

# 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

## RELATIONSHIPS AND SUPPORTS STUDY

Handbook developed by  
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National Institute for Intellectual Disability

# STEPS TO DO THE RESEARCH



**1. Get a person to support me**



**2. Talk to the organisation / advocacy group**



**3. Find a good place for the focus group**



**4. Give out information forms and flyers**



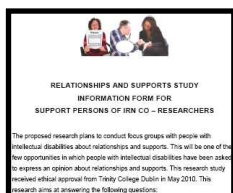
**5. Do the focus group**



**6. Send back recording, notes and all forms to the NIID**



# 1. GET A PERSON TO SUPPORT ME



Give the **information form** to the person who is going to support me


☐

(I can find this form on pages 24 and 25 of the handbook)



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

☐

(I can find the form on page 26 of this handbook)

☐ I agree to take part in this project.

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

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

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



Make sure the person **signs the consent form**

☐

Ask my support person to

- **Help me** go through the next steps

☐


Can you help me with the steps for this research?

- **Practice** with my support person

☐



## 2. TALK TO THE ORGANISATION/ ADVOCACY GROUP



**Make a list** of people who I am  
going to talk to about the study

☐

**LIST  
PEOPLE I WILL TALK TO ABOUT THE STUDY**



## 2. TALK TO THE ORGANISATION/ ADVOCACY GROUP



### **Copy the flyer and information forms**

for people with intellectual  
disabilities, supporters,  
organisations and family  
members

☐

(I can find the flyer on page 27 of  
this handbook)

(I can find the information forms in  
pages 28 to 35 of this handbook)



### **Go to the organization / advocacy group**

☐

### **Talk to the organization / advocacy group**

- check if they are  
interested in the study
- ask when would be a  
good time and day to run  
the focus group

☐☐

### **Talk to the social worker / key worker at the organization**

- Make sure she / he is  
available to talk to any focus  
group participant in case the  
focus group discussion  
makes them feel upset

☐



## 2. TALK TO THE ORGANISATION/ ADVOCACY GROUP



Check with the managers of  
The organization that it's ok to  
run the focus group

☐

Ask if you can use one of their  
rooms

☐

Check the room

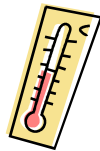
☐



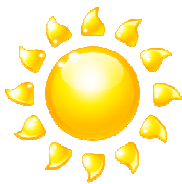
### 3. FIND A GOOD PLACE FOR THE FOCUS GROUP



**Make sure that the room:**



is comfortable (not too hot, not too cold)

☐

is bright

☐

is easy to get to

☐

Is close to **bathrooms** that everyone can use

☐

has **enough space** for 10 chairs

☐



## 4. GIVE OUT INFORMATION FORMS AND FLYERS



Ask people for a good time / day they can come to the focus group

☐

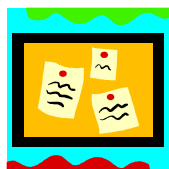
Organize the focus group at least one week after you have talked to the organization / advocacy group

☐

**Book a room** to run the focus group

☐

Add the **day, time and place** on the flyer

☐

Put up **flyer** with information

(You can find the flyer on page 27 of this handbook)

☐

Give people **information forms**

(I can find the information forms on pages 28 to 35 of this handbook)

☐

**Talk** to people with intellectual disabilities and supporters about the study

☐

Answer any **questions** they have

☐





## 5. DO THE FOCUS GROUP

### BEFORE PEOPLE ARRIVE



**12:30**

you arrive



**1:00**

group starts

Arrive about 30 minutes before group starts


☐

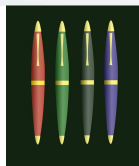
### Check you have



Flip chart, paper and stand

☐


Markers

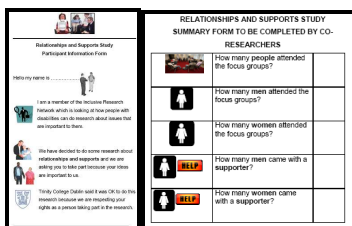
☐


Pens for people taking part in the focus group

☐


### Recorder and batteries

(You can borrow one from Edel or Edurne if you don't have one)

☐


Consent, information and summary forms

☐

(You can find the consent forms on pages 36 to 44)

(You can find the information forms on pages 30 to 35)

(You can find the summary form on page 47)



## 5. DO THE FOCUS GROUP

### What to do next



Put out the chairs in a circle  
(leave spaces for wheelchair users)

☐

Put flip chart, paper and stand at  
top of the circle

☐

Put drinks and snacks on table to  
the side

☐

When you have all ready, you must wait for the people to come.

- When the people come, greet them. There are some tips at the end on how you can do that.
- Once you read the information form to the focus group participants you need to check that they understand the study \*



**Remember!**

\*You already gave the information form to them when you went to the organization.



## 5. DO THE FOCUS GROUP

### WHEN PEOPLE ARRIVE



**Meet people at the door**, chat to them and make them feel comfortable.

**You could say...**

**In your own words**

Thanks for coming, how are you today?



Show them where the **drinks and snacks** are.

**You could say...**

Here is the tea and coffee. Please help yourself.



Ask the participants to **sit down**.

**You could say...**

There are lots of chairs. Please take a seat.





## 5. DO THE FOCUS GROUP



**Introduce** yourself. Ask the participants to introduce themselves.

**You could say...**

Hi, my name is \_\_\_\_\_. Could everybody say their name, one at a time. Who wants to start?



**Explain** what the study is about.

**You could say...**

We are here today to talk about relationships and supports



**NOW YOU ARE GOING TO GET CONSENT  
FROM THE FOCUS GROUP PARTICIPANTS  
AND THEIR SUPPORTERS**





## 5. DO THE FOCUS GROUP

### GET CONSENT



Relationships and Supports Study  
Participant Information Form

Hello my name is .....

**Read information form out loud for everyone. Ask people if they have any questions.**

**You could say...**

Please ask any questions you have about this.



**Ask your supporter to check if everyone understands.**

**You could say...**

\_\_\_ is going to ask you four questions to see if I explained everything well to you.



**Explain consent forms and ask if they want to sign them.**

**You could say...**

If you are happy taking part in the focus group, please sign the consent form.



## 5. DO THE FOCUS GROUP



Ask if everyone is OK with being recorded. Remind them that their participation is voluntary and they can stop taking part in the focus group if they want to.

**You could say...**

We want to record this so we don't forget what you say. Is this OK?



## 5. DO THE FOCUS GROUP

### RUN THE FOCUS GROUP



If everyone is ok with being recorded, put the recorder in the middle and **press record**. If somebody says “no”, ask my supporter to take notes.



Explain the **rules**.

Ask focus group participants to tell you the rules.

1. Have mobile phones switched off
2. One person talks at a time
3. Listen carefully to each other
4. There are no right or wrong answers
5. It is OK if somebody does not want to talk
6. We must respect everybody in the group
7. Any other rules?



## 5. DO THE FOCUS GROUP

### SOME TIPS TO RUN THE FOCUS GROUP



Ask the questions.

1. What do you think makes a good friend?
2. What do you think about having a boyfriend / girlfriend?
3. What supports do you need to have friends and a boyfriend / girlfriend?



My supporter will **write down ideas** that people talk about **on the flip chart**.



Give people time to talk about each question.

**You could say...**

Does anyone else want to say something?





## 5. DO THE FOCUS GROUP



Listen carefully to what people are saying.



Show people you are listening. For example, nod your head and smile.



Stop others interrupting.

**You could say...**



Our rule is one person talking at a time



Ask the participants if they would like to say something else.

**You could say...**

Is there anything else you would like to say about this?



## 5. DO THE FOCUS GROUP

### BEFORE PEOPLE LEAVE



Ask the participants how they are feeling after the focus group.

**You could say...**

How is everybody feeling now?



Thank them for coming to the focus group.

**You could say...**

Thanks for coming today and telling me what you think.



## 5. DO THE FOCUS GROUP



Tell participants the **next steps**.

- We are going to send these recordings to NIID.
- The findings of the study will be published as a report.
- We'll be happy to come and present the results of the study when we have the final report.



Make sure the room is tidy when you finish. Bring everything with you.



## 6. SEND BACK RECORDING, NOTES AND ALL FORMS BACK TO NIID



Play the recorder to make sure the sound is OK.  
If the recorder didn't work, try to summarize all the responses in a new recording

☐

Talk to your supporter about how the group went:

- What was good about the focus group?
- What wasn't that good about the focus group?
- How do you think participants felt?

☐

Fill out the summary form

(You can find the summary form on page 47 of the handbook)

☐

Gather consent forms. Put notes from flipchart in the envelope

☐

Put the forms in an envelope

☐

Put the recorder in an envelope

☐



## 6. SEND BACK RECORDING, NOTES AND ALL FORMS BACK TO NIID

Send the forms, notes and recording back to NIID



# FORMS

## Supporters of co - researchers



Information form

24 – 25



Consent form

26

## Focus group flyer

27

## Organizations and family members



Information form

28 – 29

## Focus group participants



Information form

30 – 33

## Supporters of focus group participants



Information form

34 – 35



Consent form

36

# FORMS

## Focus group participants



Pre – consent form 37 – 42



Consent form 43 – 44



Personal information form 45 – 46

## To be completed by co - researchers



Summary form 47



## **RELATIONSHIPS AND SUPPORTS STUDY INFORMATION FORM FOR SUPPORT PERSONS OF IRN CO – RESEARCHERS**

The proposed research plans to conduct focus groups with people with intellectual disabilities about relationships and supports. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about relationships and supports. This research study received ethical approval from Trinity College Dublin in May 2010. This research aims at answering the following questions:

- What makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need to have friends and a boyfriend / girlfriend?

Information forms and flyers about the research will be distributed to organisations and advocacy agencies as well as other people with intellectual disabilities. Focus group participants will have the opportunity to ask questions about the research project and will join the focus group voluntarily upon signing the consent form.

Each focus group will last from 45 minutes to 1 hour. Members of the IRN who have been trained in this methodology will facilitate the focus groups. Members of the IRN will record the main points of the discussion on a flip chart and the focus group's discussion will be recorded with the agreement and signed consent of all participants.





As a support person of the IRN co – researchers, your involvement in the study will include:

1. Supporting the IRN co – researcher through all the steps in the research process, including:
  - recruitment of research participants
  - making arrangements for the focus groups
  - running the focus groups
  - collecting the data
2. Tasks specific to the support person of IRN co – researcher, which are described in the *Supporter Handbook*.

This can be an emotional and sensitive topic for some people and during the course of running the focus groups it is possible that a person may become upset or reveal personal difficulties.

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, a research report will be developed and available at the NIID and NFVB websites. A major purpose of this research is to hear the voice of citizens with intellectual disabilities so that their needs and wishes regarding relationships and supports can be better addressed.

If you have any questions about this research please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220. Thank you.



## **RELATIONSHIPS AND SUPPORTS STUDY**

### **CONSENT FORM FOR**

### **SUPPORT PERSONS OF IRN CO – RESEARCHERS**

**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 of the IRN co – researcher.
- ☐ I will support the IRN co - researcher through the different research steps:
  - recruitment of research participants
  - making arrangements for the focus groups
  - running the focus groups
  - collecting the data
- ☐ I will not speak for the researcher unless invited to do so by them.
- ☐ I understand that the focus group will be recorded using audio equipment.
- ☐ I will not speak for the focus group participants taking part.
- ☐ I will not talk about what goes on in the focus group to other people.
- ☐ I agree to take part in this project.

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

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

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

# Focus Group Invitation

The Inclusive Research Network is pleased to invite you to talk about supports and relationships in a focus group.

We are inviting you because we think your views are important.

We will ask you questions about



What makes a good friend?



What do you think about having a boyfriend / girlfriend?



What supports do you need to have a good friend, a boyfriend, and a girlfriend?

The research will not change how many people help and support you or your relationships, but will help us know more about what needs to be done to help you live a good life.

We will meet:

Where? \_\_\_\_\_



When? \_\_\_\_\_



What time? \_\_\_\_\_



There will be snacks.

Your organisation has a copy of this flyer.



If you have any questions, please contact the Inclusive Research Network (IRN) on



(091)792316 or email



irn@fedvol.ie



## **RELATIONSHIPS AND SUPPORTS STUDY**

### **INFORMATION FORM FOR**

### **ORGANISATIONS AND FAMILY MEMBERS.**

The proposed research plans to conduct focus groups with people with intellectual disabilities about relationships and supports. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about relationships and supports. This research study received ethical approval from Trinity College Dublin in May 2010. This research aims at answering the following questions:

- What makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need to have friends and a boyfriend / girlfriend?

Information forms and flyers about the research will be distributed to organisations and advocacy agencies as well as other people with intellectual disabilities. Focus group participants will have the opportunity to ask questions about the research project and will join the focus group voluntarily upon signing the consent form.

Each focus group will last from 45 minutes to 1 hour. Members of the IRN, co – researchers with intellectual disabilities and their supporters, who have been trained in this methodology, will facilitate the focus groups. Members of the IRN will record the main points of the discussion on a flip chart and the focus group's discussion will be recorded with the agreement and signed consent of all participants.



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.

This can be an emotional and sensitive topic for some people and during the course of running the focus groups it is possible that a person may become upset or reveal personal difficulties.

We have asked supporters of the co – researchers to be aware of this and to take the necessary steps in supporting the co – researchers and focus group participants to talk about this topic. This may mean referring the person(s) to a third party for further ongoing discussion or support.

When the research is completed, a research report will be developed and available at the NIID and NFVB websites. A major purpose of this research is to hear the voice of citizens with intellectual disabilities so that their needs and wishes regarding relationships and supports can be better addressed.

If you have any questions about this research please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220. Thank you.



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## Relationships and Supports Study

### 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 **friends, boyfriends and girlfriends.**



We are asking you to take part because your ideas are important to us.



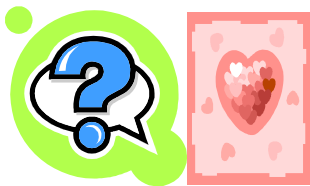
Trinity College Dublin said it is OK to do this research.



This means we would like you to come to a group and talk about:



- What makes a good friend?



- What do you think about having a boyfriend / girlfriend?



- What supports do you need to have friends and a boyfriend / girlfriend?



What you say in the group will be kept private. People outside the room will not know anything you say.





The research will not change how many people help and support you. It will not change how many friends, boyfriends or girlfriends you have, but will help us know more about what needs to be done to help you live a good life.



We will write a report about what everyone says. This will be available on the Internet (NFVB and NIID websites).



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 take part in this research, I will ask you to sign the consent form.



If you decide to take part in this research, it is OK to stop at any time.





This can be an emotional and sensitive topic for some people. If you become upset, we will ask you if you want to stop taking part in the focus group. The social worker / key worker at your organization will be happy to talk to you about it too.

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 (091) 792316 or Edurne Garcia at (01) 896220.

Thank you!



## **RELATIONSHIPS AND SUPPORTS STUDY**

### **INFORMATION FORM FOR**

### **SUPPORTERS OF FOCUS GROUP PARTICIPANTS**

The proposed research plans to conduct focus groups with people with intellectual disabilities about relationships and supports. This will be one of the few opportunities in which people with intellectual disabilities have been asked to express an opinion about relationships and supports. This research study received ethical approval from Trinity College Dublin in May 2010. This research aims at answering the following questions:

- What makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need to have friends and a boyfriend / girlfriend?

Information forms and flyers about the research will be distributed to organisations and advocacy agencies as well as other people with intellectual disabilities. Focus group participants will have the opportunity to ask questions about the research project and will join the focus group voluntarily upon signing the consent form.

Each focus group will last from 45 minutes to 1 hour. Members of the IRN who have been trained in this methodology will facilitate the focus groups. Members of the IRN will record the main points of the discussion on a flip chart and the focus group's discussion will be recorded with the agreement and signed consent of all participants.



As a supporter of a person with an intellectual disability you will be asked to help the person communicate his / her views in the focus group by asking questions e.g. 'What do you think?' or prompting e.g. 'Do you want to say anything about that?'.

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, a research report will be developed and available at the NIID and NFVB websites. A major purpose of this research is to hear the voice of citizens with intellectual disabilities so that their needs and wishes regarding relationships and supports can be better addressed.

If you have any questions about this research please contact Edel Tierney at (091) 792316 or Edurne Garcia at (01) 896220. Thank you.



## **RELATIONSHIPS AND SUPPORTS STUDY CONSENT FORM FOR SUPPORT PERSONS OF FOCUS GROUP PARTICIPANTS**

**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 of the focus group participant (help him / her express their own views).
- ☐ I will support the focus group participant to speak up at the focus group.
- ☐ I will not speak for the focus group participant I support unless invited to do so by him / her.
- ☐ I will not speak for the other focus group participants and the IRN co – researcher.
- ☐ I understand that the focus group will be recorded using audio equipment.
- ☐ I will not talk about what goes on in the meeting to other people.
- ☐ I agree to take part in this project.

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

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

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



**Now check that the person you are going to take part in the focus group understands**

- **what she or he is going to do and**
- **what the study 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)

- ... relationships and supports? ☐



OR

- ... arts and crafts? ☐





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

- Going bowling ☐



OR

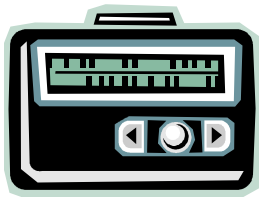
- Coming to a group to talk and answer questions ☐





3. If you take part in this group...

- More people will know what you are telling me ☐



- Outside the focus group, nobody will know about what you tell me. Whatever we say in the room stays in the room ☐





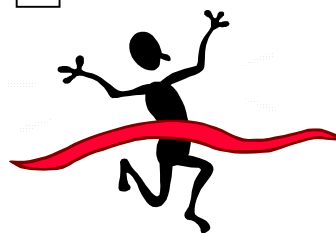


4. If you don't want to keep answering the questions...

- You can stop answering the questions at any time ☐



- You have to answer every question. You are not allowed to stop ☐





**Now check the answers:**

**If all the answers are correct, ask the person to sign the consent form.**

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

**If one or more of the answers are incorrect, explain the information form again to them and repeat the questions.**

**If one or more of the answers are still incorrect, explain to the person that they can't take part in the study.**



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## RELATIONSHIPS AND SUPPORTS STUDY CONSENT FORM FOR RESEARCH PARTICIPANTS

**Please tick if you agree**

☐ The researcher has talked about the research to me.

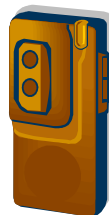


☐ I have been able to ask questions about the research.



☐ I understand that I will join a group of people and I will talk about friends, boyfriends and girlfriends with them.

☐ I agree to have what I say recorded.





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☐ I can stop being involved at any time on this project.



☐ My answers will be kept confidential.



☐ I would be happy to talk to another person if I am unhappy about anything in this focus group.



☐ I agree to take part in this project.



Signed:

\_\_\_\_\_

Printed name

\_\_\_\_\_

Signature of witness:

\_\_\_\_\_

Printed name:

\_\_\_\_\_

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

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




## RELATIONSHIPS AND SUPPORTS STUDY

### PERSONAL INFORMATION FORM FOR FOCUS GROUP PARTICIPANTS

Please tick one box for each question or write your answer. You don't have to answer the questions if you do not want to. This information is private. Nobody will know it was you who wrote this.

	What age are you?	
	Are you a man or a woman?	Man..... <input type="checkbox"/> Woman..... <input type="checkbox"/>
	Where do you live?	with family..... <input type="checkbox"/> in a group home..... <input type="checkbox"/> in a semi – independent apartment..... <input type="checkbox"/> other _____
	What do you do during the day? (you can choose more than one)	Home based..... <input type="checkbox"/> Day / Training centre..... <input type="checkbox"/> Sheltered workshop..... <input type="checkbox"/> Regular paid employment.... <input type="checkbox"/> Regular unpaid employment.. <input type="checkbox"/> Supported employment..... <input type="checkbox"/> Mainstream school..... <input type="checkbox"/> Special school..... <input type="checkbox"/> College / University..... <input type="checkbox"/> Other _____ No day activities..... <input type="checkbox"/>
	Are you in a self – advocacy group?	yes..... <input type="checkbox"/> no..... <input type="checkbox"/>
	Are you ?	married..... <input type="checkbox"/> single..... <input type="checkbox"/> divorced..... <input type="checkbox"/> widowed..... <input type="checkbox"/>





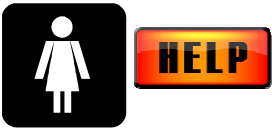


	<p>Are you or have you been in a romantic relationship?</p>	<p>Yes, I have been..... <input type="checkbox"/></p> <p>No, I haven't been..... <input type="checkbox"/></p> <p>Yes I am..... <input type="checkbox"/></p> <p>No I am not..... <input type="checkbox"/></p>
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## RELATIONSHIPS AND SUPPORTS STUDY

### SUMMARY FORM TO BE COMPLETED BY CO-RESEARCHERS

	How many <b>people</b> attended the focus groups?	
	How many <b>men</b> attended the focus groups?	
	How many <b>women</b> attended the focus groups?	
	How many <b>men</b> came with a <b>supporter</b> ?	
	How many <b>women</b> came with a <b>supporter</b> ?	