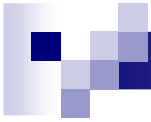


# Relationships and Supports Study







# We all did this presentation:

## ■ Co-researchers:

- Martin Corry
- Marie Deely
- Brian Donohoe
- Martin Dooher
- Padriac McDonagh
- Ger Minogue
- Marie Wolfe

## ■ Supporters:

- Josephine Flaherty
- Rob Hopkins



# We all did this presentation:

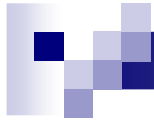
- National Institute for Intellectual Disability:
  - Eburne Garcia
  - Siobhain O'Doherty

- National Federation of Voluntary Bodies:
  - Edel Tierney



# Today, we are going to talk about:

- The Inclusive Research Network
- Our experiences doing research
- Why did we do this study?
- Our research questions
- Who were the co-researchers and supporters?
- How did we find out the answers?
- Who took part in the research?
- What did people tell us?
- What do we think about the results?



# **The Inclusive Research Network**

# Inclusive Research Network

- We are a group of researchers with intellectual disabilities, supporters and university researchers
- We are a national network



# Inclusive Research Network

- We have an international influence. We are taking our work out to Finland, Australia, and Italy
- We're like a family. We are welcoming.
- People listen more to what you say as a researcher



# Inclusive Inclusive Research Network – What we do

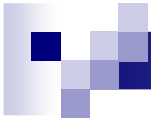


- We do a lot of work
  - Drama about relationships, organising work for conferences / workshops, talking for yourself and to other people, recorded focus groups, asked people questions, transcribe focus groups, facilitate focus group

# Inclusive Inclusive Research Network – What we do



- We decide:
  - what research to do
  - how to do the research
  
- We do training about the research



# **Our experiences doing research**

# My experience of this project



- I feel more confident, relaxed. It's an important topic. From this experience I'm more used to public speaking. This might inspire other people to do the same



# My experience of this project



- Focus group facilitation (running a focus group) was new to me so it's a milestone to me in my career as a researcher.
  - More confident, less nervous
  - A new skill

# My experience of this project



- I felt very good about it. It has given me something to do. If you have nothing to do you can do nothing. It keeps people working. I'd like to do more research like this. I could do more.



# My experience of this project



- It was good. I like to listen to people. Listening is important. I'd like to do more. It was hard and we learned a lot.



# My experience of this project



- Doing research is good.  
You learn more.

# My experience of this project

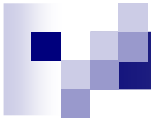


- I felt that I'm a part of Trinity and I feel privileged and I'm up there. I feel that the bubble is getting bigger. I'm enjoying it
- In the inclusive research network, we are learning from each other, co – researchers with intellectual disabilities, academic researchers. Academic researchers are learning from people with intellectual disabilities.
- We are teaching everybody and we are learning from each other. We are sharing skills. The bubble is getting bigger.

# My experience of this project



- We've opened a door (the Inclusive Research Network) that wasn't open 5 years ago. We are working together to learn more.
  - There is room for us all
- We are listened to by all researchers after working with university researchers and researchers from the National Federation of Voluntary Bodies.
- We are aware that we are making services look good but it must be real – they must ask us what we think
- It opens doors to do other research



**Why did we do this study?**

# Why we wanted to study relationships?

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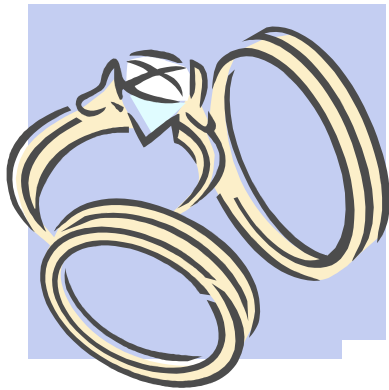
- Because people should have relationships -
- It's part of everyday life
- Families should support people to have relationships, to have their own lives

# Why we wanted to study relationships?



- It was good to find out what other people do, that they can go out for a drink with their girlfriend – staff have too much control

# Why we wanted to study relationships?



- I'd like to get married and it's not right that people can't

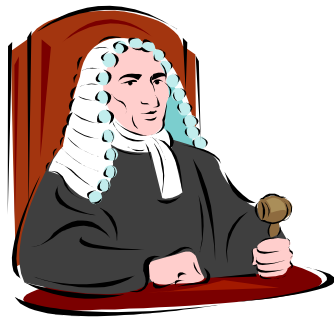


# Why we wanted to study relationships?

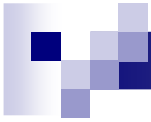


- it's a topic that is not out there – it's not seen for people to have relationships, it's not seen as something important by services.
- It's not on their list.
- There is a fear that people will end up pregnant.
- Services feel people will make mistakes. But we need to make mistakes to learn. Relationships are hard work.

# Why we wanted to study relationships?



- Laws in Ireland are outdated:
  - The Criminal Act 1993 and
  - The Mental Capacity Bill 2008
- The United Nations Convention on the rights of persons with disabilities says it's ok to have relationships.



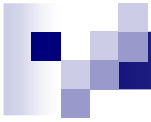
# **Our research questions**



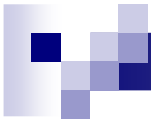
# Research Questions



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



**Who were the co-researchers,  
supporters and the university  
researchers?**



**Ruth  
Costello**



**Marie Deely**



**Brian  
Donohoe**



**Martin  
Dooher**



**Jimmy  
Dooner**



**Michael  
Freiberg**



**Belinda  
Henrey**



**Louisa  
Iannucci**



**Sean  
Keaveney**



**Helen Liffe**



**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**



Geraldine  
Bane



Simon  
Buggy



Antonio  
Cebas



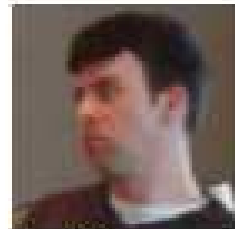
Josephine  
Flaherty



Rob Hopkins



Orla  
Kelly



Kieran  
Keon



Anna Nolan



Liz Phelan



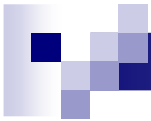
Stephen  
Shannon



Aine Taylor



Mick Teehan



## The National Federation of Voluntary Bodies



Edel Tierney



Orla Kelly



Mary Barrett

## The National Institute for Intellectual Disability



Edurne  
García Iriarte



Siobhain  
O' Doherty



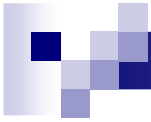
Darren  
Chadwick



Pamela  
Gallagher



Roy Mc Conkey



**How did we find out the  
answers?**

# How did we find out the answers?



- We had focus groups and we asked people what they thought themselves
  - They spoke as a group

# What is a focus group?



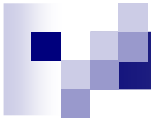
- A group of people coming together to discuss a topic.
- The questions would be the centre of the discussion.
- You would facilitate to make sure everybody got to tell their opinion.
- There were 5- 6 people in the focus groups on average.



# How many focus groups did we do?



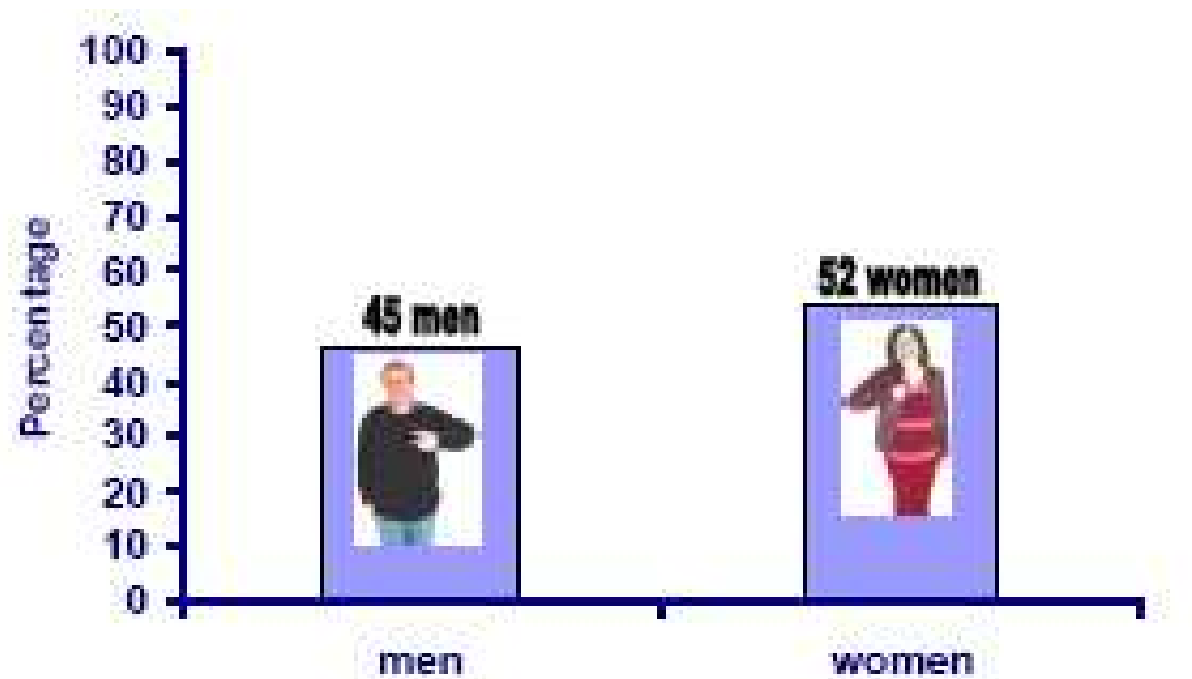
- We did 16 focus groups. For example we did them in Galway, Ennis, Kilrush, Ennistymon, Milltown Malbay, Monasterevin.



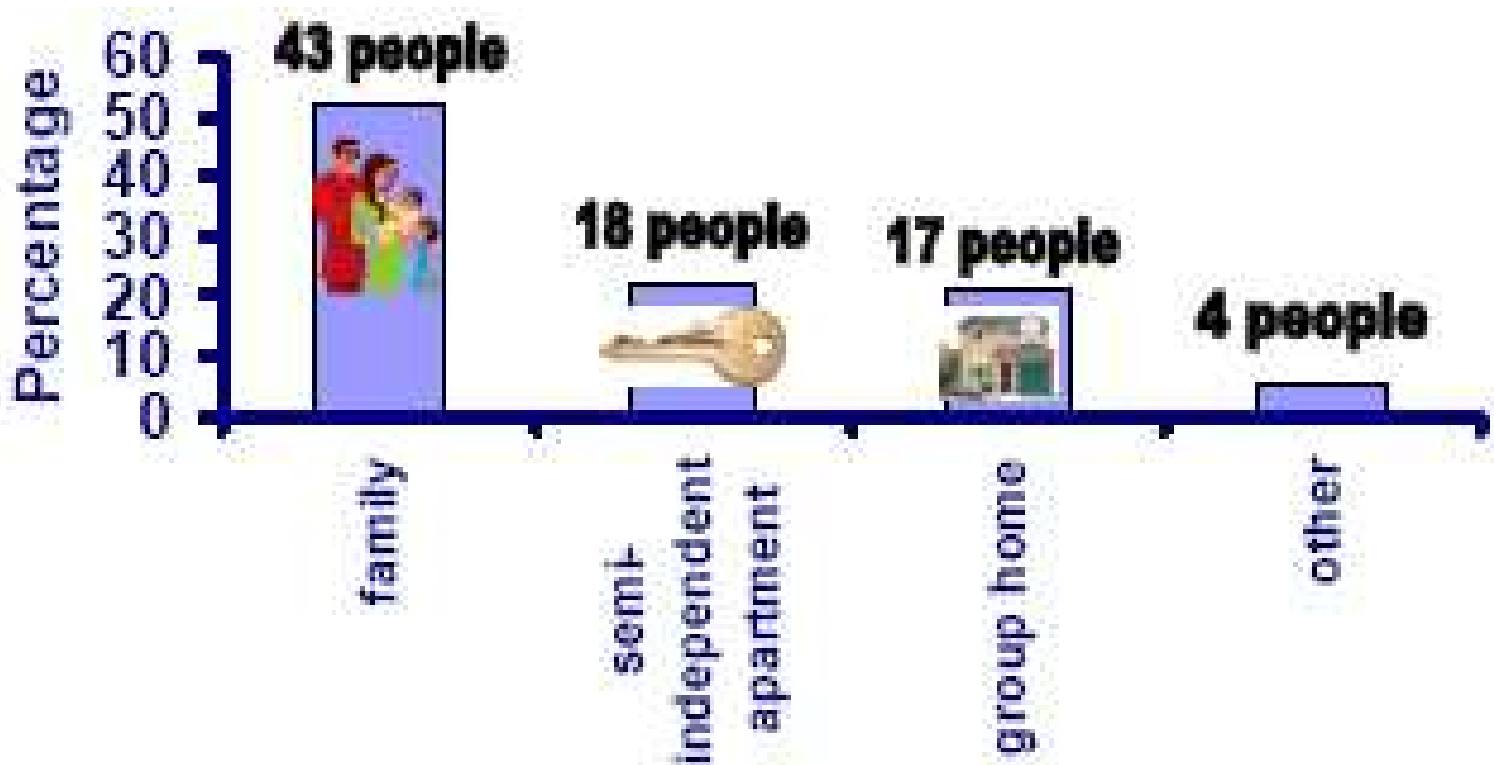
**Who took part in the research?**

# Who took part in the focus groups?

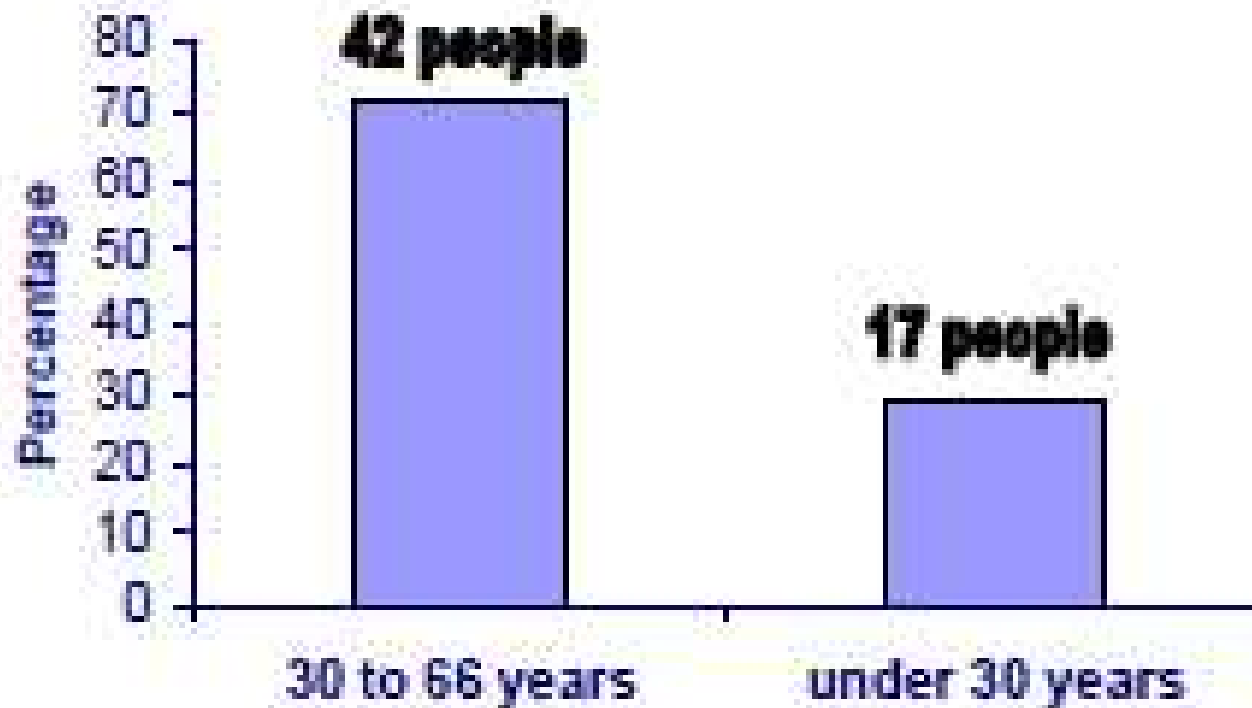
- 97 people took part, 45 men and 52 women.



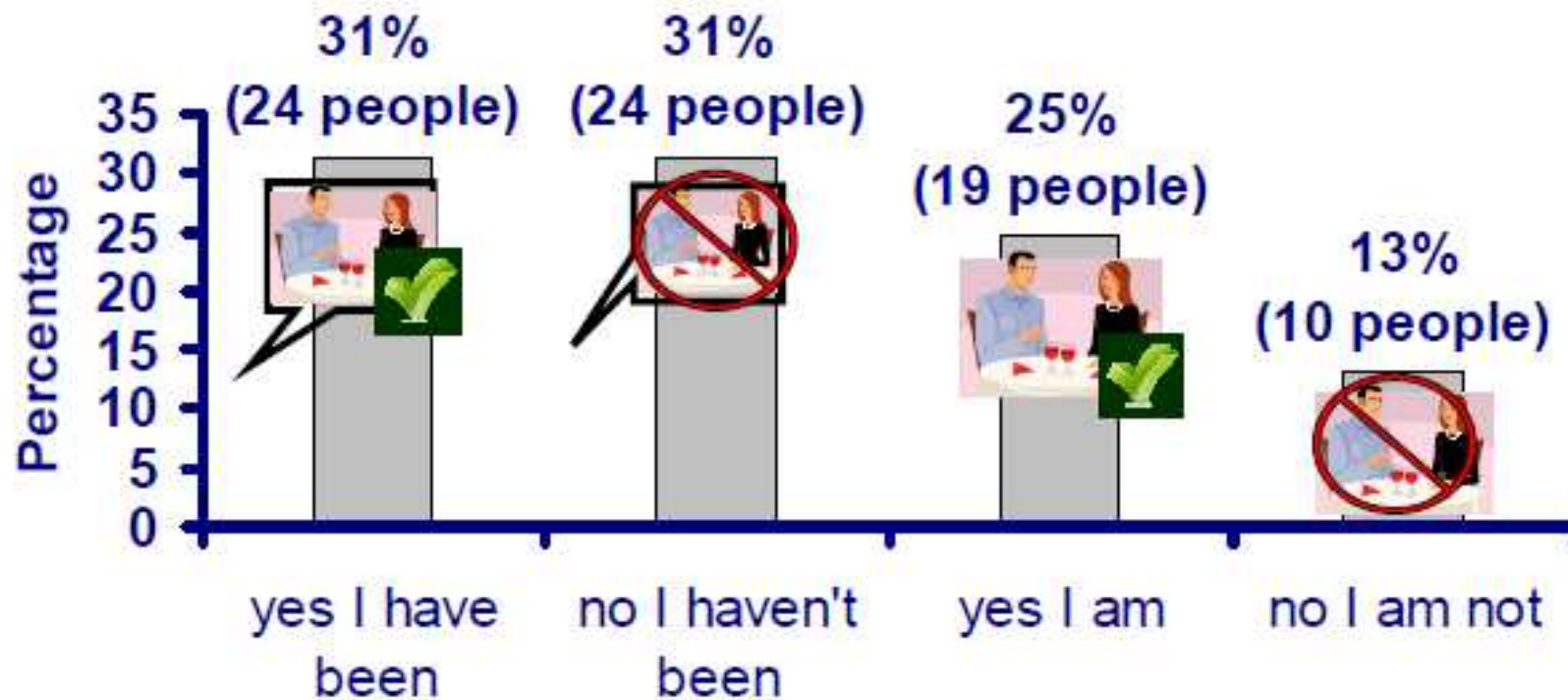
- 43 people lived with their families.



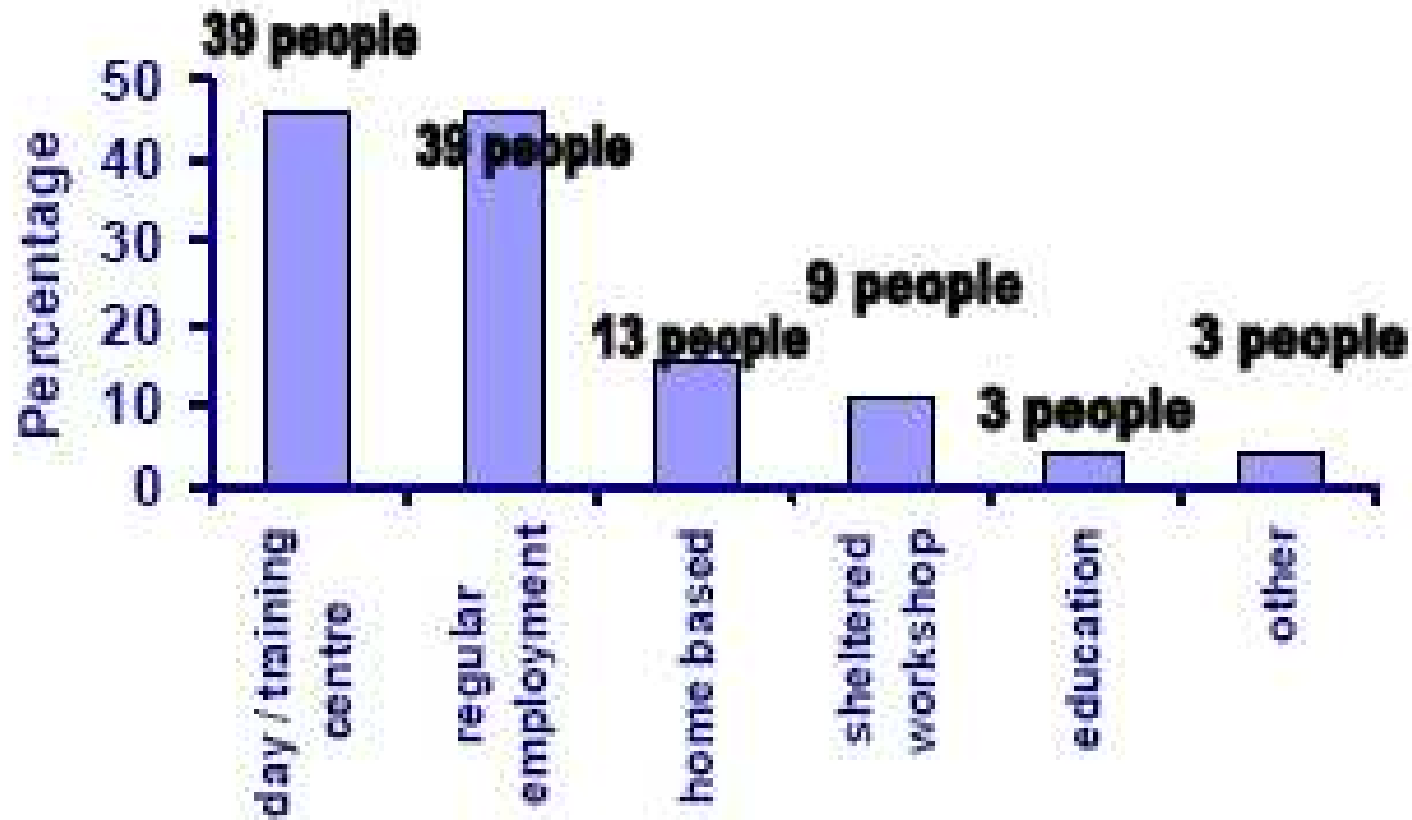
Most people were 30 years of age or older. 42 were between 30 and 66 and 17 were under 30.



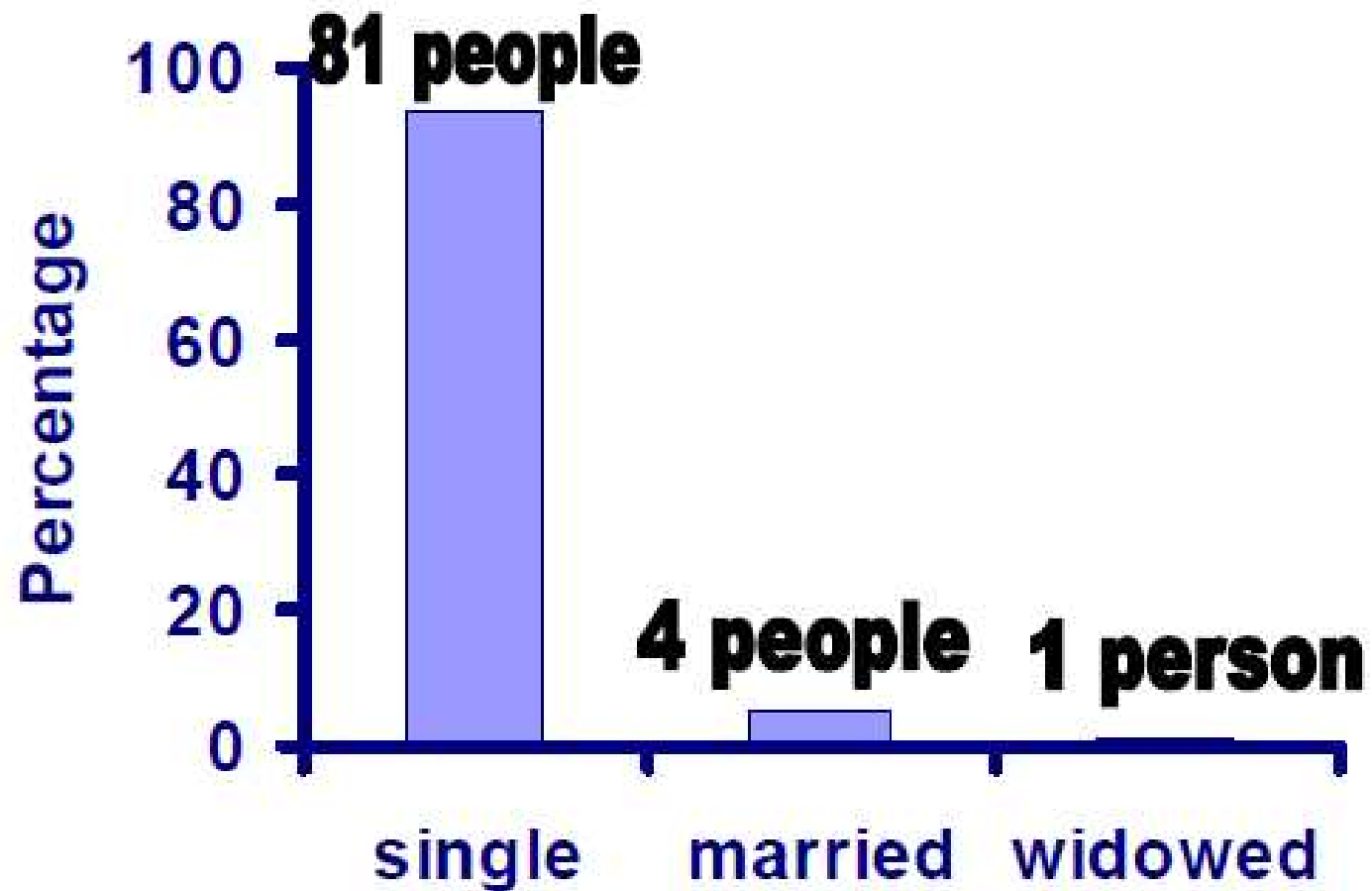
24 had been in a relationship, 24 hadn't been. 19 were in a relationship and 10 were not.



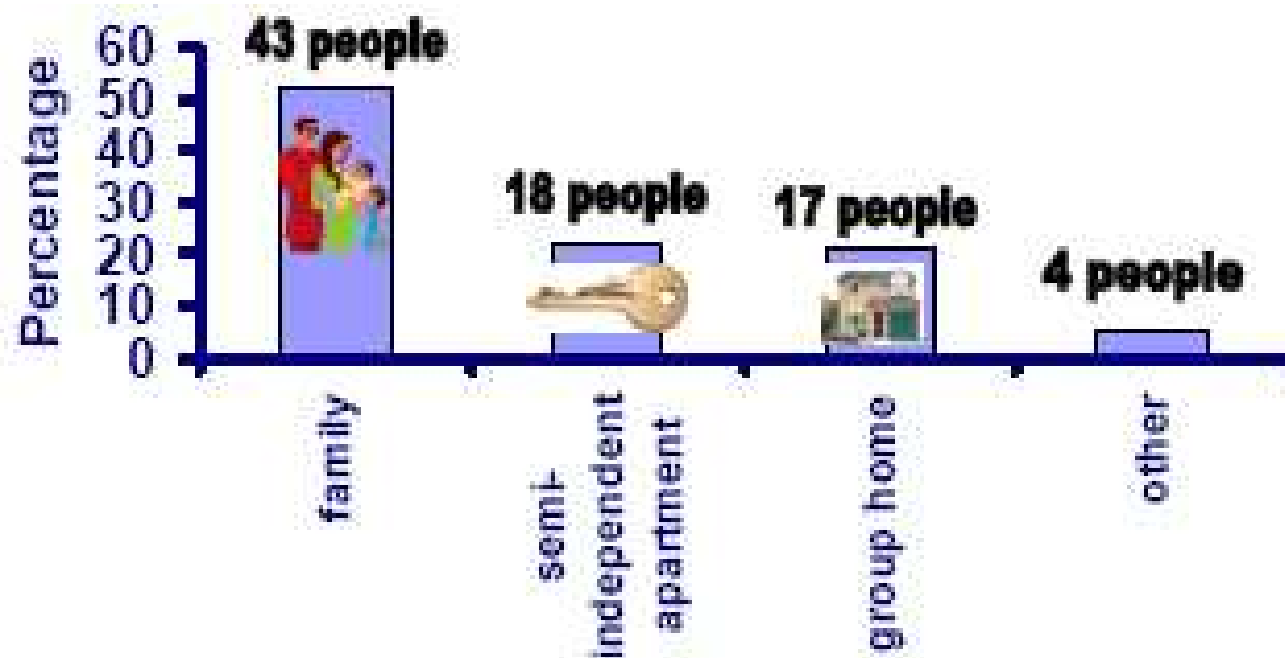
39 people worked in day/ training centres, 39 in regular employment

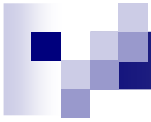


The majority were single (81 people)



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.





**What did people tell us?**

# This is a summary of what people told us

FINDINGS						
A summary of what people said in the focus groups						
<b>What do you think makes a good friend?</b>						
						
be there for you	do things together	are we just friends!	It's hard – my parents are too strict.			
<b>What do you think about having a boyfriend / girlfriend?</b>						
						
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
<b>What supports do you need?</b>				<b>Other things people told us</b>		
						
funding for staff to get around	staff to talk over your problems	family helps you through everything	transport to go out	transport to get around	getting a house	

# What does it make to be a good friend?

## 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.

## What does it make to be a good friend?

### 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 we these lads here. Didn't I!

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

## 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



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

**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.

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

## 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.

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

## 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.

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

### 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.



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

**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.

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

## I wish I had one



### About having a boyfriend:

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

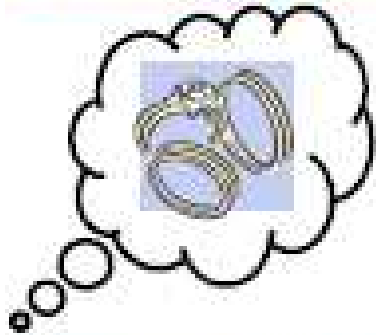
## It's hard – in general you're treated like children



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.

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

### 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.

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

### 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 a friend, a boyfriend or a girlfriend?

## 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.

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

**STAFF**  
Funding of 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 out it, because I am older now. I am 38 now. And I like having a boyfriend. I'd like to have one.

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

**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.

What else would you like?

**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

## What else would you like?

### 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.

What else would you like?

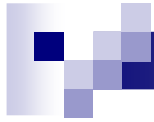
**We're getting a house**



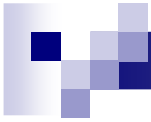
We're getting a house. Joey has a house in Belfast.

Are you two getting a house together?

Yes



**What do we think about the  
results?**



- We need support from our families
  - Don't want to fall out with family
- It's our choice to have a relationship
- We need private space
- It's difficult for some people to go to dating agencies
  - People are shy
  - People might think that they need permission



## **Our questions to you:**

- Where do we go from here with the research?
- Where else is it happening?
- What are we doing as a result of the findings?
- What about getting paid for the research that we do?
- Why are so many people single?



# Thanks!

## The Inclusive Research Network

You can find us:

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

[http://www.fedvol.ie/Inclusive\\_Research\\_Network\\_IRN/Default.241.html](http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html)