

INCLUSIVE RESEARCH NETWORK

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

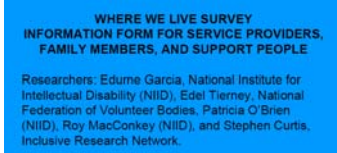
SUPPORTER HANDBOOK

WHERE WE LIVE SURVEY

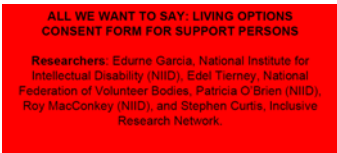
Steps to support co-researchers

Step 1

Information and consent



Read the **information sheet** about this research and ask if you have any questions.



Sign the **consent form** if you want to participate in this research.

Work with the co-researcher:



- Supporting him/her through the next steps
- Practice asking the questions

Step 2

Support the Co-Researcher to try to Find some people with Disabilities

The co-researcher will go through these steps but you can support him/her if they ask you for support. Your support is very important so the person is able to do all the steps for this project and be in control.



Some men and some women



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



Support the co-researcher to give the information sheet to:

- The person who he/she wants to talk to
- The person's family members
- The boss of the staff



Support the co-researcher to talk to them, one at a time, about the project.

Support the co-researcher to use the information sheet if she/he wants to.

Step 3

Support the Co-Researcher to Consent



Support the co-researcher to ask questions to check if potential respondents understood the information.



If the respondent understands what the study is about and what she/he will have to do, SUPPORTER will ask them to sign the consent form.

Step 4

Support the Co-Researcher to Interview

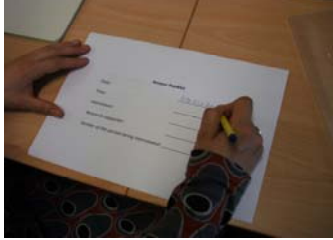


Support the co-researcher to take the needed time when interviewing the person.

Support the co-researcher to give the respondent enough time to respond



Support the co-researcher to read/ask the questions and to show the respondent the questions and pictures in the question booklet.



Record the interviewee's answers in the answer booklet while the co-researcher asks the questions in the question booklet.



Support the co-researcher to ask the respondent if there is anything else they would like to add.



Support the co-researcher to acknowledge participation and close interview.

Step 1

Information and consent

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.

Read the **information sheet** about this research and ask if you have any questions.

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.

Sign the **consent form** if you want to participate in this research.

Work with the co-researcher:

- Supporting him/her through the next steps
- Practice asking the questions



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!

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.

Please tick

- 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: _____

Step 2

Support the Co-Researcher to try to Find some people with Disabilities

The co-researcher will go through these steps but you can support him/her if they ask you for support. Your support is very important so the person is able to do all the steps for this project and be in control.



Some men and some women



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



Support the co-researcher to give the information sheet to:

- The person who he/she wants to talk to
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- The boss of the staff



Support the co-researcher to talk to them, one at a time, about the project.

Support the co-researcher to use the information sheet if she/he wants to.

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 where you live 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 6th 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

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.

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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.

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

Step 3

Support the Co-Researcher to Consent

CONFIDENTIAL

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



I agree to take part in this project



Sign: _____
Printed name: _____
Date: _____



Support the co-researcher to ask questions to check if potential respondents understood the information.

If the respondent understands what the study is about and what she/he will have to do, **SUPPORTER** will ask them to sign the consent form.

This section contains 2 very important items. The first form being a checklist that you must tick off as people choose the answers on the understanding consent form in the survey booklet. If you tick “No” in any of the boxes you cannot give the person the survey as they do not understand what is expected of them. You must support the co-researcher to explain the survey and consent again and give the person to be surveyed the understanding consent test and only when you have ticked “Yes” to each box here can you continue and get the person’s consent.

Checklist and test to make sure the person being interviewed understands the consent form and the purpose of this study.

Q1: Did the respondent understand what the survey is about?

Yes No

Q2: Did the participant understand that they will be answering questions in the survey?

Yes No

Q3: Did the person understand that their answers will be kept private and confidential?

Yes No

Q4: Does the person know that they can stop participating at anytime?

Yes No

You cannot ask the participant to take part in this survey if any “No” was ticked on this checklist.

WHERE WE LIVE SURVEY CONSENT FORM FOR RESEARCH PARTICIPANTS

Please Tick

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

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

Support the Co-Researcher to Interview



Support the co-researcher to take the needed time when interviewing the person.

Support the co-researcher to give the respondent enough time to respond



Support the co-researcher to read the questions and to show the respondent the questions and pictures in the question booklet.



Record the interviewee's answers in the answer booklet while the co-researcher asks the questions in the question booklet.



Support the co-researcher to ask the respondent if there is anything else they would like to add.



Support the co-researcher to acknowledge participation and close interview.

Supporter's Answer Booklet

Date: _____/_____/_____

Time: _____

Interviewer: _____

Research supporter: _____

Gender of the person being interviewed: _____

E-mail address: _____

Address: _____

Q: Respondent's Age:

(Please tick the appropriate box)

- Under 20
- 20-35 years
- 36-50 years
- 51-65 years
- 66-80 years
- 81+ years

Q: Tell me about where you live

(Tick the boxes and record the answer on the next page to represent the respondent's answer). Support the co-researcher giving prompts.

- In a group home:
- Staffed-All day
- Staffed-Evenings
- With your family
- Hostel
- In a house
- How many bedrooms
- In a residential centre
- In an apartment/ flat
- Respite
- Mini institution
- Group home
- Social housing
- Private rented accommodation
- Semi-independent Apartment

Q: Describe the type of home you live in:

Q: How many people live in your home? _____

Q: How Long have you lived there? _____

Q: Own kitchen?

Yes No

Are you able to use the kitchen when you want?

Yes No

Q: Own bathroom?

Yes No

Q: Own bedroom?

Yes No

Do you have a key to your bedroom?

Yes No

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

Yes No

Q: Do you live in a...

city

town

countryside

other _____

Q: Distance from nearest town/ town center: _____ miles/km

_____ minutes by _____ (transport)

Q: Do you have access to...

(Please tick which transport methods are available to the respondent)

Taxi

- Train
- Bus
- Tram
- Aeroplane
- Other

Q: Do you like where you live?

Yes No

Q: Why?

(Support co-researcher prompt respondent if there is no reply with: About the people you live with? About the staff who support you? About the house and the area in which you live?)

Q: Did you choose:

a): Who you live with?

Yes No Don't Know

b): Where you live?

Yes No Don't Know

Q: Are there any things you would like to change? *(Support co-researcher to prompt respondent if there is no reply with: More independent or more supportive accommodation? A smaller or a larger home? With less or with more people?)*

About home Yes No

What? _____

About people you live with Yes No

What? _____

About support you get Yes No

What? _____

Q: Is there anything else you would like to say?
