



Relationships and Supports Study: People with Intellectual Disabilities in Ireland



November 2010

**Members of the Inclusive Research
Network with Intellectual Disabilities**

**National Federation of Voluntary
Bodies**

**National Institute for Intellectual
Disability**

The artwork on the cover “Happy” is by Joanne Cullin.

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Inclusive Research Network

National Federation of Voluntary Bodies

http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html

National Institute for Intellectual Disability

<http://www.tcd.ie/niid/research/irn/>

THANKS

Many people have worked on this project:



- people with intellectual disabilities who participated in the focus groups
- supporters of focus group participants

NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

- Ronan O' Donnell from the National Federation of Voluntary Bodies who supported the Inclusive Research Network (IRN) members with intellectual disabilities in the training workshops

NIID
NATIONAL INSTITUTE FOR INTELLECTUAL DISABILITY
TRINITY COLLEGE DUBLIN

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- organisations and staff that supported IRN members with intellectual disabilities to recruit people for focus groups



- Joanne Cullin for allowing us to use an image of her artwork “Happy” for the cover of the report



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SUMMARY

What is the Inclusive Research Network?



- It is a group of co-researchers with intellectual disabilities, supporters, and university co-researchers from Ireland who do research.

What is this study about?



- We came up with the idea of doing a research project on what people think about friendships, relationships, and supports.

How did we do the study?



- We decided to do focus groups to find out the answers:
 - we organised 3 research workshops in 2010 where we learnt how to do focus groups.



- 20 members of the Inclusive Research Network ran the focus groups.
- We ran 16 focus groups around Ireland from June to September of 2010.
- We asked people in the focus groups what they thought about:
 - having friends, boyfriends, and girlfriends
 - the supports they need to have friends and a boyfriend or a girlfriend.



Who took part in the focus groups?



- In total, 97 people took part:
 - about half men and half women
 - many lived with their families
 - most of them were single but some had been in a romantic relationship.

What did we find out?



- People told us that:
 - good friends are there for you
 - you do things together with your friends
 - you can be friends with someone and not be their boyfriend or girlfriend.



- People in the focus groups talked about:
 - how they used to have a boyfriend or a girlfriend
 - getting embarrassed talking about boyfriends and girlfriends
 - being treated like children over boyfriends and girlfriends
 - not having a boyfriend or girlfriend and wishing they had one
 - not wanting a boyfriend or a girlfriend
 - their right to get married.



- In general, people said that:
 - it was nice to have someone
 - a boyfriend or girlfriend treats you well
 - you can do things with your boyfriend and girlfriend and go on dates.



- People said that they needed support to have friends, boyfriends, and girlfriends from:
 - staff
 - their families.



- People also said that they wanted:
 - to be able to use transport to get out at night and to get around visiting people more
 - a house of their own to invite friends, boyfriends and girlfriends.



TEAM

The co-researchers with intellectual disabilities



**Ruth
Costello**



Marie Deely



**Brian
Donohoe**



**Martin
Doohar**



**Jimmy
Dooner**



**Michael
Freiberg**



**Belinda
Henrey**



**Louisa
Iannucci**



**Sean
Keaveney**



Helen Liffey



**Kathleen
Mc Meel**



**Regina
Maguire**



Ann Mahon



**Ger
Minogue**



**Seamus
Murphy**



**Patricia
O'Dea**



**Pauline
O'Meara**



**Helen
O'Regan**



**Kathleen
Ryan**



**Arthur
Sexton**



Marie Wolfe

The supporters



**Geraldine
Bane**



**Simon
Buggy**



**Antonio
Cebas**



**Josephine
Flaherty**



Rob Hopkins



**Orla
Kelly**



**Kieran
Keon**



Anna Nolan



Liz Phelan



**Stephen
Shannon**



Aine Taylor



Mick Teehan

The university co-researchers

The National Federation of Voluntary Bodies



Edel Tierney



Orla Kelly



Mary Barrett

The National Institute for Intellectual Disability



**Edurne
García Iriarte**



**Siobhain
O' Doherty**



**Darren
Chadwick**



**Pamela
Gallagher**

External Advisor



Roy Mc Conkey

TIMELINE

2010



February We launched the “Where We Live” study.
We did training on focus groups.



We decided to do the study on friendships, relationships and supports.
April We decided to do focus groups for the study.

May University co-researchers got ethical approval to do the study from Trinity College Dublin.



June We did training on how to do focus groups in Galway and Dublin.

July - September Co-researchers with intellectual disabilities and supporters did focus groups.



University co-researchers:

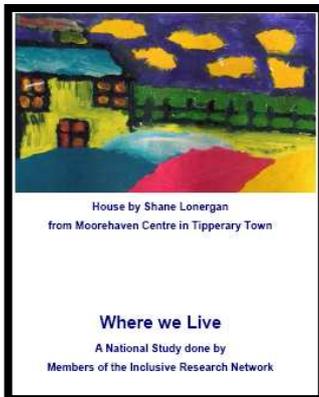
- transcribed the focus groups
- did a first analysis of the focus groups.

October We got together at Trinity College Dublin to make sense of what people told us.

We wrote this report.

INTRODUCTION

The Inclusive Research Network is a group of people who come together to do research and talk about research that is important to people with intellectual disabilities in Ireland.



The IRN members are:

- people with intellectual disabilities
- university researchers from the National Federation of Voluntary Bodies and the National Institute for Intellectual Disabilities, Trinity College Dublin.
- supporters
- Last year, in 2009 we did a study on living options called “Where We Live.”
- This year we decided to do a study on relationships and supports.
- In this report we talk about:
 - what we did
 - how we did it
 - what we found out.

Our voice

- Co-researchers with intellectual disabilities, supporters, and university co-researchers are all part of the research team.
- We are all needed to do the research study.
- So, in this report **we** means all of us.
- However we have different roles.
- So, sometimes we say what:
 - **co-researchers with intellectual disabilities** did
 - **supporters** did
 - **university co-researchers** did
- It is important to say what each of us did so other people can do a similar study.



Why did we choose to do a study on relationships and supports?

During one of the IRN workshops in 2008 – 2009 members of the IRN said that they wanted to do a study on relationships.



- Some of the IRN co-researchers also did another study called **All We Want to Say** in 2009.
 - This study was about life for people with intellectual disabilities in Ireland.
 - One of the findings from “All We Want to Say” was that people with intellectual disabilities wanted to be partners in relationships.
- The United Nations Convention on the Rights of Persons with Disabilities (UN Convention) says in article 23 that people with disabilities have the same right as everyone else to have relationships and to get married.



- However, the laws in Ireland say that it is illegal to have a sexual relationship with a person who has an intellectual disability and cannot live without support.
- Many people with intellectual disabilities in Ireland want to have boyfriends and girlfriends but there are barriers:
 - people do not have enough information
 - services can make it difficult to have boyfriends and girlfriends (Kelly, Crowley & Hamilton, 2009; Healy, McGuire, Evans & Carley, 2009).
- The United Nations Convention on the Rights of Persons with Disabilities says in article 31 that we need research to know what people with disabilities think so we can change the laws in Ireland.

METHODS

How did we choose to do focus groups?

- We had to decide the way to find out the answers. The ways to find out the answers are called **Research Methods**.
- We all took on different roles:
 - The university co-researchers sent the co-researchers with intellectual disabilities and supporters information about:
 - surveys
 - focus groups
 - interviews
 - the work we had to do with each method.
 - The co-researchers with intellectual disabilities and supporters made the decision to do focus groups.

This is the information about the research methods:



1)SURVEYS

- In a survey you make a list of questions.
- You do the survey with each person at a different time.
- You ask everybody the same questions and write down their answers.

Tell me about where you live



Tell me about where you live

I live in a house in town



2) FOCUS GROUPS

- In a focus group you make a list of questions.
 - There are usually between 3 and 4 main questions.
- In a focus group you ask a group of people the questions at the same time.
 - People in the group talk to each other.
- You record the discussion and take notes.

3) INTERVIEWS

- You make a list of questions.
- You ask the questions to 1 person at a time.
- You ask the questions, write down the answers, and record it.

Here is the information about the work we had to do with the different methods:

	Have we done them before?	Co-researchers with intellectual disabilities	Supporter's work: They support co-researchers with intellectual disabilities to:	Analysis
Surveys	Yes	Come up with questions Do the survey	Arrange meetings with each person Get consent Write down responses	University co-researchers do preliminary analysis. Everyone works on making sense of what we found out.
Focus Groups	We got some training.	Come up with questions Do the focus group	Arrange a meeting with a group of people Arrange room and equipment Get consent Write down responses	University co-researchers do preliminary analysis. Everyone works on making sense of what we found out.
Interviews	No	Come up with questions Do the interviews	Arrange meetings with each person Get consent Write down responses	University co-researchers do preliminary analysis. Everyone works on making sense of what we found out.

Ethics

The university co-researchers applied for ethical approval to do the study to the research ethics committee at Trinity College Dublin. The university co-researchers had to explain to the committee:



- the questions we wanted to ask
- why these questions were important
- who would take part in the focus groups
- what would happen during the study
- how we would tell people about the study.

The research ethics committee at Trinity College Dublin said that it was OK to do the study on May 21st 2010.

Materials

To do the study, the university co-researchers developed:

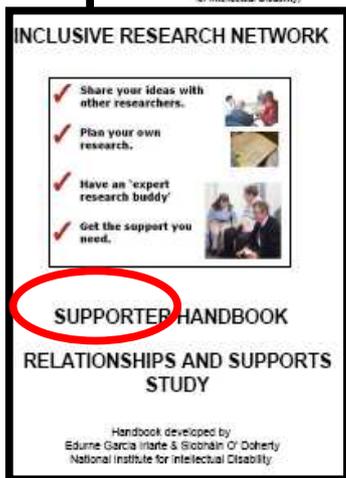
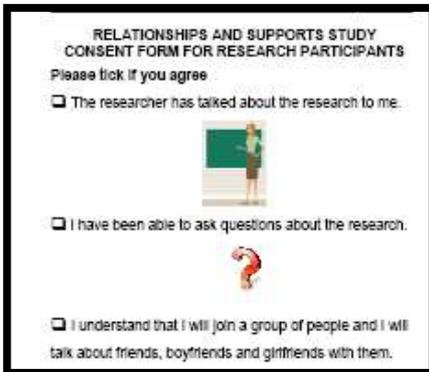
- 1) information forms
- 2) consent forms
- 3) 2 handbooks: 1 for co-researchers with intellectual disabilities and 1 for supporters.



The image shows a sample of a Participant Information Form. The title is "Relationships and Support Study Participant Information Form". It includes a line for the participant's name, a paragraph explaining the Inclusive Research Network's focus on research about issues important to people with disabilities, and a paragraph stating the researchers' interest in studying relationships with friends, boyfriends, and girlfriends, and their request for participation based on the importance of the participant's ideas.

1) INFORMATION FORMS

- Had information about the study:
 - what the study was about
 - how the information people give would be kept private
 - that Trinity College Dublin said it was OK to do the study
 - that it was OK to stop taking part at any time
 - that if you got upset at the focus group, you could talk to a social worker or key worker.
- There were information forms for:
 - people in the focus group
 - their supporters
 - organisations
 - family members.



2) CONSENT FORMS

- They were like a contract.
- People signed the consent forms to say they were happy that:
 - the study was about relationships and supports
 - people that wanted to take part would be in a focus group
 - the focus group was recorded
 - the answers people gave would be kept private.

3) HANDBOOKS

- They were step-by-step guides to:
 - organise a focus group
 - run a focus group.
- There were 2 different handbooks:
 - 1 for co-researchers with intellectual disabilities
 - 1 for supporters of co-researchers with intellectual disabilities.
- We explain how we did the handbooks in the next pages.

What information was there in the handbooks?

In the handbooks, there was information on:



Meeting hall



- finding a person to support the co-researchers with intellectual disabilities
- talking to the organisation or advocacy group about the study to see if they were interested in taking part
- finding a good place for the focus group to take place
- giving out information forms and flyers
- doing the focus group
- sending back the recording, notes, and all forms to the NIID.

How did we make the handbooks easy to read?

This is easy to read



- The university co-researchers used plain language.
- 3 students from the Certificate in Contemporary Living in Trinity College Dublin checked the handbooks. We called them reviewers.
- The reviewers:
 - took turns to read the handbooks
 - made comments about words and pictures
 - gave suggestions about how to make the handbooks easier to read and understand.

The suggestions of the reviewers were:

	Check with the managers of the organization that it's ok to run the focus group..... <input type="checkbox"/>
	Ask if you can use one of their rooms..... <input type="checkbox"/>

Drinks and Snacks

- to put all the forms (information, consent) together at the back of the handbook so they were separate from the instructions on how to do focus groups
- to change some of the words. For example “refreshments” was changed to “drinks and snacks”

Equipment
Things I need

**You can stop any
time without
negative
consequences**

**It's OK to stop at
any time**

- to change some of the words in the consent and information forms so they explained the study better. For example “equipment” was changed to “things I need.”
- to take out some words that made the handbooks too long and complicated. For example, they took out the words “without negative consequences” and said “It’s OK” instead.

We used pictures that we took from:

- Microsoft Office Word clipart
- the CHANGE picture bank
- photos taken at IRN workshops with members’ permission.

Research Training

The IRN had 2 training days in June 2010 on how to organise and run focus groups:

- 1 in Dublin
- 1 in Galway.

The co-researchers with intellectual disabilities and the supporters learned how to organise and run a focus group.



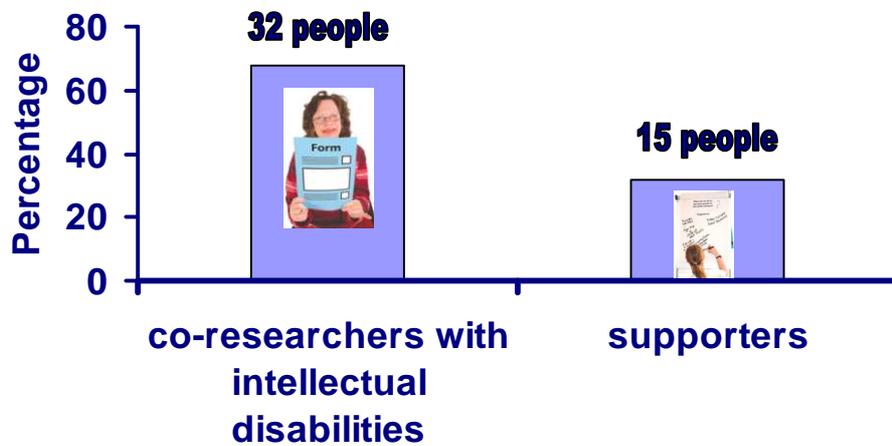
- At the training workshops we worked on:
 - how to ask for a support person to help co-researchers with intellectual disabilities
 - how to get people to take part in the focus group
 - how to run the focus groups
 - how to ask the questions
- We did a lot of role plays.

People came from all over Ireland: Cork, Clare, Dublin, Galway, Kildare, Limerick, Roscommon, Tipperary, and Wicklow.

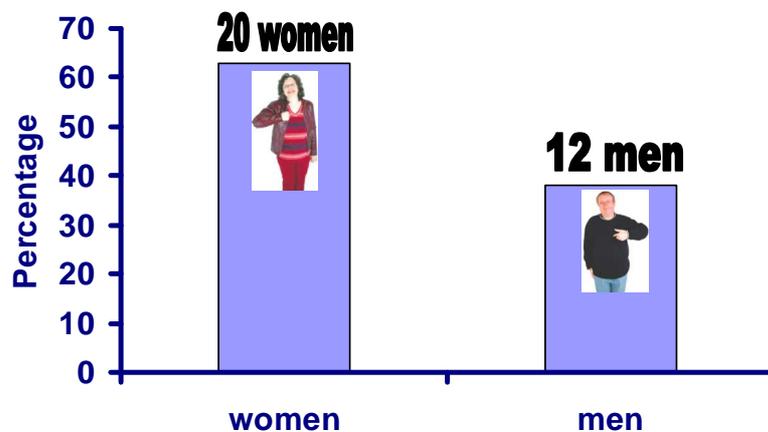
In total, 47 people went to the training workshops.

- 18 people came to the training workshop in Dublin.
- 29 people came to the training workshop in Galway.
- 19 people were new to the IRN.

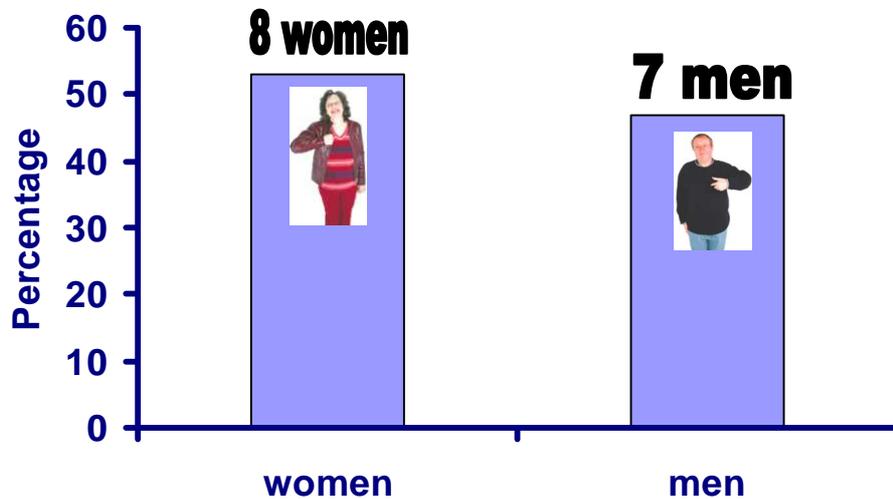
32 of the people who came were co-researchers with intellectual disabilities and 15 were supporters.



More than half of the co-researchers with intellectual disabilities at the training workshops were women.



About half of the supporters were women and half men.

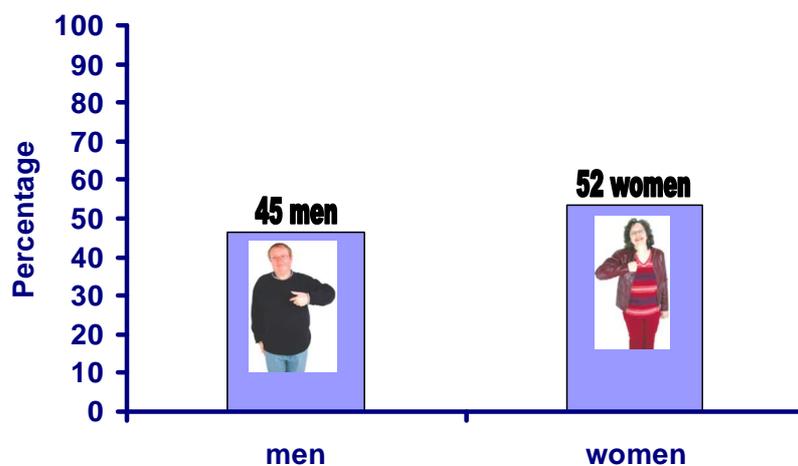


The Focus Groups

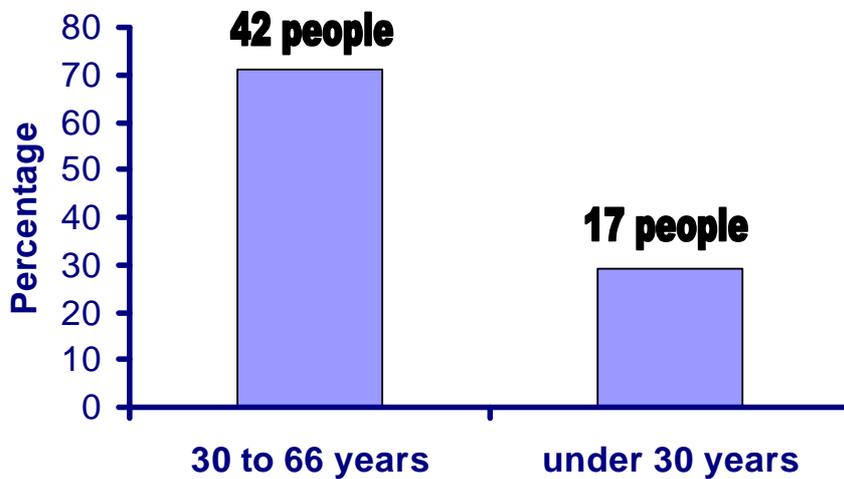
We ran 16 focus groups and 97 people with intellectual disabilities took part.

Who came to the focus groups?

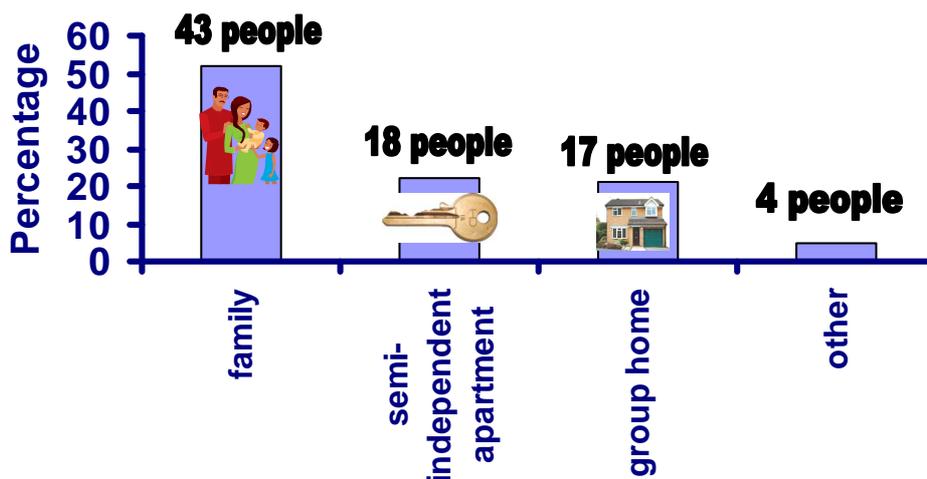
About half of the people were men and half women.



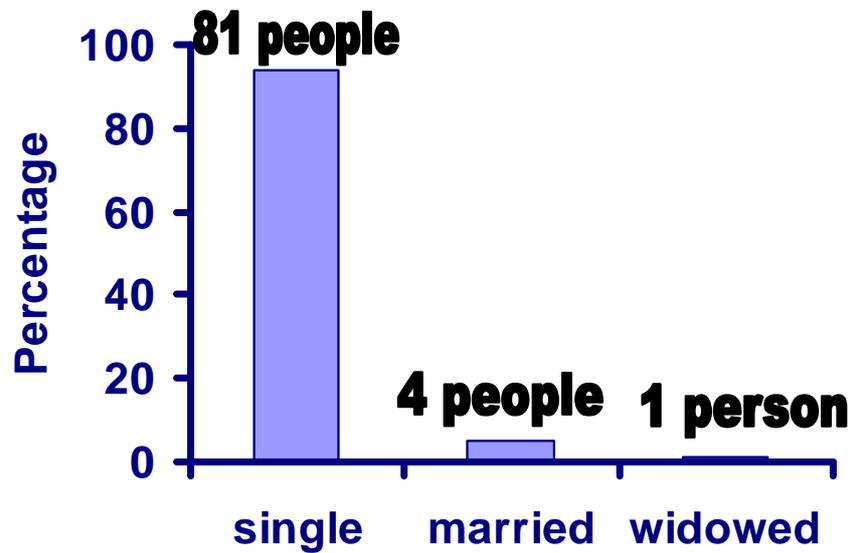
Most people were 30 years of age or older and some people were under 30 years of age.



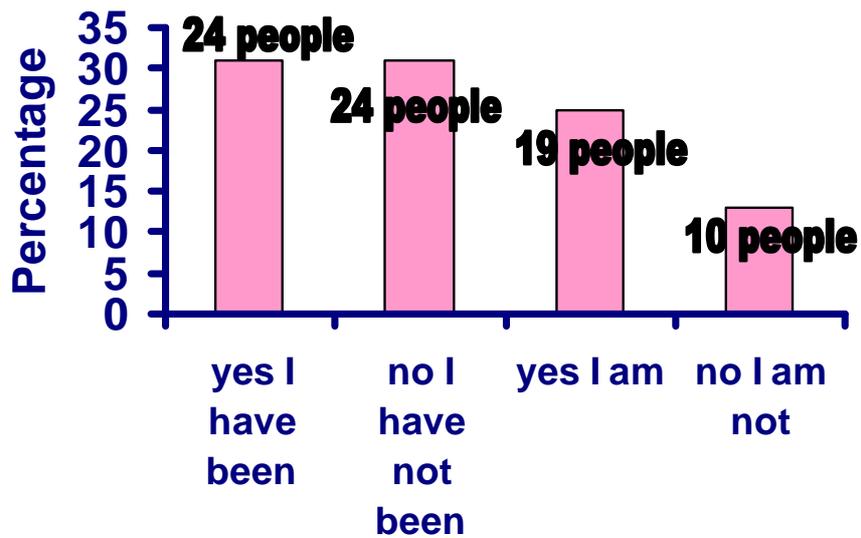
Most people lived with their families, some people lived in group homes and semi-independent apartments, a few lived in other places like a life sharing community and a rented house.



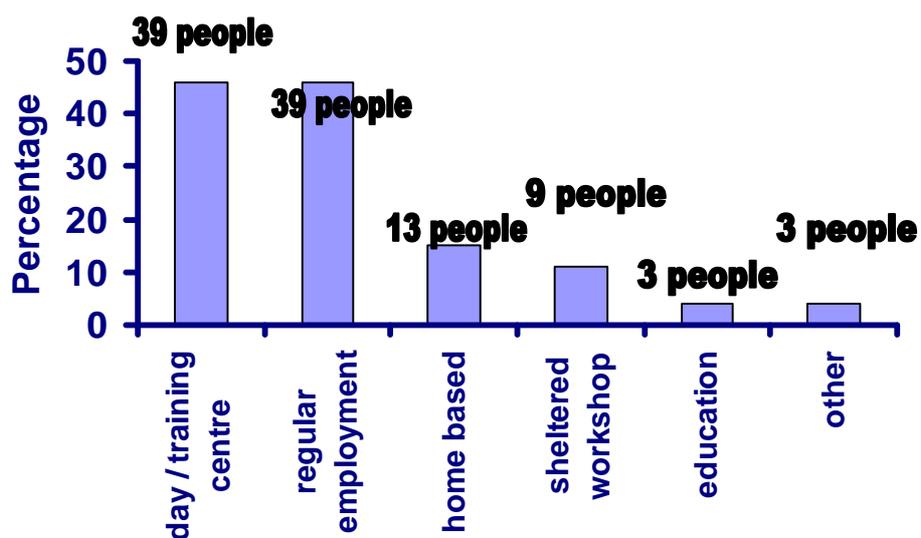
Most of the people were single, only a few were married, and one person was widowed.



Some had been in a romantic relationship, some hadn't been, and some said they were in a romantic relationship when we asked them.



- Many of the people went to a day training centre.
- Many of the people were working
 - 16 people were paid for their work
 - 17 people were not paid for their work
 - 1 person was self employed.
 - 5 people were in supported employment.
- Some of the people were home based.
- Some people were in a sheltered workshop.
- A few people were in education. 1 person was going to college.
- A few people said other things. 1 person did painting, 1 person was on an advocacy council and 1 person had no day services.



Making Sense of What People Said

How did we make sense of what people in the focus group said?

The university co-researchers did a first analysis of what people talked about in the focus groups. The university co-researchers used themes to do that analysis.



A theme is an important thing that people talked about.

- For example in the focus groups people said:

When you're talking about that we're getting embarrassed

AND

It's our right to be embarrassed.

- The university co-researchers said that the theme was **“getting embarrassed”**
- The university co-researchers used the words of the focus group participants for the themes.

The university co-researchers made a summary of all the themes.

**“We’re Not Really Boyfriend
And Girlfriend”**



The thing is I have a girlfriend right ... but we’re not really boyfriend and girlfriend really... only best of friends

In the summary there was:

- the name of each theme
- a picture for each theme
- a quote for each theme.

The university co-researchers sent the summary out to the co-researchers with intellectual disabilities and the supporters.

We met to discuss what people said in the focus groups and the summary of themes. We used questions, coloured cards, and role play for the discussion.



Questions

We asked these questions:

- is this a good summary?
- is this what people said?
- is there a better way to do a summary of what people said?
- is there anything else that people said?



Coloured cards

We used coloured cards to say:

- it's a good code
- I don't like the code
- I have a better code.

Role plays

We did role plays to explain the themes.

These were the conclusions of the meeting:



The co-researchers with intellectual disabilities and the supporters said:

- the answers to the research questions should be clear
- education was also a support to have relationship although people didn't talk about that in the focus group
- some of the theme names should have different names, for example:
 - "treats you well" to "treat each other well."
 - "my parents are a bit unfair" to "my parents are too strict."

FINDINGS

A summary of what people said in the focus groups

What do you think makes a good friend?



be there for you



do things together



are we just friends!



It's hard – my parents are too strict.

What do you think about having a boyfriend / girlfriend?



nice to have someone



treat each other well



we do things together



love one another



we go dating



I've been there



getting married



I don't know what a boyfriend is



embarrassing for us to ask people out



we're getting embarrassed



that job is up to the boy



I don't want a boyfriend/ I wish I had one



treated like children



we are out of the picture

What supports do you need?



funding for staff to get around



staff to talk over your problems



family helps you through everything

Other things people told us



transport to go out



transport to get around



getting a house

What did people say in the focus groups?

What do you think makes a good friend ?

What people told us in the focus groups

Be there for you



A best friend is someone who looks out for you.

Do things together



I do a lot of things. I go to swimming. I go to the pictures.

Are we just friends!



The thing is I have a girlfriend right and I'm not going to mention her name now but we're not really boyfriend and girlfriend really. We're only best of friends but we will be there for each other and help each other out.

It's hard – my parents are too strict



I just want to say one thing. My parents are a bit unfair about letting me out with my friends and stuff because it's not fair and it upsets me because I use to go out bowling with these lads here. Didn't !!

What do you think about having a boyfriend or a girlfriend ?

What people told us in the focus groups

It's nice to have someone



I think it is nice to be girlfriend and boyfriend.

Treat each other well



If you bring a girl any girl out, you are going to treat her to something anyway whether it's a mineral* or a bloody ice-cream or whatever you like to give a girl you give it to her, whether it's a smart or a kiss.

* soft drink in Ireland

We do things together



We go on walks and things like that, go to bookshops. All those things.

Love one another



It's good to have a boyfriend because they care about you and cuddle and snuggle and mind you and help you and stuff like that.

We go dating



I think em well boyfriend and girlfriend, I think, well have a big romance out of it, go out at night, have a candle light dinner, bit of music, close dancing, few glasses of whatever drink you're drinking then, one thing leads to another. I think that's what that is.

I've been there



As I was saying I used to have a girlfriend once. Four, not four but three girlfriends.

I don't know what a boyfriend is



Well I don't know what a boyfriend is. If I went out with Sean* I would not know what to do with a boyfriend.

* We have changed all the names in the quotes. The names are all fake.

It's embarrassing for us to ask people out



He'd say to her
'Do you want to go out with me on the first date?'

She'd say
'Yes I will come out with you.'

But at the same time it's very embarrassing for them as well.

We're getting embarrassed



When you're talking about that we're getting embarrassed.

That job is up to the boy



There is no problems there, like, wanting to have a boyfriend or a girlfriend, but that job is up to the boy.

I wish I had one



About having a boyfriend:

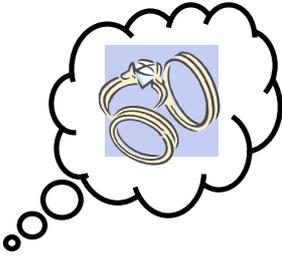
I wish I had one. I had one and I broke up from him.

It's hard – in general you're treated like children



Maybe people have different attitudes to other people that have a disability and people are in wheelchairs and they can't have a boyfriend. Like attitude of respecting. You're kind of looked down on. You're kind of treated like children.

I'd like to get married



I want to get married myself. I want to get married.

It's up to us if we want to get married



It's our choice if we want to get engaged or married. It's up to us.

I don't want a boyfriend



I don't really want a boyfriend. I am quite happy the way I am. I have good friends. I have you as a good friend and I have Michelle and Barbara as a good friend and my key worker as a good friend and I have Thomas and Ryan as a good friend.

I'm out of the picture



I have a lot of friends around me too that have a boyfriend or a girlfriend. I'm the only person in the house that doesn't have a boyfriend and everyone has a girlfriend and a boyfriend at home, so I can feel I'm out of the picture.

What supports do you need to have friends, a boyfriend or a girlfriend ?

What people told us in the focus groups

STAFF

Funding for staff to get around



Well I would like to get to go out a lot more. To get to know a lot of more new friends, I would. Because like since I have moved here, to Letterkenny, I hadn't got to know any new friends. It's because of the funding of staffs. The money is not there for that.

STAFF

Staff to talk over your problems



How staff could help you have a boyfriend:

Just talking about it, because I am older now. I am 38 now. And I like having a boyfriend. I'd like to have one.

FAMILY

Family helps you through everything



Just help you through everything if you are going through a rough time. Just on the phone after breaking up with someone. Give support.

Other things people told us

What people told us in the focus groups

WISHES

Use transport to get a chance to go on a night out



Me and Carol are trying to use public transport more often so that we can use it if we get a chance to go out on a night somewhere

WISHES

To get around



My own boyfriend – he lives out in the country and his mother can't drive and Mammy has asked him several times to meet up with me in the city for a couple of hours. That has happened several times. I would like that.

WISHES

Getting a house



Help that a person with an intellectual disability needs to keep her friends

Get your own place. Your own house.

We're getting a house



We're getting a house. Joey has a house in Belfast.

Are you two getting a house together?

Yes

RECOMMENDATIONS

- The co-researchers with intellectual disabilities and the supporters talked about their experiences of organising and running a focus group and came up with some recommendations for the future:



2



- to have 2 focus group sessions:
 - 1 for giving information and getting consent
 - 1 for running the focus group
- to have a break between getting consent and having the focus group
- to make it more relaxed for people in the focus group
- to give training to supporters of people in the focus group
- to show a DVD to people about the study because some people did not understand the information sheet.

CONCLUSIONS

This study was the first inclusive research study about relationships and supports of people with intellectual disabilities in Ireland.

We did this study because relationships are very important to people with intellectual disabilities and there was only one study about this in Ireland. The UN Convention also says in article 23 that it is the right of people with intellectual disabilities to have relationships like everyone else.

We did focus groups because we could ask more people at the same time and that worked ok. We found that people with intellectual disabilities have different opinions and some of them want to have a boyfriend or a girlfriend and some don't. It is very important, then, that people ask people with intellectual disabilities what they want and what they need.

We all need supports to keep friends, boyfriends, and girlfriends. People with intellectual disabilities need staff in their organisations and families to support them with transportation and talking about issues. People with intellectual disabilities need their organisations to give more money to the staff to support them getting around.

Finally, we know it is the right of people with intellectual disabilities to have relationships like everyone else but they feel out of the picture. People with intellectual disabilities don't have their own houses, they don't get around that much, and people still treat them like children. We need to change the laws in Ireland to have the rights of people with intellectual disabilities respected

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