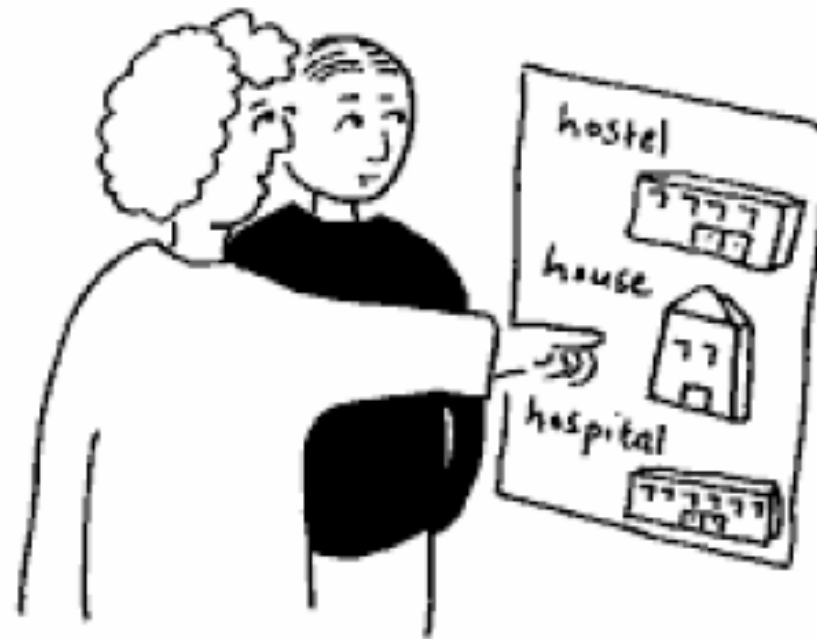


You don't like it, why?

Did you choose who you live with?



Did you choose where you live?



Are there any things you'd like to change about your home?



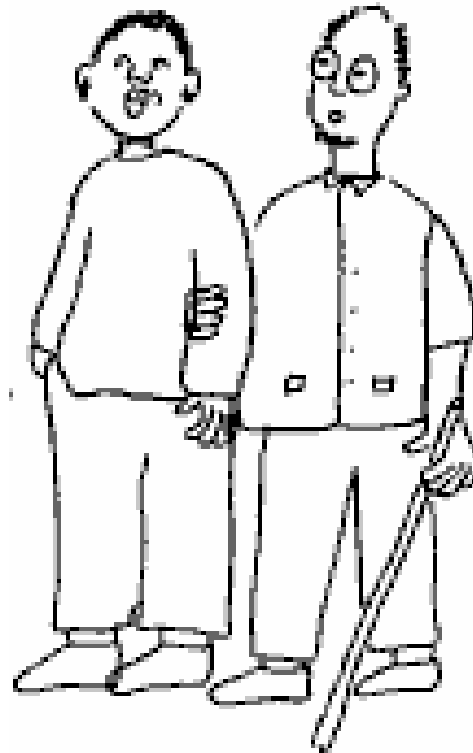
If you answered yes, what would you like to change?

Are there any things you'd like to change about the people you live with?



If you answered yes, what would you like to change?

Are there any things you'd like to change about the support you get?



If you answered yes, what would you like to change?

Is there anything else you would like to say about where you live?



Thank you very much  
for answering these questions.

We have finished.

We will send you the results of  
the survey to the address you  
gave me.