



**Inclusive
Research
Network**

Our Homes

Home and Independence Project

Inclusive Research Network



UNIVERSITY of LIMERICK
OILScoil LUIMNIGH



TRINITY COLLEGE DUBLIN
COLÁISTE NA TRÍONÓIDE















NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

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Key Points

The IRN



The IRN is a group of researchers who do research that is important to people with intellectual disabilities in Ireland.

Our Homes Project



This book is about a research project we did to learn what it was like for people with intellectual disabilities in Ireland to move from one home to another.

How did we find out about people's stories



Co-researchers with intellectual disabilities and their supporters looked for people who:

- had moved recently to another home or
- wanted to move to a new home

They asked them if they wanted to take part in the study and to do an interview.

The people we talked to



- We did interviews with 35 people with intellectual disabilities from Ireland
 - 19 men and 16 women
- They were, on average, 47 years of age
- Most had been to school, about half to special schools and about half to regular schools
- More than half were working, most of them in paid employment and a few were not paid for their jobs.

Finding connections



We wrote word by word what people told us. We worked together to:

- Do summaries of what people had told us
- See how the stories linked up and where they were different.

What we found out

Where people lived in the past



- People had lived in a number of places: institutions, group homes and the family home.

What they liked about the place



- Being involved in everyday tasks
- Living with their housemates
- Having privacy
- Getting experience to live independently
- Some activities they used to do
- Not having to pay rent.

What they did not like



- Lack of privacy
- Feeling lonely
- The cost of transport
- Separation of staff and residents to eat
- Having problems with other people with whom they lived and with staff
- Abuse by staff
- Not having enough freedom and having too many rules
- Cost of living and lack of safety.

What was it like for people to move home

What choices did people make?

Choices about moving out

- 18 people said they had chosen:
 - to move out and
 - the house where they lived
- 11 people had no choice about moving out
- Other people did not answer the question.



Choices about the house

The reasons people chose their house included:

- Location
- Close to transport, shops, family and work
- Good design
- Space for company
- Being wheelchair accessible
- More independence
- Lower cost.

What steps did people take to move?

People took different steps:

- Looking at houses
- Asking for help from service providers
- Using independent living services
- Going to meetings
- Developing independent living skills
- Getting legal support and support with practical things like reading.





How long did people wait to move?

- Some people moved right away because of safety issues
- Some people waited a long time, up to 20 years.



Who helped with the move?

People got help from:

- The council
- Staff
- Families.

Where people lived in 2014



- 26 people lived in a supported flat or house
- 4 people lived with their family
- 4 people lived in a group home
- 1 person lived in a home with 10 or more people.

What they liked about where they lived in 2014

29 people said that where they lived in 2014 was better than where they had lived before:

- Closer to friends
- More control over the house
- Having more company
- Closer to shops and restaurants
- Better design and accessibility
- Better support
- Getting to know the neighbours
- Safer area.



What support people had where they lived in 2014



19 people said they chose their supporters. Most participants had at least one person who supported them with:

- Managing the house
- Personal care
- Getting out in the community
- Reading, writing and using the computer
- Emotional issues
- Meeting their needs and wishes.

People were looking for paid supporters who were



- Friendly and with a sense of humour
- Respectful, agreeable and punctual
- Good listeners
- Good planners
- Supportive of people getting out when they want
- Helpful with decision making.

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Credits

There are many people who made this research possible. We thank all of them for their time and support:

- 35 people who shared their stories of moving homes with us.
- Supporters who helped the people we interviewed to speak up for themselves.
- Organisations who let us do interviews at their sites.
- Organisations supporting the IRN co-researchers, for giving IRN supporters the time to come to meetings and to assist IRN co-researchers in being part of the whole research process:
Brothers of Charity (Galway, Clare, Roscommon, Limerick, South East), CoAction, Dara Residential, Daughters of Charity and Rehab Care, Ability West and St. Cronans.
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- The Inclusive Research Network sponsors: Trinity College Dublin, the National Federation of Voluntary Bodies, and the University of Limerick.

Chapter 1: Opening

What is the IRN?



The IRN is a group of researchers who do research that is important to people with intellectual disabilities in Ireland.

What is this book about?



This book is about the stories of 35 people with intellectual disabilities in Ireland moving homes. It is called 'Our Homes'.

What is the context?



Time to Move on from Congregated Settings
A Strategy for Community Inclusion



House by Shane Loneran
from Moorehaven Centre in Tipperary Town

Where we Live

A National Study done by
Members of the Inclusive Research Network



CONVENTION on the RIGHTS of
PERSONS with DISABILITIES

- In 2008 there were 4,000 people with intellectual disabilities living in institutions (with 10 or more people) in Ireland
- When people move out of the institutions, many go to group homes
- Few people move to independent living (to a place they choose and with the people they choose)
- Support to people moving to new accommodation and to live independently is very important
- The United Nations Convention on the Rights of Persons with Disabilities (in this report, we call it the Convention) says that people have the right to choose:
 - Where they live
 - Who they live with
- Ireland has not ratified this Convention.



Why did we do this research?



We chose to do this research because we wanted to:

- Give people a chance to tell their stories about moving homes
- Find out where people used to live in the past
- Find out what steps people took to move from one home to another
- Know where people lived in 2014
- Learn about what support people:
 - had to move homes
 - had where they lived in 2014.

Chapter 2: What steps did the IRN take to do this project?

In 2012



Research theme

We started our project in Spring 2012 when we talked about research ideas. The research theme we agreed on was “**home and independence.**”



Research methods

In September 2012, we decided to use **interviews** as our way of finding out what people with intellectual disabilities thought about moving from one home to another.

We wrote our first draft interview questions.

Literature review

In November 2012 we looked at what other researchers had written about this topic.



We did not want to repeat what others were doing!

We looked at various reports:

- HSE (2011). Time to move on from congregated settings.
- IRN (2009). Where we live.
- HIQA (2009). National Quality standards: residential services for people with disabilities.
- Genio (2011). Evaluation of individualised supports.





Check with research experts

In Spring 2013, we talked with researchers who were also doing work on this topic in Ireland:

- Roy McConkey
- Christine Linehan
- Nancy Salmon

We then wrote our ideas for a unique project on moving houses.



Ethical approval

We received ethics approval from Trinity College Dublin to do our project.

*We had to apply later in the project for ethical approval from two service provider organisations so IRN co-researchers could interview people with intellectual disabilities in these services.

Pilot the interview

At our Autumn 2013 meeting, we tested our draft interview guide. We asked people about

- their school and work experience
- where they lived before
- where they lived in 2014
- how they moved to their new home
- the supports they had to make the move
- things they liked where they lived.

We changed the wording of some questions, deleted questions and added new questions based on their answers. In the end, we agreed on 50 questions for the interview.





Handbook

We made a handbook for co-researchers that included:

- steps to do the interviews
- how to tell people about the project
- information sheets about the project
- consent forms for people to sign if they wanted to be interviewed
- interview questions
- where to send the audio file when the interview was done.



Video

We made a video clip to help our co-researchers and their supporters learn how to do the interview.



Training workshops

We had two training workshops at the University of Limerick and at Trinity College Dublin to practise:

- using the audio recorder and
- doing interviews.



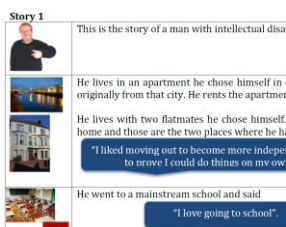
Interviews

26 co-researchers did the interviews and listened to people's stories:

- Co-researchers used the handbook and video to practise
- They were supported by 13 supporters.
- Most people who took part in the study agreed to have the interview audio-recorded. We took notes if people didn't want to have their interviews recorded.

Analysis

- Co-researchers sent the recordings of the interviews to the academic researchers and assistants
- Three people wrote word by word the 35 stories
- We used an excel file to type in the interviews
- We did the following to make sense of the data:
 - We counted the number of responses people gave to questions such as “How many people do you live with?”
 - We wrote as an easy to read summary the stories of the 35 people and agreed on the main points each person made
 - You can read these stories on the website for the National Federation of Voluntary Bodies.



In 2015



Write this book

- We agreed on the key points from the stories and the responses to the interview questions
- We wrote them down in this book
- We chose the quotes that best suited the main points
- We chose the pictures that best showed the main points
- We read out loud sections and made changes so it was easier to read.

Note to Readers

To make this book easier to read the quotes from participants are included in colored boxes in the report.

You will see the use of **red font** in some of the quotes. This means that there was a word we had to change to protect the person's privacy. For example, if someone said the name of a support person we put in **support staff** instead. If they talked about a certain place, we put in **town** instead.

Sometimes when we talk, we leave out words. To make sure the meaning of quotes is clear we also used **red font** when we put in a missing word.

To protect the privacy of people we talked to we sometimes changed the gender of the person in quotes. This means that at times we replaced 'him' with 'her' or used 'she' instead of 'he' in the text.

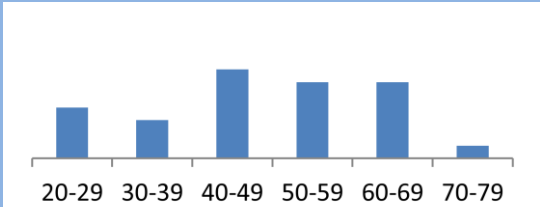
Some people told us their age, while others chose not to give their age. For this reason some quotes do not have ages beside them.

Chapter 3: What were the people we talked to like?

Gender



Age



School



Work

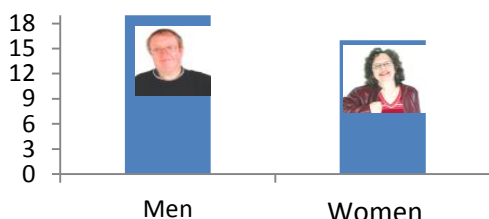


In this section, we talk about what people we interviewed were like



- How many women and men we talked to
- How old they were
- If they had been to school
- If they were working.

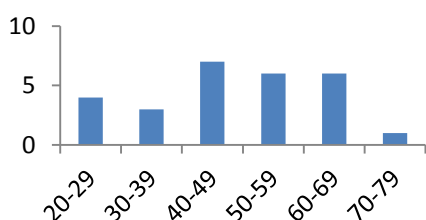
Gender



We talked to 35 people with intellectual disabilities:

- 19 men
- 16 women.

Age

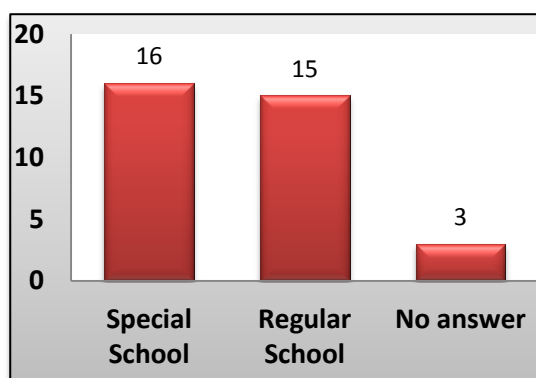


Their average age was 47 years.

The youngest person we talked to was 22 years old and the oldest person we talked to was 77 years old.

7 people did not tell us their age.

School

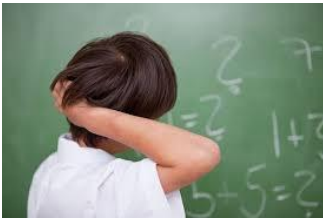


- 34 people went to school
 - 16 people went to a special school
 - 15 people said they went to a regular school
 - 3 people did not say what type of school they had attended.
- 1 person did not answer the question “did you go to school?”

Experiences of going to school



“I was in a special school but stopped going because I was working.”



Comments about school varied from good to bad. A person in her 60s said,

“I learnt nothing 51 years ago. I didn't learn much. I could read and write but was no good with sums. Not a nice experience. I left **at** age 14.”



Others said they enjoyed their time in school. For example, a 41 year old stated

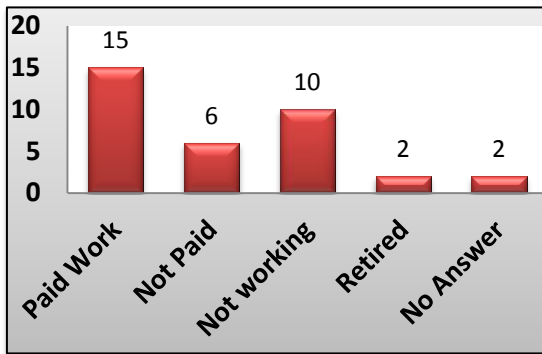
“We went horse riding, swimming, playing outside with friends; sat on bike; walking.”



Going to school was a long time ago and people said they could not remember. A 52 year old said,

“Well I was 6 and a half until the age of... I can't remember... it was a long time ago.”

Work



21 people said they were working:

- 15 were in paid employment
- 6 were not paid for their work

12 people said they were not working:

- 2 people were retired
- 2 people did not answer the question about work.



Jobs people had

People said they worked in:

- Horticulture
- Charity shops
- Retail
- Craft
- Domestic work
- Cafes
- Clothing store
- Fast food
- Online employment agency
- FAS
- Picture framing.



Work experiences



A 25 year old proudly said,
“I work in McDonalds.”



Another person in their mid-20s noted,
“I work two days a week in the post room
and doing the stock shelves.”



A person in their 50s talked about having a
few jobs.

“I got a couple of jobs on the go. I work in
a charity shop in town and I work at an
online employment agency.”



A 65 year old man said

“I'm retired, but still go to the garden each
day. I set the table for the lunch, tidy up. I
do the washing up. I used to work in the
kitchen a long time ago and washed the
floors and got paid.”



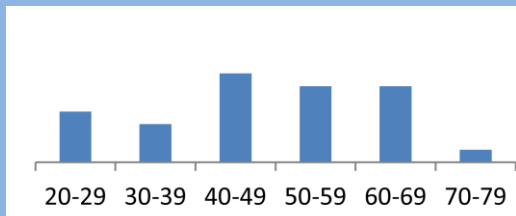
Summary Points

Gender



- About half of the people we talked to were men and about half of them were women.

Age



- People were, on average, 47 years old.

School



- Most people had been to school
- About half attended a special school
- About half attended a regular school.

Work



- Almost half of all the people we interviewed were in paid work. The others were not at work and two had retired.

Chapter 4: Where did people live in the past?

What places



How many places



What they liked about the places



What they did not like about the places



In this chapter, we talk about the places where people lived in the past (before we did this study)



- How many places had people lived in before?
- Where did they live before?
- What did they like about the places where they lived?
- What did they not like about the places where they lived?

We asked people how many places they had lived in before

When asked how many places people had lived in before, the most places someone lived in was 7.

- 17 people said they had lived with 10 or more people before
- 14 people said they had lived in their family home before
- 13 said they had lived in group homes before
- 2 people said they had lived with flatmates
- 2 people said they had lived alone or with partners
- 3 people said they had only lived in one place
- 2 people did not respond to this question.



What people said about the places where they lived before

People had moved from one place to another. Someone in his 70s told us he moved a few times



“Four **places** I used to live. We were in a house in **town**. Then we moved to **another place in same town**. Then an apartment.”

People said they had lived with various members of their family.



“I was born in my grandmother’s house. There were no hospitals at that time. I lived with my sister. And then here. I lived with my family until my parents died.”

One person said that moving from one place to another was difficult. A 31 year old man told us:



“I **lived at** home first, then due to family conflict, I moved to **a** group home. **The** family instigated the move supported by day and residential services. I **put myself** on **the** council waiting list... I was removed from **the** list because I lived in **a** group home - but reapplied when I moved to semi-independent living. Now I **live in a** two bedroomed terraced bungalow with front and back **garden** – **a** bathroom, **a** kitchen, **and a** living room combined.”

What people thought was good about where they lived before



People who lived at their family home said:

- They had been close to family members and often talked with them
- They had good memories of going places with family.

Being involved in everyday tasks

When living at home with family, people recalled doing daily tasks. One 41 year old man said,



“I helped around the house, helping my father.”

Living with housemates

Others said they enjoyed living with their housemates. A woman aged 65 said,



“I liked the people.”

Privacy

Other people said they liked having privacy. A 25 year old woman explained,



“I loved having my own bedroom, my own space.”

Getting experience to live independently

Some people talked about how they learned to live independently in the place they lived before. A woman in her mid-20s said,



“I got more experience of doing my own washing and cooking. I had my own key to come and go.”

Enjoying the activities

People talked about enjoying the activities they used to do. One man in his 50s recalled,



“Well we go for spins, go for trips... Get out more with staff, went to the pictures, I like to go for spins, great times.”

Not having to pay rent

Not having to pay rent while living with family was seen by some as good. One person in his mid-40s said,



“When I moved into private accommodation I had to pay rent all the time. So you were laying out a lot of money.”

Things people said were not good about where they used to live

Lack of privacy

A woman in her 60s gave the example of a landlord who did not respect her privacy.



“One morning **the landlady** went out and gave the key of the house to a man to mix concrete in her kitchen. When I came back from work I saw where the man had mixed concrete in the kitchen. That’s no lie.”

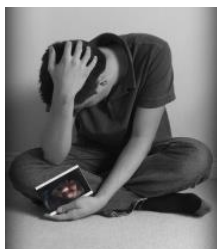
Another woman in her mid-60s told this story.



“The landlady, she was right mean to me. Didn’t give me any heating, she was nicking stuff from me. When I went out to work in the morning she came into my apartment. I had no privacy. It was very unfair so I had to lock everything up. I had to get the press locked. She would take my toilet roll and things. Then my gas cylinder was missing. She blamed the travellers and the people beside me. One morning I went to dry my hair (...). No hairdryer! she took it without asking. That went on. I went to work with my hair wet. I could write a book on it all.”

Feeling lonely

Others said they were lonely before they moved. One woman in her mid-40s said,



“I was very lonely before I moved.”

The cost of transport and lack of transport to attend recreational sport



“If I had to go to soccer it cost me 5 euros. There was no public transport or staff support for soccer training. Now staff pick me up.”

Staff and residents ate separately

A person who used to live in a group home told us,



“There was no room at the table for staff to eat together with residents.”

Problems with others they lived with



Some people talked about problems with others they lived with or with staff.

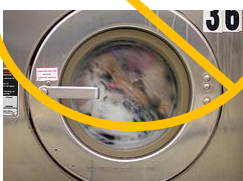
Abuse by staff

A woman in her late 70s told a very difficult story about abuse by staff in a place she used to live.



“We didn’t like **that place** because there was a **staff person** there. He was one of the **staff members** who had a stick down in the bathroom. We all had to have baths before the staff would go off duty. They had to keep the bathroom locked. He had a stick with a hook on the top of it. He had done it to one **of my housemates**. I escaped that thank God. The Garda found out that was going on and it stopped.”

Not having enough freedom and having too many rules



One man in his 60s who lived in a group home explained,

“**I was** not allowed to do my own cooking, wash my clothes. Staff did it all for me. Staff do everything.”

Another man in his late 50s who also lived in a group home said,

“You could not go out when you wanted.”



A 62 year old man, also thinking back to his life in a group home agreed when he told us,

“I could not go out to town on my own, big groups went everywhere together. Staff controlled money. I can pay for my lunch now.”

Cost and poor fire safety



“Not a lot to do and not a lot of freedom and landlord not great; too expensive and fire safety below standard.”

Summary Points

What places



- Most people had lived in a number of places before, institutions, group homes and in their family homes.

How many places



- The most places someone had lived in was 7.

What they liked about the places



- People liked being involved in everyday tasks, living with housemates, having privacy, getting experience to live independently, enjoying the social activities, and not having to pay rent.

What they did not like about the places



- People did not like the lack of privacy, feeling lonely, the cost of transport, the separation between staff and residents, problems with others they lived with, abuse by staff, not having enough freedom, cost, and poor safety

Chapter 5: How was it to move homes?

Whose idea was it to move?



Did people have a choice about moving and where?



What steps did people take to move?



How long did people wait to move?



Who helped with the move?



In this chapter, we present the details about moving homes



- Whose idea was it to move?
- Did people have a choice about:
 - moving?
 - where to move?
- What steps did people take to move?
- How long did people wait to move?
- Who did help with the move?

Whose idea was it to move?



A person in their late 70s told us,

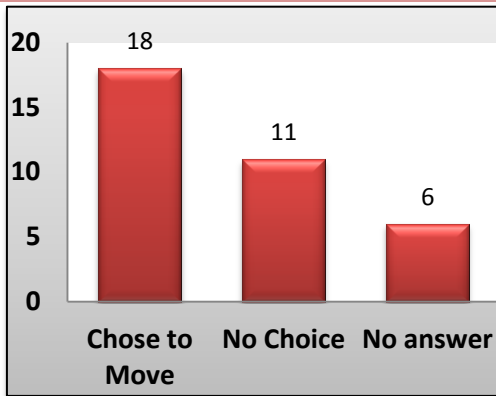
“I don’t know. No - my father and mother got a paper and there was something on the paper about the **name of service organisation**. It was not my idea to move.”

Only 9 people answered this question:

- 4 people said it was their own idea
- 4 people said that it was staff or family who made the decision to move
 - One person said it was necessary to move because fire safety was not up to standard
- One person named the place they lived before and the place they lived in when we talked to them, but didn’t say whose idea it was to move.

A 41 year old said,
“It was my own idea to move.”

Did people have a choice about moving?



We asked people if they chose to move:

- 18 participants said they chose to move
- 11 people had no choice
- 6 people did not answer the question.

People who chose to move out said



A 32 year old man told us, "I did have a choice about moving out when I was becoming 18 it was my dream and ambition to live independently, well, as I got older I always wanted to be independent but I had to be patient, I had to learn about paying the gas and electricity bills, they were the things I couldn't ignore."



A man who moved into a rented place of his own said, "I had a choice to move out. I was speaking up for myself."



A woman in her mid-20s who moved to a flat with friends noted, "I thought it was best for me to move out because I had to learn how to do things myself and not rely on others to do things for me."

Some people did not choose to move out

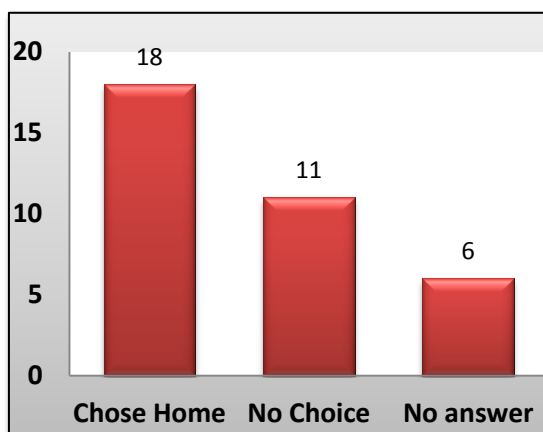


For example, a woman who lived in a group home before moving into her shared apartment said,
“I was told I was moving. I had no choice.”



Another person recalled,
“I was told I had to move because of fire safety problems.”

Did people have a choice about where to move?



We asked people if they had a choice about where to move:

- 18 people chose where to move
- 11 did not choose where to move
- 6 people did not answer.

We also asked people if they saw the house before they moved in:

- 30 people saw the house before they moved in
- 3 people did not see the house
- 2 people gave no answer.

The reasons people gave to move were

Location



“I feel in love with **this town** because I am from here.”

A woman in her 50s told us, “It has a good location in the community.”

Close to transport, shops, family and work



A 30 year old woman said she liked where she moved.

“Because it's near bus routes, trains, shops, family and my training centre.”



A man in his early 40s told us he liked his home,

“Because it was a great place and I can get plenty of work and do a few jobs for people.”

Design or layout of the house



“I prefer a house with one room. There was a big house with an awful lot of rooms. That is why I wanted to pick a small house for myself.”

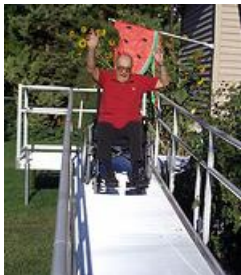
Space for company



X 2

A 46 year old man said,
“It is a 2 bed **house** so I can have people stay with me if I want. Will you come visit me?”

Wheelchair access



A 30 year old woman offered details about her home.
“It's community supported independent living. We pay rent. It's a bigger apartment on the second floor. We both like living there. It also has wheelchair access.”

Independence



A 41 year old man said,
“It is great I can do anything I want and go places and meet people.”

Cost



A few people said their new home cost less. For example a man in his 40s said he liked his new place, “Because it was cheaper rent.”

Regret

A woman used to live in a rented house with her sisters before moving into a group home. She wanted to move at first and then regretted it.



“Yes I did want to move for a while and now I want to move again, back to my own house.”

Steps people took to make the move to a new home

Looking at houses and asking for help from service providers



A man in his late 40s told us,
“I started looking at houses in a neighbourly village up the road from me. And I approached **service provider organisation** to purchase the house.”

Another person in her mid-60s said,
“The support was very good. Before I moved I was shown the house and it was very different to the one I shared.”

Using independent living services



One person in their mid-20s explained,
“I used to live with my aunty and my mam was talking to my friend’s mam and she was involved with independent living and I wanted to get involved.”

Going to meetings to plan the move



A 42 year old told us,
“I met with **day services**. They fought for me to have Independent living.”

Developing independent living skills for managing a home



Another 30 year old explained,
“We did courses on independent living, budgeting money, learning about fire safety, setting alarms and spent one night to see how we got on.”

Getting legal support and support with practical things like reading



A person in his mid-40s told us,
“The only support I got to move; **my support person** wrote a letter to the council saying I could live alone and that was the only help I got.”

How long did people wait to move?



There was a big range of answers to this question.

- A few people moved right away, for example because of safety issues.
- Others waited a very long time

A person in their late 50s said, “20 years, I always wanted to live on my own.”



“I was waiting for a long time.”

“I don’t know how long. A good long time.”

Who helped with the move?

The council



“I was interviewed by the council and came and saw the condition of the house that I was renting and they came back to me in a few months.”

Family



A 41 year old said, “I went looking at different houses. My sisters and brother and my father helped me.”

Staff



A 30 year old explained,
“Very helpful support. **Staff** helped me understand about living independently and if I am in difficulty I can phone them for help.”



“**My support worker** gave me a hand with my stuff. We did it together.”



Another person in her 50s told us,
“I was very happy with the help from staff and I was able to ask lots of questions.”

Summary Points

Whose idea was it to move?



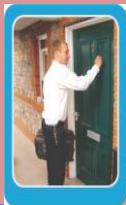
- Some people said it was their own idea to move and others said it was the idea of staff or family. Many people did not answer this question.

Did people have a choice about moving and where to move?



- About half of the participants said they chose to move, 11 had no choice and 6 did not answer the question.
- The reasons to move were location, being close to transport, shops, family and work, design of the house, having space for company, having wheelchair access, independence and low cost.

What steps did people take to move?



- Looking at houses and asking for help from service providers, using independent living services, going to meetings, developing independent living skills, getting legal support and support with practical things were some of the steps people took to move to a new home.

How long did people wait to move?



- Some people moved right away and some people took a very long time to move.

Who helped with the move?



- The council, family, and staff helped with the move.

Chapter 6: Where did people live in 2014?

Where did people live in 2014?



Who did people live with?



What did they like about the place where they lived?



In this chapter, we talk about where people lived when we talked to them in 2014



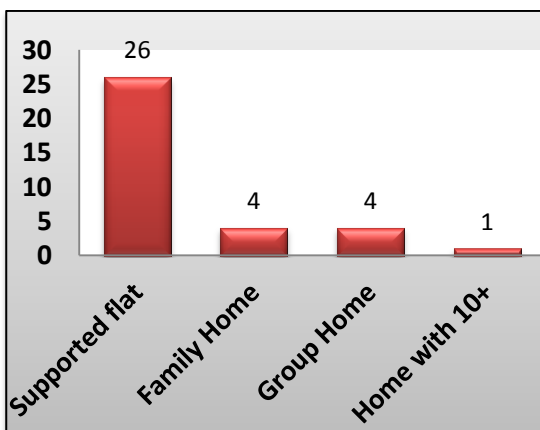
- Where did people live in 2014?
- Who did people live with?
- Did people choose who they lived with?
- What did they like about the place where they lived when we talked to them?

Where people lived in 2014

- 14 people lived in a city
- 12 people lived in a town
- 3 people lived in a rural area
- 6 people did not answer the question.

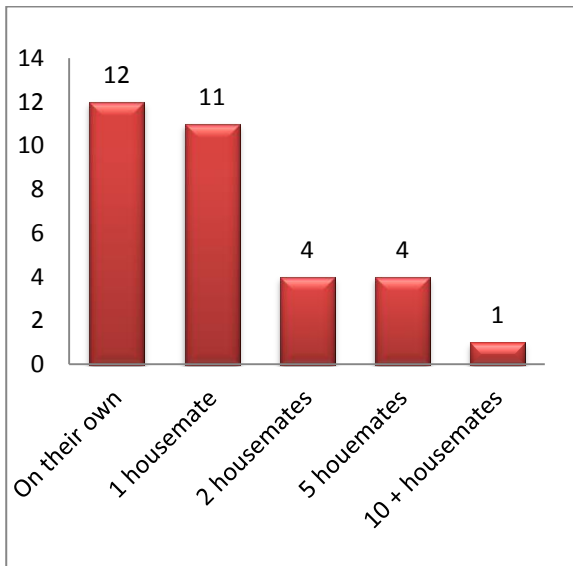
- 21 people lived in a different city or town from where they were
- 9 people lived in the same city or town from where they were
- 5 people did not answer the question.

Places where people lived in 2014



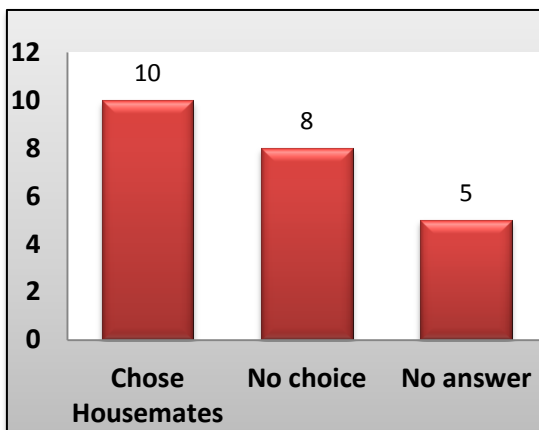
- 26 people lived in a supported flat or house (alone, with one, or with two other persons)
 - 2 of them said they lived in council houses
- 4 people lived in a group home
- 4 people lived with their family
- Only one person lived in a home with 10 or more people.

Who did people live with?



- 12 people lived on their own
- 11 people lived with one other person
- 4 people lived with 2 others
- One person lived with 3 others
- One person lived with 4 others
- 4 people lived with 5 others
- One person lived with 10 or more people
- One person did not answer the question.

Did people choose who they lived with?



Of the 23 people who lived with one or more people

- 10 people said they chose the people they lived with
- 8 did not choose the people they lived with
- 5 people did not answer the question.

What people said they liked about where they lived in 2014?

- 29 people said that where they lived in 2014 was better than where they lived before.
- People said that they liked the house for the same reasons they had chosen it:



Having more company



The house is closer to friends



Better design and accessibility



Being closer to shops and restaurants

- People also added other reasons why they liked the house:



Safer area



Better support



Getting to know the neighbours

These are some comments people made



“I prefer to live on my own. Really I didn’t like some of the **staff**. And I didn’t like living with the other group. I was attacked before in the house, I moved out of **that house** and I lived with a brother of mine and I moved from there to a small apartment and I am happy there now.”



A person aged 25 told us, “**Where I live now is** better since I’ve more responsibility and **I am** more independent.”



A 41 year old explained, “**I like it where I live** because I am getting to know the neighbours.”



“The roads were too dangerous where I was before. There was no footpath. You cannot go anywhere, you could get knocked down.”



A person in her early 40s said, “Loads of help and the cat.”

Some people also thought the place where they lived before was better



A person aged 67 recalled, “My old place had a nice garden and we grew our own crops; it was nice.”

Summary Points

Where did people live in 2014?



- Most people lived in a flat or apartment. Other people lived with their family, or in a group home.

Who did people live with?



- About 1 in 3 persons lived alone
- About 1 in 3 persons lived with one other person
- About 1 in 3 persons lived with 2 or more people.
- 10 people said they chose the people they lived with.

What did they like about the place where they lived?



- Most people said that where they lived in 2014 was better than where they lived before.
- People said that they liked the houses because they were in safer areas, had better support and they got to know the neighbours.

Chapter 7: What support did people have where they lived in 2014?

Support people got from others



Choosing supporters



What people were looking for in a supporter



Relationship with supporters



Other support people needed



In this chapter, we talk about the support people got where they lived in 2014



- Support people got from others
- Choosing supporters
- What people were looking for in a supporter
- Relationships with supporters
- Other support people needed.

There were many different kinds of support people got from others. The people we interviewed spoke about support with:



- Managing the house
- Personal care
- Getting out in the community
- Reading, writing and using the computer
- Emotional issues
- Their needs and wishes.

What people said about the support they got from others

Support managing the house, house chores and finances



“We do the cooking and cleaning ourselves. **We get help** with the recycling. More things too. To get things in town. Patio stones in the garden when it was flooded. He helped put down the patio with his brother in law.”



A person in his 50s told us, “They help me with my money situations and any bills I get stuck on.”

Support with personal care such as taking tablets



“**They** help me with my walk and my tablets in the morning.”

Support when out in the community



A 30 year old explained,
“Yes, I am grateful for them. They help me through all my day to day appointments, shopping and answer my questions.”

Support for reading, writing and using the computer.



A person in her mid-60s said,
“If I want to spell a word she helps me to write. Sometimes I get a problem with spelling words, say if I am writing a card. I ask her and she helps me. She is very good.”



A 65 year old told us,
“**My support person** comes to help me with the laptop.”

Emotional support



“They come in around to visit to check on me and maybe asking if everything is grand and do I need anything.”

Support with people’s needs and wishes



A person in his mid-60s gave this example, “Staff support me with my groceries, and bills, and medical needs, and going out for dinner, and into town at the weekends.”

Some people said they did not need support



A 25 year old explained, “I go to work on my own. I can go food shopping on my own.”

A 45 year old told us, “I do my own activities myself.”

Number of supporters people had



- Most participants had at least one supporter.
- A few people named up to 5 supporters that included:
 - family members and
 - paid staff.

A person aged 25 said,

“My mam and my dad and my family support me. I did have a key worker but due to funding she got let go so I don’t have a key worker anymore.”

Choosing supporters



- 19 people said they chose their supporters.

“Yes I did **choose my supporters**. I interviewed them.”



- 15 people said that they did not choose their support staff.

One person in her 40s said, “Because the **organisation** chose them.”

- 1 person did not answer the question.

One person said it was hard to make the right choice



“It’s hard to get them right.”

One person was not aware that she could choose her own support



A 44 year old asked,
“Is it possible to choose your own support?”

What people were looking for in a supporter

Sense of humour and advice making decisions



For example, one 32 years old said,
“I’m looking for advice, humour, friendly,
and help with making decisions.”

Agreeable, good sense of humour, and help managing the house



A person in his late 40s said,
“Someone that will help with
tidying and managing the house.
Good sense of humour, agree to
do what I need doing.”

Friendly, respectful, and support getting out in the community



“They should be kind to me and have respect for me and be nice to me.”

Another example is from a 56 year old who said, “Somebody who will help and support me in the community. Someone who is a friend and is friendly. Someone who is respectful.”

Timely help



A 41 year old noted that a support person is there to...

“Help me. They get paid.”

Help making decisions and getting out in the community



For example a 30 year old said they wanted,

“Help with decisions; to deal with difficult situations, to accompany me at appointments.”

A person in his late 50s asked,

“Can they drive? Sure I **will** be swimming.”

Good planning and good listening skills



Someone aged 46 told us that a supporter is,
“A person that can listen to me if I have any difficulty.”

One 57 year old person said that he was not looking for support



“I am not looking for support.”

This is what people said they were looking for in a supporter



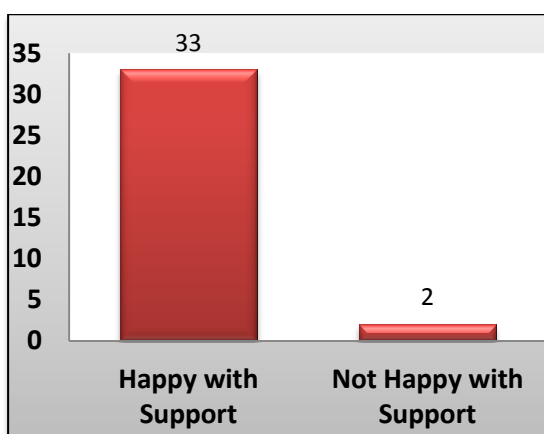
Things people were looking for in paid supporters:

- Sense of humour, fun
- Friendly
- Agreeable
- On time
- Good listeners
- Show respect
- Good planning skills
- Support people getting out in the community
- Help managing the house.

One person aged 24 summed it up by saying:

“All of those things put together really.”

What people said about their relationship with their supporters



- 33 people said they were happy with their supporters
- 2 people said they were not happy with their supporters.

Many people were happy with their supporters



For example, a 22 year old told us,
“Love, they give me love.”

A 65 year old explained,

“God I am delighted. If I want him, I can ring, I have a number if I want anything, and they don't mind. If there is something I want.”

One person said she was happy with the supporter but that was not enough

“I have good support but I would like more hours to do the things I want to do.”

One person who was not happy with the supporters said



“I would, I want to go places. I like to go to Galway and Dublin and they are bossing me. They stop me going places.”

Many people said they got on well with their supporters



For example, a person in their 50s said, “I might ring them to talk to them.”

Some people were not sure whether they got on well with supporters



A 77 year old said,
“I get on good with them,
good not too bad.”

A 30 year old said,
“Ok there is a new staff member who has started working with me so I don't know her very well yet.”

What people said about whether or not they needed other support to live independently

Most people said they didn't need any additional support to live on their own



A person in their 60s said,
“Yeah, I’m independent.”

“No, I can go where I want to.”

Others said they needed more support with independent living skills



A 42 year old told us,
“I would like to learn to cook.”

Another person in their 40s said,
“I am getting support from my sister to help me with money as I am not that good at it”.

Summary Points

Support people got from others



Most people had at least one supporter. People spoke about support with:

- Managing the house
- Personal care
- Getting out in the community
- Reading, writing and using the computer
- Emotional issues
- Their needs and wishes.

Choosing supporters



- 19 people chose their supporters
- 15 people did not choose them
- 1 person did not answer the question.

What people were looking for in a supporter?



- Sense of humour, fun, friendly, agreeable, on time
- Good listener
- Respectful
- Good planning skills
- Support people getting out in the community
- Help with managing the house.

Relationship with supporters



- Many people said they got on well with their supporters. They were happy with them.

**Other support
people needed**



- Most people did not need any additional support
- Some people said they needed some support with independent living skills.

Chapter 8: IRN thinking back on the project

What went well?



What challenges did we find?



In this chapter, we talk about what went well and some of the challenges we found doing this project

What IRN members said that went well

It was good to meet new people in the IRN from different counties and make new friends.

It was my first time for helping write a book.

I liked to be in the video.

I liked working with many people who have great ideas.

The IRN meetings are something to look forward to.

Being part of the research group gave me confidence. It was good to be part of a team and to meet new people.

It is interesting to speak with other people.

I learned more about being independent.

Supporters

I have really enjoyed the rapport of the group as it has grown through this study, getting to know and work with people from different parts of the country. I have been fortunate to see individuals growing in confidence during the interview process.

University researchers

Many new people joined this project and we all learned about doing inclusive research better. We tried new things such as using video to train people conduct their interviews. We found out valuable information about people's stories of moving homes in Ireland.

What IRN members said about the challenges

Figuring out how to get to the IRN meetings.

Sometimes deciding on what words to use in the book is hard.

Some members of the IRN don't read.

The project has been going on quite a long time.

Supporters

I would like us to explore a freer unstructured questioning format which would enable our researchers to develop the enquiry in a less "supporter dependant" interviewing process. Put more simply - give the researchers more direct responsibility.

University researchers

We piloted the interview but we still found some of the questions were difficult to answer. They were not conducive to recall some of the information we asked. The project was too long and it was challenging to keep everyone involved through the project.

Chapter 9: Closing

The IRN did this study to learn about:

- People with intellectual disabilities moving homes in Ireland
 - Where people lived in the past
 - The support people got to move homes
 - Where people lived when we talked to them
 - The support people had to live where they lived.

This is what we found.

1. Where people lived in the past

- People we interviewed had lived in a number of places, for example, family homes, institutions and group homes. A few had only lived in one place.
- People moved homes because of good location, accessible design of the house, space for company, independence and cost.

The United Nations Convention on the Rights of Persons with Disabilities (the Convention) says that people with disabilities have the right to choose where they live!

- About half of the participants had a choice about:
 - Whether they wanted to move homes or not
 - Where to move.
- Everyone should have had a choice about moving homes and where to move.

2. The support people got to move homes

- People got support to move homes from staff, family and the council.

3. Where people lived when we talked to them

- Most people we interviewed lived in a supported flat or house, only a few lived with their families or in a group home.
 - About 1 in 3 people lived with one other person
 - About 1 in 3 people lived on their own
 - About 1 in 3 people lived with two or more people.
- Most people said that where they lived in 2014 was better than where they lived in the past.
- Almost half of the people who shared their home chose who they lived with.

The Convention says that people with disabilities have the right to choose with whom they live!

- Everyone should have had a choice about who they lived with.

4. The support people had where they lived in 2014

- Most people had at least one supporter and most said they were happy with their supporters. Just about half of the people chose their supporters.

The Convention says that people with disabilities have the right to make decisions!

- Although some of the people we interviewed had made choices and were happy where they lived, about half of them had not chosen where and with whom they lived and who supported them. This is against what the Convention says. Ireland has to ratify the Convention and comply with the Convention. That is, people with intellectual disabilities have to make decisions about moving homes and have support to live where they live.
- In conclusion, when people make their own choices and have good support, they live better lives.

Key messages

To people with intellectual disabilities



Don't leave your dreams to someone else.

You have the right to choose your support and where you live.

To the Department of Health and Health Service Executive



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Becoming more independent should not cause people with intellectual disabilities to lose access to the supports needed to live well in their own homes.

People should move into homes they choose as soon as possible.

To families



People want to be responsible and mature about making decisions so that they can live on their own.

People need to choose where they live and with whom.

To service providers



It is important to work well with people first and also with families.

People need to know they have a choice and be able to make that choice.

People need to get on well with their supporters.

To supporters



Listen to people and support them in doing the things they want to do.

Have you checked with the person to see if you are giving them the support they want?

References

Health Information and Quality Authority (HIQA) (2009). National Quality Standards: Residential services for people with disabilities.

Health Service Executive (2011). Time to Move on from Congregated Settings: A strategy for Community Inclusion. Report of the Working Group on Congregated settings. Dublin, Health Service Executive.

Inclusive Research Network (2010). Where we live: A national study done by members of the Inclusive Research Network through surveys. Galway: National Federation of Voluntary Bodies; Dublin: National Institute for Intellectual Disability, Trinity College Dublin.

McConkey, R., Bunting, B., Ferry, F., García Iriarte, E., & Stevens, R. (2014). An evaluation of personalised supports to individuals with disabilities and mental health difficulties. Mullingar: Genio Trust.

United Nations (2006). Convention on the rights of persons with disabilities.