



**House by Shane Lonergan
from Moorehaven Centre in Tipperary Town**

Where we Live

**A National Study done by
Members of the Inclusive Research Network**

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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/>

ACKNOWLEDGEMENTS

Many people have worked on this project:

- People with intellectual disabilities who participated in the surveys.
- Ray Murray, Zoe Hughes, and Errol Cocks, research staff at the National Institute for Intellectual Disability, who participated in the Galway workshop.
- Mary Barrett, administration staff at the National Federation of Voluntary Bodies who supported members of the Inclusive Research Network, helped in the organisation of meetings and made contact with members of the Inclusive Research Network to write this report.
- Sarah Jones, research administrator at the National Institute for Intellectual Disability also helped following up with co-researchers and supporters when they did the survey and helped in the reviewing of this report.
- Co-researchers and supporters that did not do the surveys but have attended the workshops and shared their knowledge and ideas.
- Organisations and staff that supported co-researchers to survey people getting services from them.
- Everyone who kindly reviewed this report and made comments to make it easier to read.

We would like to thank them all for their effort in making this research project and report possible.

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EXECUTIVE SUMMARY

The Inclusive Research Network is a group of people with intellectual disabilities from Ireland who do research.

We are supported by the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.

We organised 3 research workshops between 2008 and 2009 where we learnt research skills. We came up with the idea of doing a research project on: where people with intellectual disabilities live and how they like it.

We decided to do a survey to find out the answers. We did a survey with easy to read questions and pictures about where people live and how they like it. We practised how to ask the questions and how to write the answers.

11 members of the Inclusive Research Network did the survey with 43 people. These members did the survey from June to September of 2009. Staff at the National Institute for Intellectual Disability analysed the answers.

We then organised 2 meetings to discuss what we found out:

- Most people who did the survey were women and most people were between 20 and 35 years old.
- Most people liked where they lived.

- **Most people lived in towns and with their families.**
- **Most people had their own kitchen, bedroom and bathroom.**
- **Most people had access to taxis and buses.**
- **More than half of the people did not choose who they live with and only half of the people chose where they live.**
- **Half of the people said that they would change things in their homes, only a few would change things about the people they live with, and some would change things about the support they get.**

Members of the Inclusive Research Network said that more work needs to be done for them to live independently including: more services for people with intellectual disabilities, more control for people over funding, more choices about where and who to live with, more individualised supports, change in families' attitudes about living independently and more opportunities for people with intellectual disabilities to be heard.

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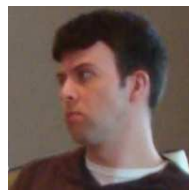
Josephine Flaherty



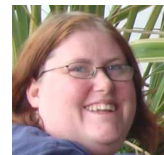
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Pauline O'Meara

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External Advisor



Roy McConkey

THE INCLUSIVE RESEARCH NETWORK

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.

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

NATIONAL INSTITUTE FOR INTELLECTUAL DISABILITY
TRINITY COLLEGE DUBLIN



- The Inclusive Research Network is a joint project of the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.
- The IRN members are:
 - Co-researchers: people with intellectual disabilities doing research;
 - Facilitators: trained researchers;
 - Supporters: people who support the co-researchers.
- This network is for anyone interested in this type of research. For example, people from services, self-advocacy groups, organisations, researchers and community groups.

THE RESEARCH WORKSHOPS

We conducted 3 research workshops between 2008 and 2009.



- We learnt:
 - Basic research knowledge and skills.
 - Research methods.
- We gained some hands-on research experience.
- We explored issues about:
 - Who can do research?
 - Why do we do research?
 - Ethics and consent.

During these workshops co-researchers said that they would be interested in researching:



- Choice about who to live with.
- Freedom to be independent.
- Moving into my own house and independent living.
- Privacy and my rights.
- Alternatives to group housing.

THE NATIONAL SURVEY “WHERE WE LIVE”

The Inclusive Research Network decided to do a study about where people with intellectual disabilities live. We wanted to look at:



- What people like and do not like.
- What supports do people need.
- What people would like to change about where they live.

We decided to do a survey. This was a way to use and transfer the skills learned in the inclusive research workshops.

Developing the Survey

We developed the survey in different steps.



Workshops 1 & 2:

- The co-researchers made suggestions about the survey questions.



After workshops 1 & 2:

- The facilitators developed potential questions and added pictures.
- The co-researchers tried out the questions in Dublin and Galway and gave feedback:
 - Suggested new questions
 - Changed some of the questions:
 - The order to ask them.
 - The wording of questions.
 - The topics.

In workshop 3:

- We all sat in small groups of four and tried out the survey.
- The facilitators asked the co-researchers and supporters again to give feedback.

You can see the final version of the “Where We Live” national survey online at www.fedvol.ie.

Ethics

The project received ethical approval through the Research Ethics Committee at Trinity College Dublin.

The Survey Tools

We developed the survey, the answer booklet, letters of information, consent forms, a checklist and instructions.

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



Q: Own kitchen?

Yes No

Are you able to use the kitchen when you want?

Yes No

Q: Own bathroom?

Yes No

Survey

Answer booklet

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.

WHERE WE LIVE SURVEY CONSENT FORM FOR RESEARCH PARTICIPANTS

The researcher has explained the research to me



I have been able to ask questions about the research



Letters of information

- For survey participants
- For supporters, organisations, and families

Consent forms

- For survey participants
- For supporters



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

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

You can say:

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

Steps to do this research

Step 1

Work with the person who will support you



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

Checklist to make sure people understood the consent form

Instructions

All documents included pictures. We also checked the documents to make sure they were easy to read.

- We used pictures and questions from the “Adults with Learning Difficulties in England” 2003/4 survey with the permission of the authors.
- Other pictures used in the Where We Live survey or in this report were taken from © Photosymbols or taken at the IRN workshops with members’ permission.

How did We Survey People?

We did a training workshop in June of 2009 in Galway.



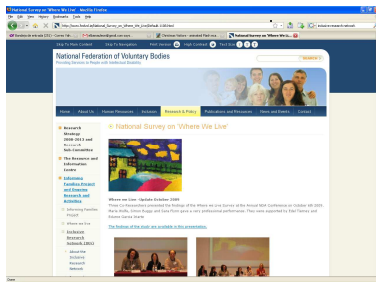
- All co-researchers had a chance to practice with the survey.
- Co-researchers took turns at asking and answering questions.
- Co-researchers had a chance to experience doing the survey and responding to the survey.
- Co-researchers also learnt about sampling different people to take part in the study:
 - Males and females.
 - People of different ages.
 - People who lived in different places (group homes, independent living, with family).

Following this meeting, some CO-RESEARCHERS volunteered to take part in the national study.

To take part in the national study, each co-researcher asked a family member, a staff person, or other people to be their SUPPORTERS to help them to do the survey.

Two FACILITATORS, one from the National Federation of Voluntary Bodies in Galway and one from the National Institute for Intellectual Disability in Dublin helped the co-researchers and supporters over the summer to keep deadlines and offered additional support.

The facilitators provided support to the co-researchers and supporters.



- The facilitators:
 - E-mailed co-researchers and supporters regularly.
 - Called some co-researchers and supporters who did not use e-mail.
 - Developed a website explaining how to do the survey and how to use all the materials.
 - Reminded the co-researchers and supporters to use the website.
 - Also worked as supporters.
- Most of the surveys were done between July and August, but we also allowed for late submissions.

11 Co-researchers did the survey.



- The co-researchers did the survey with people in their own area.
- The co-researchers were based in Galway, Clare, Monasterevin, Roscommon, Dublin, Waterford, Carrick - on - Suir and Cork.
- The role of the supporters was to:
 - Help co-researchers through all the steps.
 - Record the answers.
 - Make sure that each person who responded to the survey:
 - Understood what the study was about.
 - Signed a consent form.

The co-researchers and supporters sent the responses by post to the facilitators during August and September.

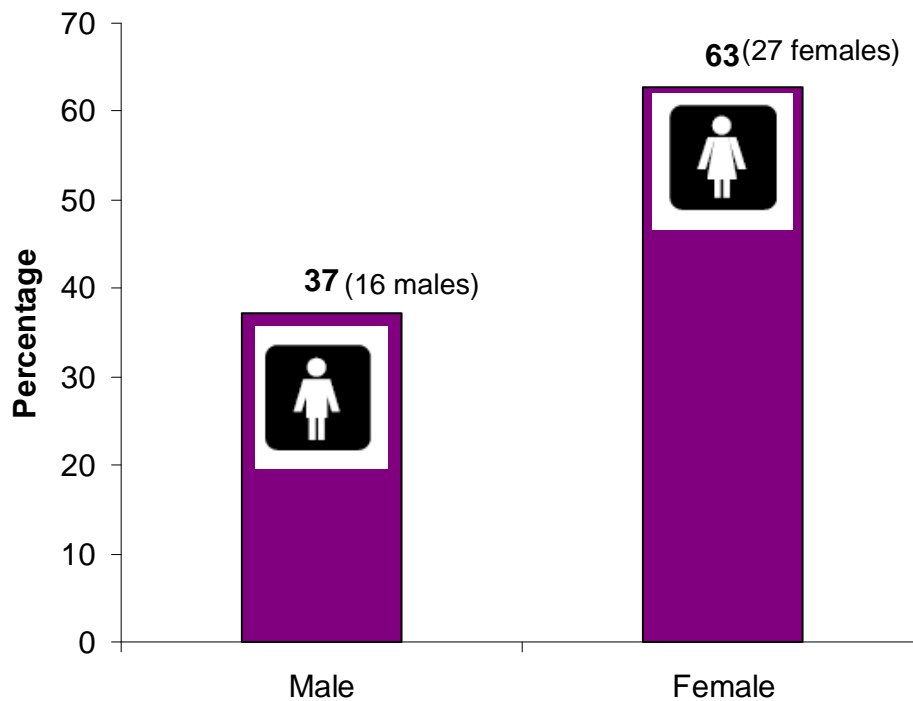


- The facilitators entered the data into a computer file and did statistical analysis.
- The facilitators presented the key findings to a group of co-researchers and supporters at a meeting.
 - The facilitators used a series of bar charts with pictures.
- Seven co-researchers and two supporters attended the meeting where everybody:
 - Discussed the findings.
 - Compared the findings from the study with co-researchers' experiences of doing the survey.
 - The co-researchers discussed the key messages for the government and decision makers in organisations.

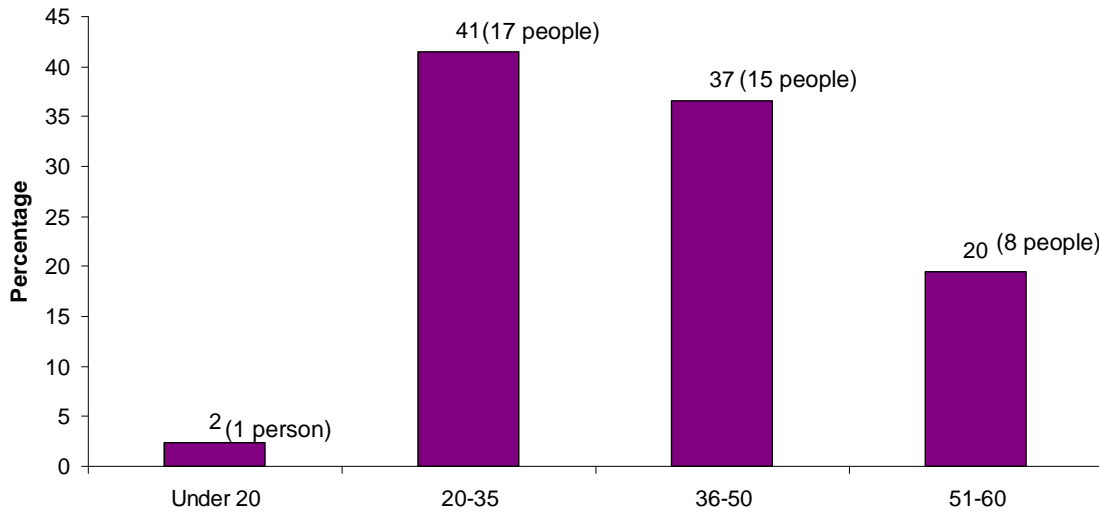
WHAT DID WE FIND OUT?

Co-researchers did 43 surveys around the country.

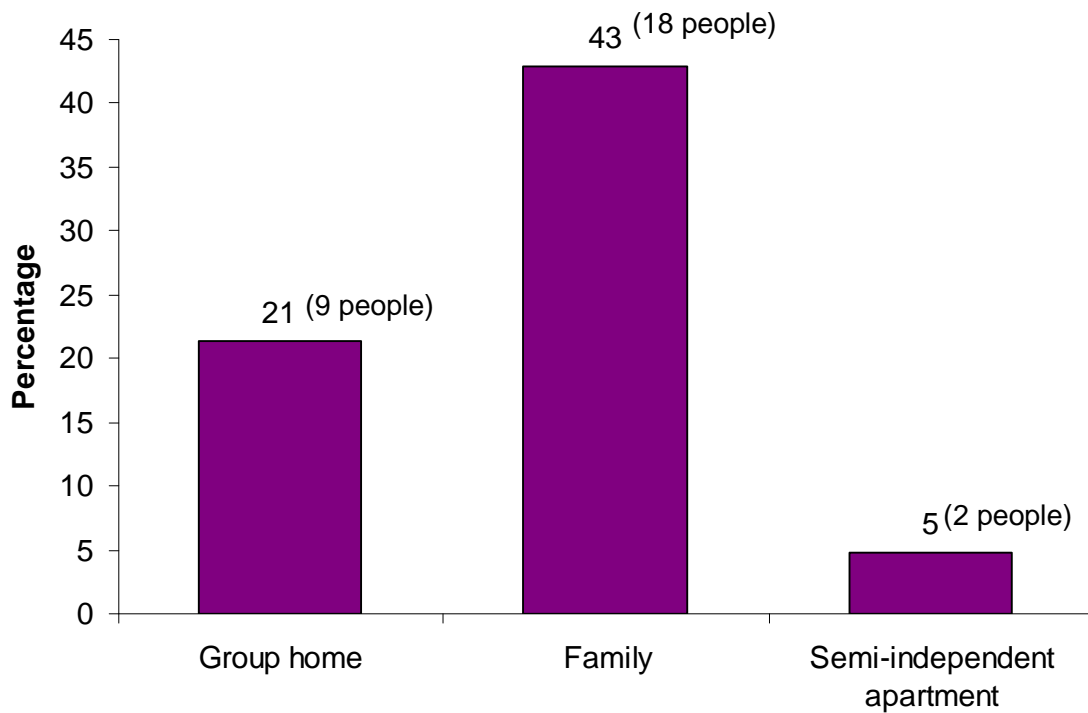
More than half of the people who responded were females and some were men.



Most people were aged between 20 and 35 years, or 36 and 50. Only a few were under 20 years or over 50 years.

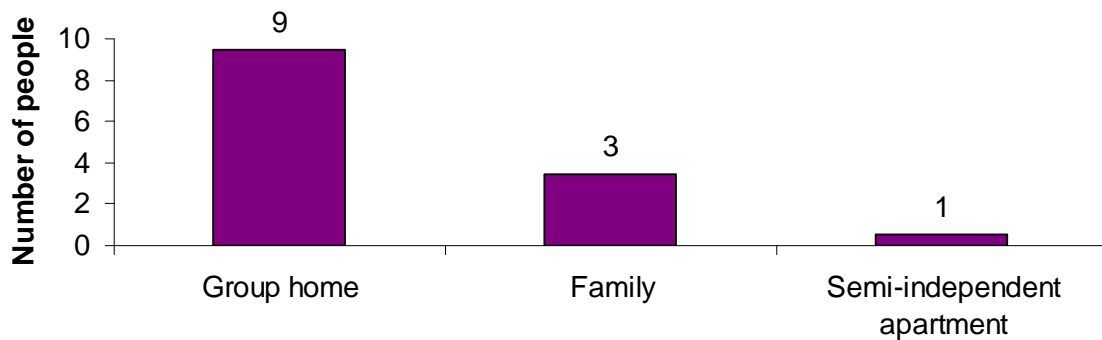


Most people lived with their families, some lived in group homes, and a few in independent living apartments.



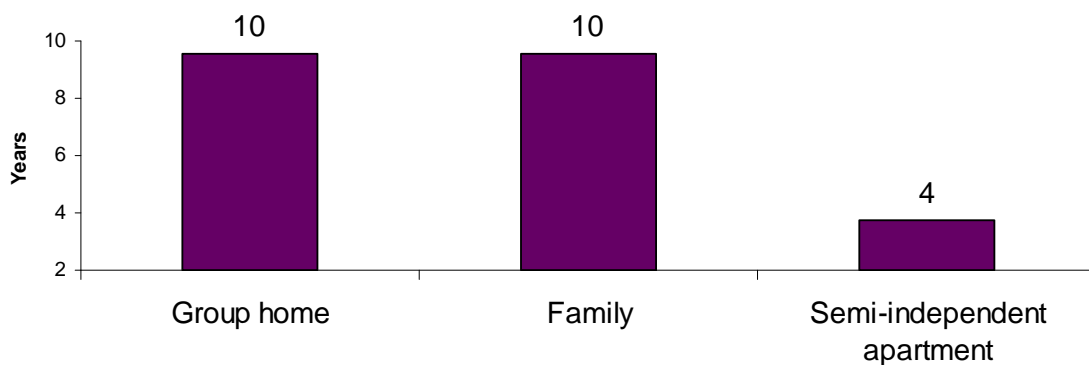
On average

- People who lived in group homes said that they lived with nine people.
- People who lived with their families said that they lived with three people.
- People who lived semi-independently, said that they lived alone or with one other person.

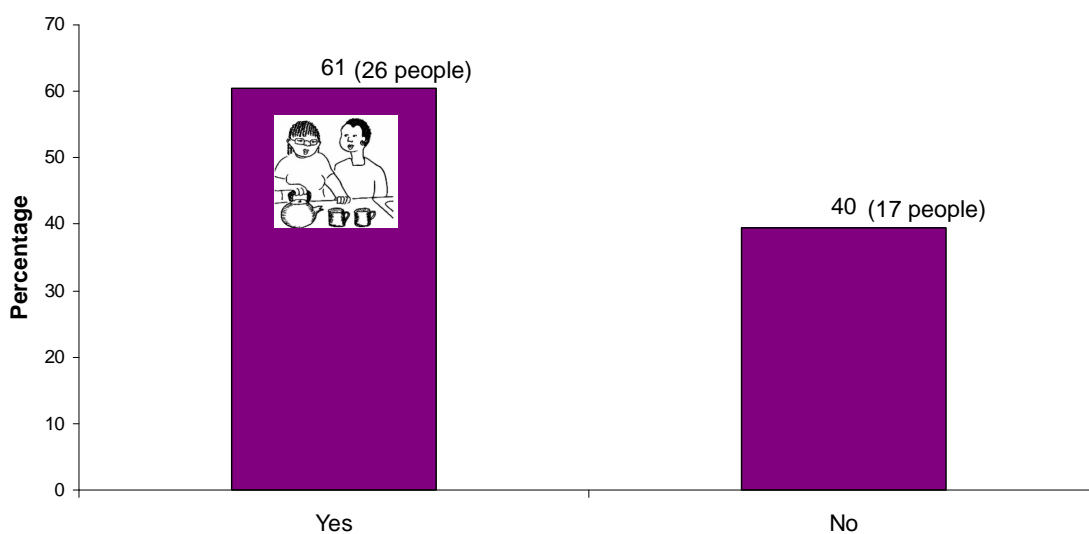


On average

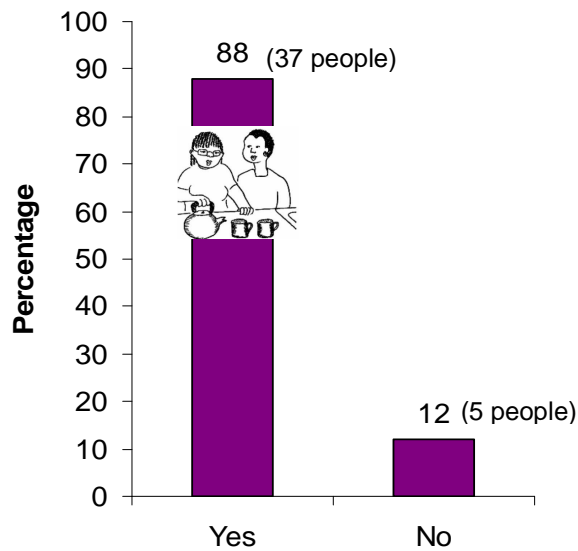
- People who lived in group homes and people who lived with their families said that they had lived there for about 10 years.
- People who lived independently said that they have lived there for only about four years.



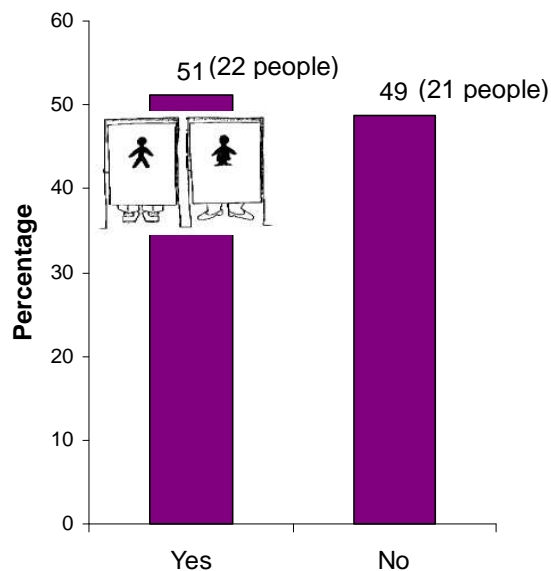
Most of the people said they had their own kitchen.



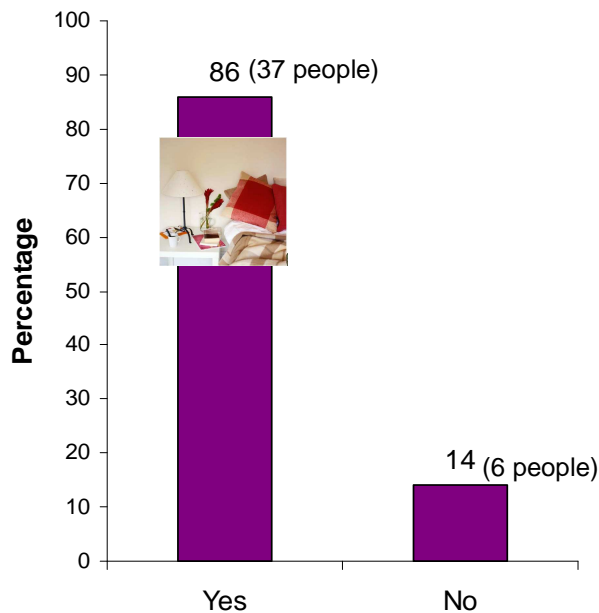
Most people said that they were able to use the kitchen when they wanted.



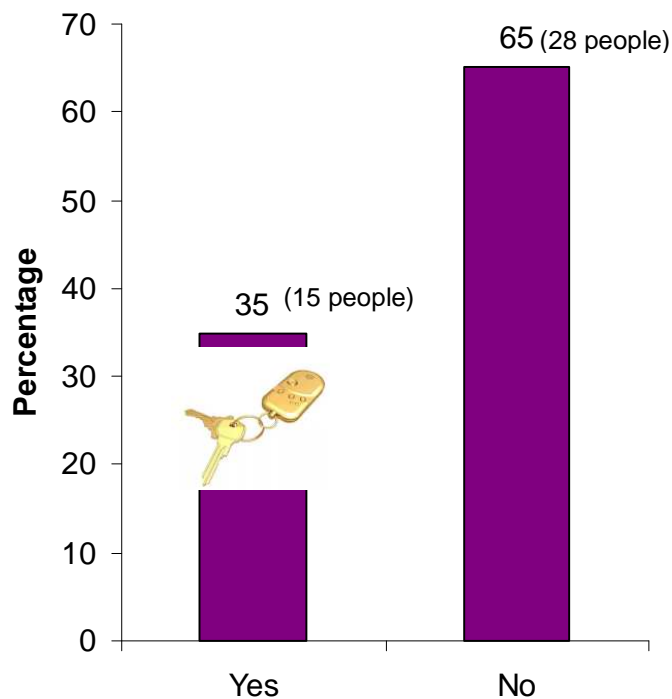
About half of the people said that they had their own bathroom.



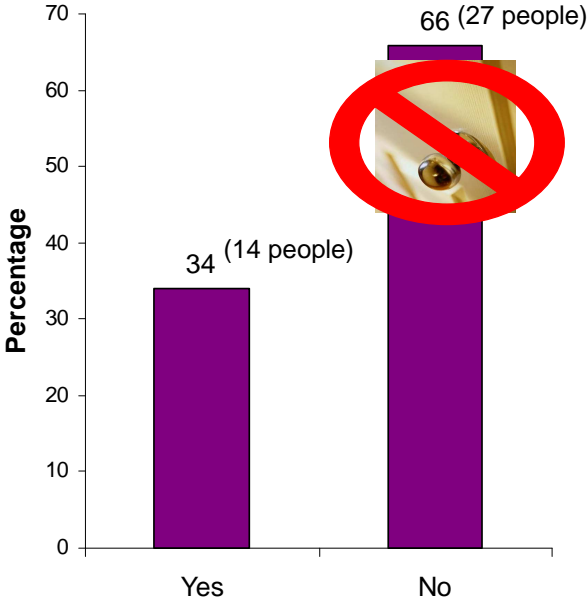
Almost all people said that they had their own bedroom.



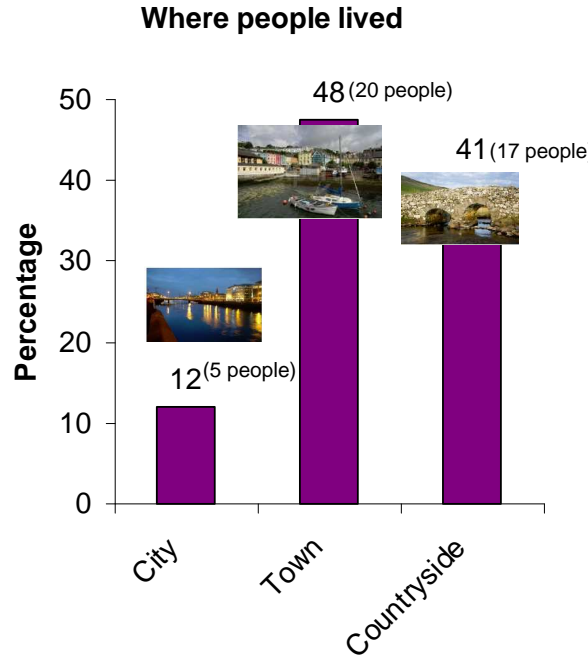
Only some people had a key to their bedroom.



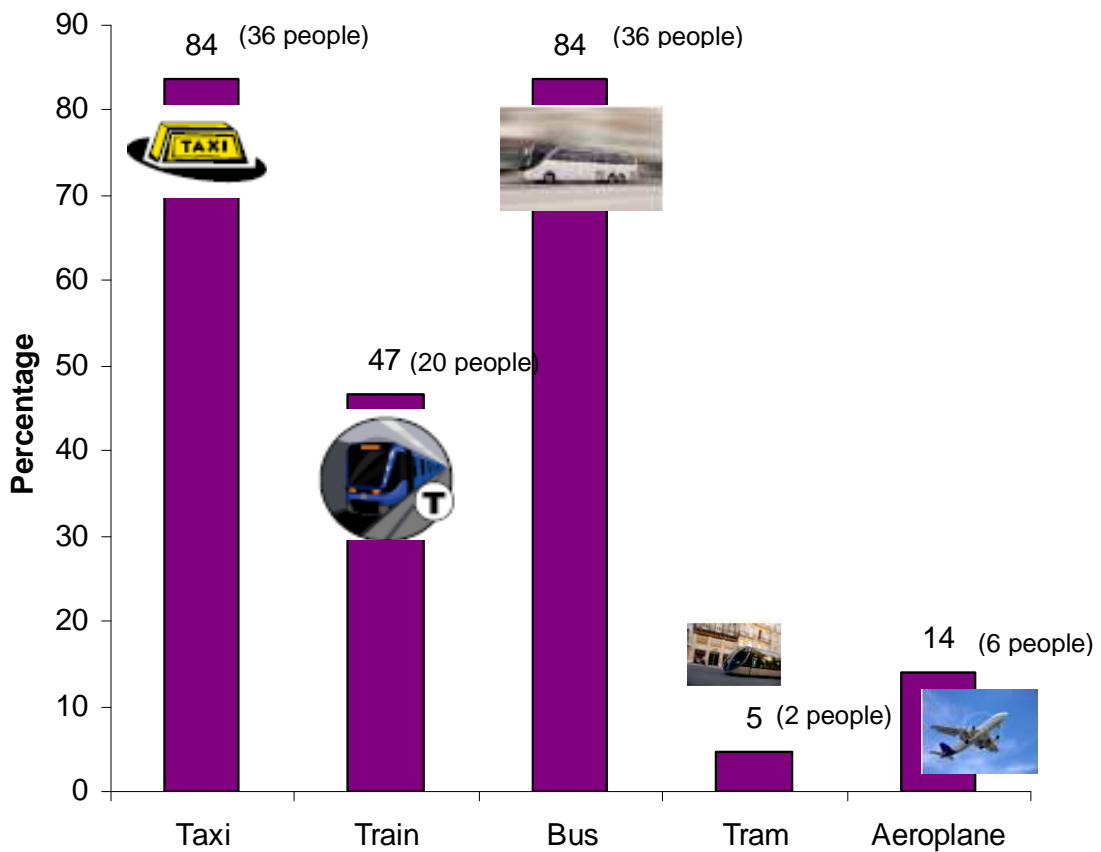
Most people said that other people did not come into their bedroom when they were not there.



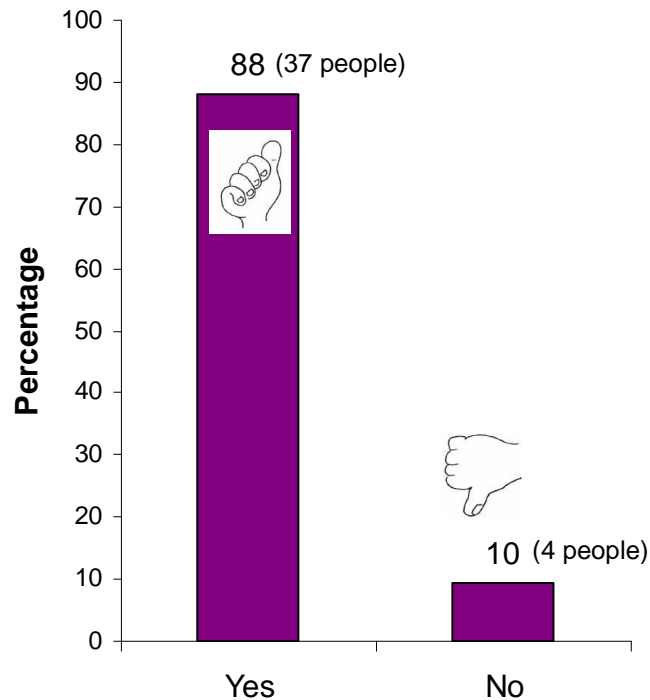
A lot of people lived in a town, many in the countryside and only a few in the city.



Most people had access to taxis and buses. Many had access to trains. Only a few had access to aeroplanes and trams.



In general, most people liked where they lived.



They said that they liked where they lived when:

- It was a nice house or flat.

It is a nice and safe place.

I like the garden, it's nice and big...

- It was near things that were important to them.

I am happy where I am because it's my home, I know my neighbours, Granny lives beside me and the church is close. I like my family.

Because it is near work and town and a shop around the corner. Nobody giving out to me...

- They could be independent.

I like it because I can help around the house. I can walk to work, staff are nice to me.

Independent, come and go as I want...

- They liked the people they lived with.

Plenty of friends, happy with staff and house mate and area.

More space, see lots of nature; like the people I live with and mom and dad support me.

They said that they didn't like where they lived when:

- There were no people around or no things to do.

Because there are a lot of old people, there are no people of my own age. It's kind of boring.

Too quiet, I have no friends there. There is not much to do or places to go.

- They wanted to have more independence.

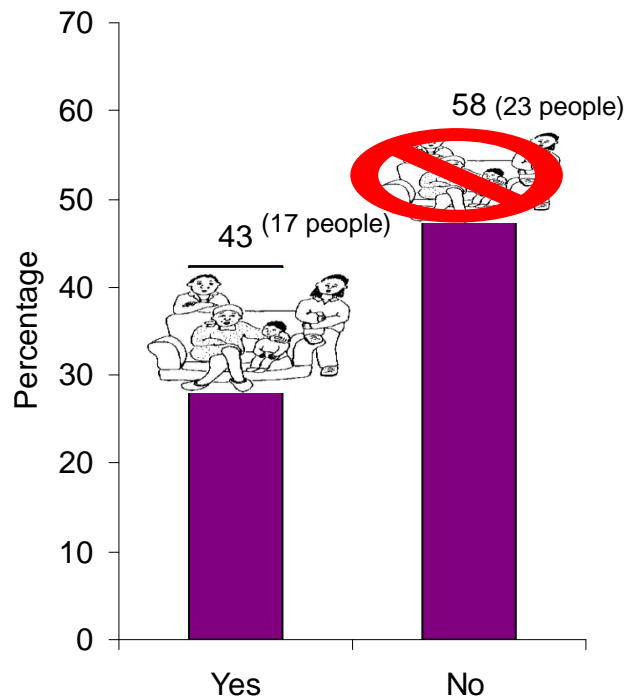
I love the countryside but want to move away from parents. I would like to live on my own independently. I want to be completely independent.

When we compared people living in group homes and people living with their families we found that:

- People living in group homes also liked where they lived because of the accessibility of their homes.

Also good because all deaf signs.

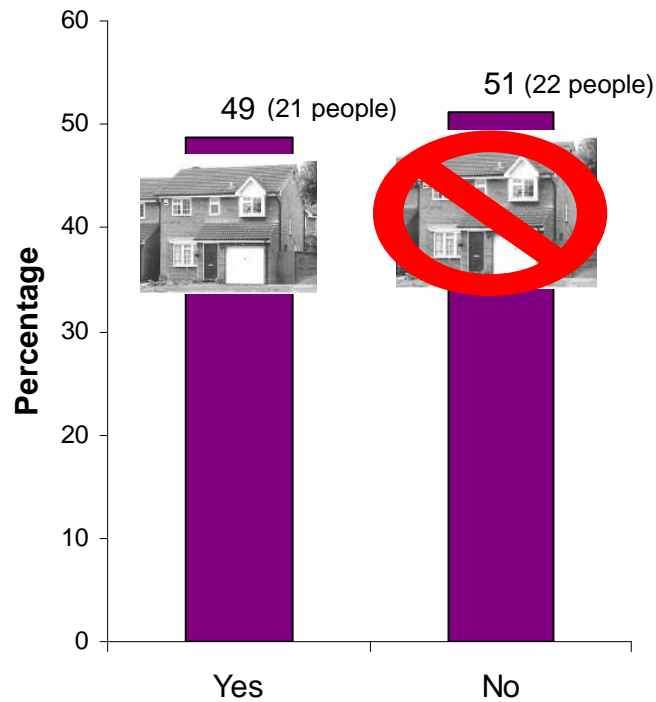
More than half of the people did not choose who they live with.



Only half of the people chose where they lived.



About half of the people said that they would change things about their homes.



The things they would change about their homes were:

- Having their own homes and rooms.

A room of my own.

I would like to live in my own house.

- Choosing the people they lived with.

To move in with people and to be able to choose the people if possible.

- Changing room or house.

A bigger room and the colour.

I'd like a new house. I would like to move, live with girls.

- Having more responsible landlords/landladies and more respectful neighbours.

Landlord should look after the house more.

The neighbours are a problem and the landlady gives out sometimes and watches my every move.

- A few people wanted to do more around their home and have their houses kept better.

Get my telly working properly, better good, be mobile as much as I can, like less people.

It's too quiet. I would like to do more things.

When we compared people living in group homes and people living with their families, we found that:

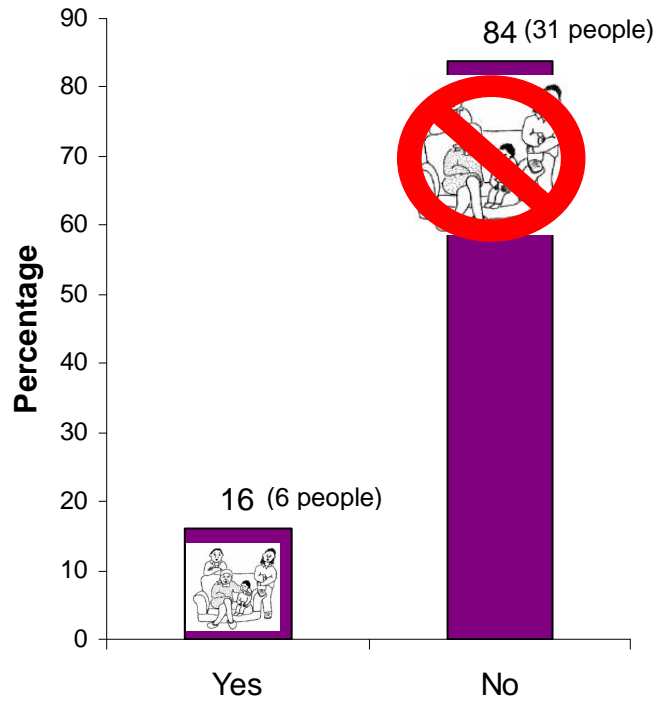
- People living in group homes said that sometimes they did not know the staff.

I like staff at the moment but sometimes relief staff come and I don't know them.

- People living with their families wanted to have independence to do more things and have more trust from their parents to go out in the community.

I don't want to be watched by my parents. I want more independence – to be allowed out more. I want more trust from my parents. I wish my parents were not afraid of others in the community hurting me.

Only a few said that they would change something about the people they live with.



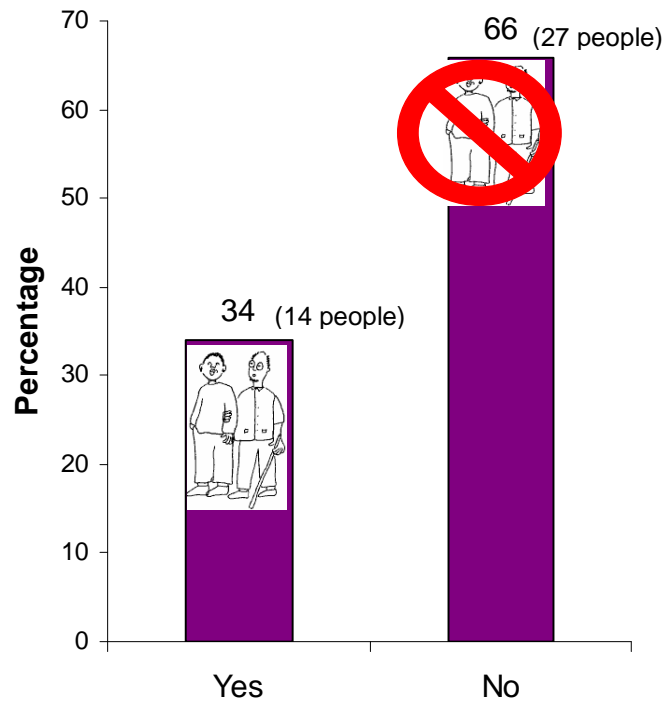
They things they would change about the people they lived with were:

- Having more choice about who they live with and the independence they had.

I would like to be more independent but the people at home are so hard to please. I need staff around all the time to keep mom happy when I am going somewhere. I would like to live alone.

It might be nice down the line to get a house mate but it would only be good if I owned the house and could choose who I live with.

Some people said that they would change things about the support they get.



They said they would change things about the support they got including:

- More support to go out.

I would like to be able to go out more in the evening with friends.

Support in going out and making friends - don't get much support.

- Different people supporting them.

I'd like to see different people supporting me.

- More support to work.

Support with work in my community.

- More support to look after the house.

When I move I would like a small house with my friends. I would need help with looking after it.

- More independence.

Less support and to be more independent.

Was there anything else that people wanted to say about where they lived?

- Some people said they liked where they lived.

Good relationship with parents and siblings... I love living on farm and with the animals. Freedom on the farm is great. I like not being forced to do things in a group like those in a group home. I was asked to join a group home and said 'no I didn't want to'. I would like to live in a house independently but not in a group home.

- Some people said they would like things changed where they lived.

I'd like to be more safer. There are a lot of gangs, young people, drunk, very loud.

In the future I'd like to move out to "K" with my boyfriend.

- Some people said they lived independently.

Nice area, nice distance from town. Quiet enough because it's a little bit out of the town. I have moved from family to semi independent housing where I lived with two people to move into my own county council house on my own.

This took 2 and half years. Showing the county council the problems with the semi independent housing it managed to speed up the process. The support person wrote a letter to the county council to say I had the ability to live independently. I got to furnish the house so I got to put the stamp on the place myself. I was supported by my family to do this and I am very happy that I got to do this myself and not have someone else doing this.

KEY MESSAGES FROM THE IRN MEMBERS

A group of co-researchers talked about what the findings meant to them. They concluded that:



- There is lack of services for individuals to seek independent living.
- More control over funding is needed for people to have choices about where they live and who they live with.
- Individual needs have to be considered and supports need to be in place so that it is less frightening for people to be independent.
- There are few choices for people to decide where they live and who they live with.
- Attitudes should change for families to allow their family member to be more independent.



- There are not enough opportunities for peoples' voices to be heard.

CHALLENGES

We found some challenges while conducting this research.



- **Ethical approval**
Some organisations required the researchers to apply for ethical approval within each organisation.



- **Support to work out of the organisation**
Supporters and co-researchers found it difficult to get to do the survey after the workshop activities.



- **Contact with co-researchers**

It was difficult to keep in touch with some IRN co-researchers through emailing. Often communication depended on the support person getting the communication and passing it onto the co-researcher.



- **Making documents easy to read**

It was difficult to make easy to read documents for everyone. The co-researchers had different skills and the organisation of making accessible materials for everyone has many rounds of feedback.



- **Holiday time**

The co-researchers had difficulty finding support. We did the survey during the summer and many supporters were on holidays. Some organisations were also closed.



- **Co- researchers' participation**

Most of the co-researchers were members of Advocacy services and it was difficult for co-researchers that were not in self-advocacy groups to do the survey.

PRESENTATION OF RESULTS

Members of the Inclusive Research Network Simon Buggy, Sarah Flynn, and Marie Wolfe presented the findings of the “Where We Live” research project at the 2009 National Disability Authority Conference in Dublin. They were supported there by Pauline O’Meara and Michael Freiberg.



This report was prepared by



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