## "Our Lived Experiences of Housing and Transport"

# A Report on the Research Findings of the National Platform of Self Advocates and Centre for Disability Law, NUI Galway











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#### **Summary of the Report**

This book is about a research project that was carried out by the National Platform of Self Advocates and the Centre for Disability Law and Policy in the National University of Ireland, Galway (NUIG). It was funded by the Irish Research Council.



The book tells the stories of people with disabilities in Ireland and their experiences of housing and transport.



It is called "Our Lived Experiences of Housing and Transport".

#### **Research Methods**

This research project started in March 2016 and finished in November 2016. The Centre for Disability Law and Policy (CDPL) asked a researcher to support the National Platform of Self Advocates (NPSA) in carrying out the research.



The National Platform of Self Advocates decided to use **interviews** and **focus groups** to gather the lived experiences of people with intellectual disabilities on transport and housing.

In total **83 participants** took part in the research of which 33 were female and 50 male. The majority of participants from Galway and Kerry lived in a rural area, whilst the Dublin and Limerick participants lived in an urban or on the outskirts of a large urban area.

Based on the lived experiences and stories shared by those who took part in the research their key messages on how to make **transport and housing** better for people with disabilities are presented in this book in an easy to read format.



#### **Key Messages from the Research**

#### Housing

From the research participant's lived experiences the key messages to make **housing better for people with disabilities** are as follows:



While housing is now better designed and old houses can be fitted to suit people with intellectual disabilities and other disabilities, participants in the research felt that:

#### **Houses should:**

- Be built or adapted in a way that is **easily accessed** by people the person living there and people visiting.
- Have paths and approaches that are clear, level, in good condition and accessible.
- Have a holistic **space that meets all their needs** physical, social, sensory and emotional.
- All have a green space or access to green spaces.

#### The wider community should:

 Become more aware of the challenges they can cause people with disabilities in the built environment. A campaign to highlight these challenges should be funded by Government.

#### **Local Authorities should:**

- Listen to what people with disabilities want and need.
- Not make people with disabilities wait so long for a home.
- Say in an easy to understand the steps to getting a house.

- Make their forms easier to understand and fill out.
- Check (evaluate) that the steps are clear to the person applying for a house.
- Present **the number of houses** that are provided for people with intellectual disabilities and other disabilities every year.
- Create **different choices** of housing apartments, houses for one, houses for sharing, houses where they are part of a community, near transports, shops, family and work, education and social supports.

#### **Support Services should:**

- Be paid to employ people to give **support** to people who are moving and have moved into their own house.
- Give support **before**, **during and after a person moves** into their home.

#### **Transport**

From the research participant's lived experiences the key messages to make **transport better for people** with disabilities are as follows:



- People with disabilities should have a say in the planning, design and running of the transport services.
- **Listen** when people with disabilities tell about the barriers they experience.
- All transport buses, trains, and taxis should be fully accessible and all transport systems work together (integrated) so people with disabilities can travel safely and in comfort and be able to move easily between different types of transport.

 Communication should be improved by bus and train companies about changes to services well in advance. They need to tell people with disabilities directly and their support services. Information should be in a range of formats to enable people with disabilities to plan and make their journeys.

#### The Train Company should:

Make sure that ramps and practical help are available at all stations.

#### **Public Bus Companies should:**

- Have all their buses accessible to people with disabilities.
- **Train their drivers** in using ramps and improving access for people with disabilities.

#### All Private Bus Companies should:

- **Take the bus pass.** The Government need to support this through funding or extending the travel pass to include a certain amount of 'private' bus trips per month or year.
- Train their drivers in using ramps and improving access for people with disabilities.

#### **Taxi Services should:**

- Have more accessible taxis. Participants know that accessible taxis are more expensive but they feel that more support has to be given to taxi drivers to buy these taxis.
- Have a voucher system or take the travel pass. The Government need to support this through funding or extending the travel pass to include a certain amount of taxi trips per month or year.

#### **Rural Transport should:**

- Have more money from Government to increase routes and services.
- Be reviewed by bus and train companies to make sure that **connections** are there between services.
- Be reviewed by bus companies to improve routes between towns and villages.

#### The wider community should:

Be more aware of the rights of people with disabilities and the challenges
that they may face on public and private transport. It would be good if
the Government or the transport companies developed an awareness
campaign of these challenges such as the use of wheelchair space on a
bus and fear of intimidation.

#### **Local Authorities and Rail/Bus Stations should:**

- Examine how accessible **approaches to their stations** are and see if their dished kerbs are working well at pedestrian lights, taxi ranks and buses stops.
- Examine **pathways around the stations** to make sure that poles, lights and other objects do not present any barriers to people with disabilities.

#### The Government should:

 Review their Transport Plan for People with Disabilities and talk and listen to people with disabilities about their experiences and learn from them.

#### **Researchers and Support Team**



# National Platform of Self Advocates Housing Working Group

#### National Platform of Self Advocates Transport Working Group

Christina Burke
Brian Carroll
David Fraughen
Brian Hayes
Maria Mahony

Martin Doohar Brian Hayes Sarah Jane Lavin Joe McGrath

#### **National Platform of Self Advocates**

Mariead Forde
Stephen Kernaghan
Dermot Lowndes
Adrian Noonan

# Centre For Disability Law and Policy (NUIG)

Eilionóir Flynn Joanna Forde Josephine Lally JB Terrins

### Acknowledgements

There are a lot of people that the project team would like to thank including the many participants who came to the focus groups and interviews and were so generous in sharing their lived experiences.

This book would not be possible without you.

We would also like to thank the support team in CDLP, the members of the National Platform of Self Advocates and its co-ordinator and administrator and the Irish Research Council for funding and supporting this project.

#### Introduction

#### What is this book about?

This book is about a research project that was carried out by the National Platform of Self Advocates and the Centre for Disability Law and Policy in the National University of Ireland, Galway (NUIG). It was funded by the Irish Research Council.

The book tells the stories of people with disabilities in Ireland and their experiences of housing and transport. It is called "Our Lived Experiences of Housing and Transport". The stories tell what housing and transport is like for people with disabilities in Ireland.

#### Who the National Platform of Self Advocates (NPSA)?

The National Platform of Self Advocates is an **independent self-advocacy organisation**. It was set up



to make sure that the voices of people with intellectual disability are heard.

A core goal of the National Platform of Self Advocates is "making the lives of people with a disability better".

#### Who the Centre for Disability Law and Policy (CDLP)?



The Centre for Disability Law and Policy (CDLP) is a place in

National University of Ireland Galway (NUIG) with people who support social justice and human rights for persons with disability. The centre works "to bring about change in disability law and policy through research and education in active partnership with the community<sup>2</sup>".

<sup>&</sup>lt;sup>1</sup> National Platform of Self Advocates (NPSA) January 2015 – December 2017

<sup>&</sup>lt;sup>2</sup> Centre for Disability Law and Policy (CDLP) Business Plan July 2011 – June 2014.

#### Who funded the research?



The Irish Research Council funded this research.

It is an organisation that supports good research and makes research, the economy and society better.

#### Why did the research examine Housing and Transport?

In 2015, the National Platform of Self Advocates wrote a three year plan presenting what they want to do.



The plan says that **housing** and **transport** are very important to them.



The National Platform of Self Advocates wanted to give people the opportunity to share their stories and write down what housing and transport is really like for people with disabilities.

The Centre for Disability Law and Policy supports the National Platform of Self Advocates in doing their work. The Centre for Disability Law and Policy also believe that it is important that the **lived experiences of people with disabilities of housing and transport is shared** with people making laws and policy and carrying out other research or teaching.

Most of all the National Platform of Self Advocates and the Centre for Disability Law and Policy want to tell government and those making decisions on the planning, designing and developing of housing and transport what it is like for people with disabilities.



Based on the stories shared by those who took part in the research the key messages on **how to make things better for people with disabilities** are presented.



It is hoped that Government and those making decisions on housing and transport will learn what supports and changes are really needed in order to make lives better for people with disabilities, their families, their supporters and wider community.

#### There are 4 parts in this book:

- 1. The first part tells you about how the project gathered the **stories** of people with disabilities.
- 2. The second part tells you about **housing** and what the project found out about the lived experiences of people with disabilities and the **key messages** from their experiences.
- 3. The third part tells you about **transport** and what the project found out about the lived experiences of people with disabilities and the **key messages** from their experiences.
- 4. The final part tells you what the participants felt needs to be done to make housing and transport better for people with disabilities in Ireland.

#### 1: Research Methods

The research project started in March 2016 and finished in November 2016. The Centre for Disability Law and Policy (CDLP) asked a researcher to support the National Platform of Self Advocates (NPSA) in carrying out the research.

The first thing that the NPSA did was set up two working groups - one on **housing** and one on **transport**. The purpose of the working groups was to guide the researcher, decide on the research questions and how the research would be carried out, and how it would be presented.

#### **Literature Review**

In April 2016 the researcher who supported the research project looked at some documents that talk people with disabilities and housing and transport.



These documents provided a context to the research. These documents included:

- The Convention on the Rights of People with Disabilities.
- Census 2011 Profile of Health, Disability and Carers in Ireland.
- National Housing Strategy for People with a Disability 2011 2016
- The Disability Act 2005 and Equal Status Act 2000.
- Sectoral Plan for Accessible Transport under the Disability Act 2005.

#### What did these documents say about housing and transport?

The **Census 2011** which counts how many people live in Ireland and helps the government plan for the future says that a total of **595,335 persons**, accounting for 13% of the population, had a disability in April 2011.

The United Nations Convention on the Rights of Persons with Disabilities says what the Rights of Persons with Disabilities are and guides countries who have signed up to the Convention what they should do to make sure that Persons with disabilities have the full and equal enjoyment of human rights on an equal basis with others including:

- Choose where and with whom to live (Article 19).
- Identify and eliminate obstacles and barriers and ensure that persons with disabilities can access their environment, transportation, public facilities and services (Article 9).



**The National Housing Strategy** is a housing plan written by Government for people with disabilities about their housing options and how they can be supported to live as independently as possible within communities according to their individual choice.

**The Disability Act 2005** supports equality and social inclusion of people with disabilities.

**The Equal Status Act 2000** stops discrimination of people with disabilities and other groups of people.

Transport for All (2012) Sectoral Plan for Accessible Transport under the Disability Act 2005 is a document that sets out targets for making public transport more accessible to people with disabilities and to see what targets have been achieved.

All these documents have at their heart the wellbeing, accessibility and inclusion of people with disabilities as equal citizens.

#### **Training for Research**

Before the research started the working group members took part in a training workshop on research skills to learn about and discuss:

- the different research steps,
- telling people about the research,
- asking for consent,
- the importance of confidentiality, and
- developing the interview and focus group questions.

A booklet of the workshop topics was developed so that the NPSA would have it as a resource after this research was completed.

#### **Gathering the Lived Experiences**

The working groups decided to use **interviews** and **focus groups** to gather the lived experiences of people with disabilities on transport and housing.



#### **Interview Questions**

The interview questions and focus group questions were very similar. The aim of the questions was to allow participants to share their **lived experiences** of **housing and transport.** 

The NPSA working group members wanted to make sure that the questions were easy to understand and encouraged participants to share their lived experiences.

Draft interview and focus group questions were tested in April 2016. Some questions were deleted and some were made easier to understand.

## The questions we asked people about housing were:

- What is your experience of housing?
- What has worked well for you?
- What hasn't worked so well for you?
- What needs to change to make housing better for people with disabilities?



#### The questions we asked people about transport:

- What is your experience of transport?
- What has worked well for you?
- What hasn't worked so well for you?
- What needs to change to make transport better for people with disabilities?

#### The Research Participants

Twelve people were interviewed 'face to face' by the researcher engaged to support the research. Six members of the working group members co-facilitated the focus groups sessions with the researcher and the NPSA Co-ordinator.

There were 4 focus groups held in different place in Ireland:

- **Dublin** with 20 participants and 6 supporters
- Limerick with 27 participants and 4 supporters
- **Kerry** with 14 participants and 4 supporters
- Galway with 12 participants and 3 supporters.



In total **83 participants** took part in the research of which 33 were female and 50 male. 17 supporters also attended

the focus group sessions. The majority of participants from Galway and Kerry lived in a rural area, whilst the Dublin and Limerick participants lived in an urban or on the outskirts of a large urban area.

#### **Recording and Presenting the Lived Experiences**

The researcher wrote word by word what participants said about their lived experiences at both the interviews and the focus group sessions.



The working groups wanted to present the findings from the research in an easy to read and clear way. It was decided that the lived experiences of people was best described through their own words and to present the outcomes in a 'case study' approach.

The case studies represent similar 'stories' and issues that arose for participants to try to convene that these stories/experiences are not unusual.

The member of the two working groups agreed the stories and the messages from the lived experiences that are presented in this book.

The working groups were very careful that no participant would be identified either by name or where they lived or anything that would identify them to ensure their privacy.

The names given to peoples lived experiences have been changed.

#### 2: Housing – Our Lived Experiences

In this section we talk about research participants lived experiences of housing.



We asked participants what worked well and a small number of participants had very good experiences of housing, supports in getting a house and living independently.

These participants were very happy because they *"had more choices"* about how they lived their lives.

When asked what had not worked well, participants shared the following issues:

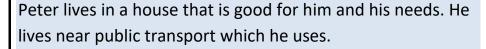
Some participants told us that they were happy with their housing but that it

was in the wrong place for "getting to transport", or "did not have a nice garden", or "the pathway to the house wasn't good".

"Right house in the wrong place".

There were many examples of this issue and the following lived experience represents the issues that were shared during the research interviews and focus groups:

**Peter** lives independently. He uses a wheelchair that is not electric.





However, the road to his house is very steep, so his journey to public transport is difficult and dangerous.

The path is in poor condition, broken up in places and narrow. Cars can often be parked on the path. He has to use the middle of roadway for going to and from his home which is very dangerous. He also worries about the speed of cars passing the bus stop and feels unsafe getting off the bus and trying to cross the road.

"All my needs are not looked after"

When local authorities support people with disabilities to get houses they do not always take account of all the needs of the person - their emotional, social, and physical well-being.

One participant in his 50's shared his story:

**Alex** lives independently. He uses an electric wheelchair. Alex lived in an institution for most of his life.

He waited a long time to get his own home and is very happy there.



However, the apartment does not have a garden and has only a very small patio.

With a slightly bigger space he would love to grow vegetables and flowers and have something to do at home.

Some participants spoke about how helpful their local authorities were in getting them a home.

"Getting a house can be hard in some local authority places because the steps are difficult to understand". However applying for a house from the local authority was confusing and the steps to getting a house, becoming a tenant and knowing the tenants' rights were not clear and "the form was very difficult to fill out".

Sean is a young man in his early 20's. He lives with his parents. He would like his own home and live independently. Sean started looking for a home and went to his local authority with the help of his family and support service. The following story highlights what many participants in the research experienced:

**Sean** lives with his parents. He wants to live independently. He attends a day service. The service is very supportive of him in his wish to live independently.

Sean got the housing (assessment) form from the local County Council which had a lot of pages to fill out.



It took Sean and three of his supporters from the day centre a long time to understand some of the questions on the form. This was very frustrating for Sean, his parents and his supporters.

It was a very hard form to understand and the questions appeared to be more directed towards his parent's circumstances than looking at Sean's needs and circumstances.

Some participants said that they "were waiting, always waiting" for a home for a "very long time" and that "we are constantly told to wait" and that this was very upsetting. This was the most common lived experience among participants.

Participants said that it took a lot of effort to become independent and live in a house on their own or share with others. Some felt that this was not understood

by services like city or county councils.

"Waiting time for a house is too long. We need more encouragement and support to live on our own from local authorities and (staff) need listen to what we want"

For example a man in his 40s told us about his experience of trying to get a house:

John had an alcohol addiction and wasn't getting on with his family. With a lot of support from his support services he sorted his addiction and was supported to get into work. He turned his life around and is very active volunteer.

However, getting a house was hard and took a lot of going to local counsellors and talking to people in the local authority.

It wasn't easy and took 8 years to get a house.

John says that it is not easy trying to live independently and that the steps to getting a house are still not clear or properly supported.

Another participant a woman in her 30's also told us about her long wait for a house of her own and her confusion about the ways to get her own home:

Mary lives in group housing and has waited for 7 years for a home of her own. She wants to be in her own community near her family and friends. She knows that there aren't many houses but she is confused about what options and supports are available for transition to her own house.



The waiting is very upsetting and the local authority staff say that Mary is on the waiting list for a house.

Mary knows others are waiting for houses but being told over and over again to wait is making her very sad. She feels that the decisions are made for her and not by her

and that she is not being listened to.

"People with disabilities do not always have a choice of housing options that best suit them".

Many participants said that the "choice" of the type of house, design of the house, the "place the house was in" and who they share their house with is not always available to them.

Many participants talked about living with others as their only option though many wanted to live on their own.

For example, Jane a woman in her 30's said:

Jane lives with three people but would prefer to live with less people or on her own.

Jane liked moving out of her parent's house.



But she feels that:

"It is too loud, the others make a lot of noise and I would like more privacy. The decision to move here was made for me not by me".

Another lived experience that showed that sometimes living independently may not work for some people due to loneliness and a lack of support came from a man in his 50's:

**Robert** tried living independently but did not like the experience:

"I missed the company and didn't like the loneliness...no one really came to visit much and I didn't like the place (community).



It's great now in a residential house where I have people to talk to and we agree where we go and what we do every day".

Robert feels that people should be given a chance to "try out first what you like".

Participants who were happy with their housing arrangements and those who were not happy with their house arrangements all felt that the demands of "up keep of a house", managing "the bills" and "looking for support" when you need it is very difficult.

"We need support in managing our homes"

A lot of participants in the research spoke about "worrying about bills and rent". There was strong feeling amongst participants that supports need to continue

"after you get your house".

One man in his 50's shared his experience of getting "into trouble" managing his bills:

Pat was very happy in his home but after a while he got behind in some of his bills. He had support when he first moved into his house but he forgot some of the things the support services told him.



His key worker was not funded to visit any more.

He was very worried and for a time did not know who to talk to about it.

His family noticed how upset he would become and helped him sort it out.

The Department of Social Protection and the county council were really nice about the problems.

It took time to get things right and now he is more confident with managing his money and bills.

A lot is taken care of by the bank and his family check with him a lot to make sure it's all ok.



One research participant who has a lot of experiencing speaking up for the rights of people with intellectual disabilities spoke about -

What people with disabilities themselves and local authorities need to do to make the move to independent housing easier for people:

**Joseph** lives independently in a rural village. He got a lot of good support in getting a house.

He now supports people with intellectual disabilities to know and have their rights respected.

Joseph says that people with disabilities need to know:

- 1. How the local authority works in each place.
- 2. What is available to help with rent (rent allowance).
- 3. How social welfare will work for you.
- 4. Which housing options are right for you.
- 5. With "your rights comes responsibilities" like rent and bills.

Joseph says:

"If it becomes difficult talk to someone, don't walk away from your responsibilities".

#### **Key Messages about Housing**

There were a lot of important messages from the participant's lived experiences of housing.

Most people agreed that while housing is now better designed and old houses can be fitted to suit people with intellectual disabilities and other disabilities, participants in the research felt that:



#### **Houses should:**

- Be built or adapted in a way that is easily accessed by the person living there and those visiting.
- Have paths and approaches that are clear, level, in good condition and accessible.
- Have a holistic space that meets all their needs physical, social, sensory and emotional.
- All have a green space or access to green spaces.

#### The wider community should:

 Become more aware of the problems they can cause people with disabilities in the built environment. There needs to be an awareness campaign for communities on the rights of people with disabilities.

#### **Local Authorities should:**

- **Listen** to what people with intellectual disabilities want and need.
- Not make people with disabilities wait so long for a home.
- Say in an easy to understand the steps to getting a house.
- Make their forms easier to understand and fill out.
- Check (evaluate) that the steps are clear to the person who is applying for a house.

- Present **the number of houses** that are provided for people with intellectual disabilities and other disabilities every year.
- Create **different choices of housing** apartments, houses for one, houses for sharing, houses where they are part of a community, near transports, shops, family and work, education and social supports.

#### **Support Services should:**

- Be paid to employ people to give **support** to people who are moving and have moved into their own house. Services like MABS could be helpful.
- Give support **before**, **during and after** a person moves into their home.

#### 3: Transport – Our Lived Experiences

In this section we talk about the participants lived experiences of transport.



We asked participants what worked well and a small number of participants had very good experiences of transport.

These participants were very happy because they because they "had good bus or train services near them" which supported them in accessing education, training, work, social and community supports and networks.

When asked what had not worked well, the majority of participants in the research said that they had a lot of issues when using transport.

The following lived experiences highlight some of these issues:

#### Train and Bus Travel

Train travel is an important means of transport for the research participants – this includes rail transport like the Luas or DART in Dublin and intercity trains that link the main towns and cities.

Though a small number of participants use the Luas or DART they were happy with the service. It was mainly the intercity trains that caused issues.

An issue that many participants in the research experienced was the difficulties

"Getting on and off trains is still a problem".

they experienced getting on and off trains if using a wheelchair or had a physical disability that required a ramp for access to or from the train.

Participants spoke about having to "ring ahead" to make sure that the ramp was at the station. Most participants said that many times they have to wait for the ramp.

One man in his 60's who is a frequent user of intercity trains told us about the problems that he has with ramps.

Martin uses the train a lot to go to meetings.

Martin is a wheelchair user.

In order to make sure the ramp is at the station in the morning so that Martin can get on the train he must telephone 24 hours ahead before the journey.



When Martin is half way through his journey he must telephone ahead to make sure that the ramp is at the station to allow him to get off the train.

He said that many times he has had to wait on the train for someone to come with the ramp.

This planning ahead means that Martin has to be organised to make a trip and he gets very upset when there is a delay in getting a ramp for him.

Martin says that "they (train company) need to do it right ...it's always a struggle".

Participants shared their experiences of approaches to rail and bus stations. The bad experiences were very common and experienced in different places around the county.

"Some (train and bus) stations and bus stops are hard to get to and leave from..."

Approaches to stations presented many challenges for the research participants including:

- Poor "broken up and uneven" pavements,
- Poorly dished kerbs on pavements,
- Poles and lights posts on pavements,
- Elevators in stations not working, and
- Bicycles chained to poles light posts near stations or bus stops.



Among the participants that shared their experiences of these issues included a man in his 60s:

Sam is a wheelchair user.

He uses the train a lot.

Sam travels from his home by bus to the train.

In order to get to the train station Sam has to use a busy city pavement to get to the train station.



There are pedestrian traffic lights at the end of the pavement however is very difficult to cross the road as the dished kerb has a lip that means he has to push really hard to get up on the pavement.

Bus travel was the most commonly used form of transport among the research participants.

Waiting for buses and connecting buses/trains presented a lot of frustration and nervousness among participants.

"Bus and train connections are not good and you have to wait for a long time for buses".

One woman in her 40's talked about the complicated journey to her work but also her long waiting times between buses:

**Sarah** travels by bus to work. Her route is complicated and she has to take more than one bus.

Sarah often has long waiting times to get connecting buses to and from her work - up to one hour. It is very hard waiting especially if the weather is not good.

Sometimes the bus passes her by because it may be full, out of service or simply does not stop.

Sarah has also experienced ringing the bell and the bus doesn't stop for her. She gets very stressed waiting for such a long time between buses or if the service does not work the way it should.

A man in his twenties talked about how difficult it is to get connections between buses and bus and train connections in rural area.

He describes waiting long periods of time to get connections and the impact of bus routes "being dropped".

When Paul gets off the train he has to wait hours to get a connection to a bus that will take him near his home.

Paul is dependent on the train and bus to get around.

The route connections used to be better but there are fewer buses now and bus routes have been dropped in recent years.

Paul does not understand why the train and bus times can't be more connected.

It takes a lot of planning for him to get the train at the right time so that he does not have to wait more than two hours for a bus.

It is very frustrating "just waiting...and I'm always afraid that I will get stranded".

He knows that he can get a taxi but that cost a lot of money.

The attitude of others such as other transport users and transport personnel was a common theme from the lived experiences of participants.

"Others using transport do not always respect people with disabilities".

This caused a range of reactions such as upset, anger, fear and confusion as participants recalled times when they experienced rudeness, being ignored and bad language.

One woman said that "people staring at me...makes me uncomfortable".

Other experiences included:

- People not waiting for the ramp to come down.
- "Being called names on the bus".
- Feeling afraid and intimidated due to over-crowding or being on "my own on the bus".
- Finding it difficult and uncomfortable when buses are "packed" (with other bus users).

Some participants spoke about how they "will get off the bus and wait for the next one (bus) to come along and hoping that one would not have so many people on it".

A particularly difficult lived experience that was shared with the researcher came from two people travelling together.

One man in his 60s and a woman in her 50s shared an experience that occurred at a large Dublin city train station.



Claire and Michael (a wheel chair user) travelled from to Dublin by train.

They wanted to transfer to a taxi to get to their destination.

At the taxi rank there is no dished kerb for ease of access to the taxi. They were deciding what the best way to transfer to the taxi was.

However, the taxi driver that pulled up first did not get out to help and the person standing behind Claire and Michael in the Q pushed past them and got into the taxi that then left.

The next taxi (not adapted for a wheelchair) tried to pull up as near as possible to the kerb however there was still a gap. The driver did support Michael to get into the taxi.

Claire was very confused and upset both by the first taxi driver but also by the behaviour of the woman in the Q.

One man in his 60s who uses a wheelchair told of his experience about how oftentimes he will get on a bus and a buggy will be in the space for a wheelchair.

**Chris** uses the bus frequently. There are many times when he gets on the bus and there is a buggy in the wheelchair space.



He has to get the bus driver to ask the person to move the buggy sometimes he has to ask the person themselves.

He knows that parents have to bring their buggies on the bus but it is very stressful asking them to make space for him.

Chris has experienced other people and bus drivers being annoyed with him and this makes him nervous about asking them to move the buggy.

"The travel pass is not taken by private bus companies"

The travel pass was of great importance to the participants in the research.

It is for most of the participants their only access to independence, work, education,

training and social networks.

However, the participants said that:

- While some private bus companies do take travel passes "most do not take travel passes".
- They have to pay for connecting transport like taxis as bus routes have been "stopped" or there is a long wait for the next bus.



Where a bus service does not meet the needs of participants there is usually an extra cost to the person to travel. Participants felt that this has an impact on their household budget.

"(Intercity and inter town) bus drivers do not all have training in using the bus ramp".

Research participants spoke about how not all intercity or inter town bus drivers (both public and private) can use the bus ramp and therefore are not the bus is not wheelchair accessible.

A man in his 50s spoke about the impact on this when trying to visit his family in the north-west from a large town in the west.

James is a wheelchair user. When he wants to visit his family in the north-west he has to get one train to a central station, change trains (often with a long wait between trains) and one train to take him to his home town. This all takes "most of the day". He does not have the choice of taking the



private bus service direct to his home town because the drivers "can't take his wheelchair as they have (had) no training in using the ramp". Not all public bus services have a ramp. Not all bus drivers have been trained in operating the ramp.

#### **Private and Services Transport**

Most of those who spoke to us had used private transport like taxis or buses used by support services.

"Paying for (private transport) taxis or services bus services costs a lot of money".

Most of the participants were happy with these types of services and many have built up loyalty to particular taxi companies and taxi drivers.

However, participants lived experiences pointed out that a lot of these services cost money but that they are forced to use them when they have no other choice.

The impact on the participants of not being able to use these services due to cost included:

Social Isolation: "Not going anywhere (because) it would cost too much.
 I get sad sometimes because I don't get into town as much as I (would)
 like".

 Opportunity for spontaneous actions is less: One young woman in her early 20s said "I can't just go to meet my friends whenever I want".

#### **Rural Transport**

There was a clear difference between the lived experiences of people living in rural areas and those living in the Dublin region.



Participants from their lived experiences said that:

- "There is very little choice in rural areas... we rely on our neighbours, family or supports services".
- "There are no direct routes between places...even once a week".
- "There are very few shelters or seats at country bus stops, this isn't good when you have to wait a long time."
- Limited bus connections: "buses go from large town to large town forgetting the small villages".
- Buses are not very frequent so they have long waits between times.
- Changes to the bus times are not discussed or communicated to people with disabilities or their support services.
- Road works and delays are not communicated to people with disabilities or their support services in advance so that they can make different arrangements.
- The rural transport schemes have been cut back in some places.

One man in his 30s shared his experience of transport in a rural community and the impact on him and family members.

It highlights some of the key challenges that poor transport supports in a rural area can cause.

**Daniel** lives with his mother in a rural area. He works in a village 20 kms away one day a week.

**Daniel** leaves home very early in the morning to catch the work bus. There is only one bus passing near his home in the evening.



He has missed the bus home many times because it has been early or he has been delayed and missed it.

Because there is no other bus he has had to hitch home on a narrow rural road in the dusk.

This worries his elderly mother who does not drive, and lives on her own apart from Daniel.

#### **Key Messages about Transport**

There were a lot of important messages from the participant's lived experiences of housing.



The research found from the lived experiences of participants that:

- People with disabilities should have **a say** in the planning, design and running of the transport services.
- **Listen** when people with disabilities tell about the barriers they experience.
- All transport buses, trains, and taxis should be fully accessible and all transport systems work together (integrated) so people with disabilities can travel safely and in comfort and be able to move easily between different types of transport.
- **Communication** should be improved by bus and train companies about changes to services well in advance.

They need to tell people with disabilities directly and to their support services. Information should be in a range of formats to enable people with disabilities to plan and make their journeys.

#### The Train Company should:

 Make sure that ramps and practical assistance are available at all stations.

#### **Public Bus Companies should:**

- Have all their buses accessible to people with disabilities.
- **Train their drivers** in using ramps and improving access for people with disabilities.

#### All Private Bus Companies should:

- **Take the bus pass.** The Government need to support this through funding or extending the travel pass to include a certain amount of 'private' bus trips per month or year.
- **Train their drivers** in using ramps and improving access for people with disabilities.

#### Taxi Services should:

- Have more accessible taxis. Participants know that accessible taxis are more expensive but they feel that more support has to be given to taxi drivers to buy these taxis.
- Have a voucher system or take the travel pass. The Government need to support this through funding or extending the travel pass to include a certain amount of taxi trips per month or year.

#### **Rural Transport should:**

- Have more money from Government to increase routes and services.
- **Be reviewed** by bus and train companies to make sure that connections are there between services.
- Be reviewed by bus companies to improve routes between towns and villages.

#### The wider community should:

• Be more aware of the rights of people with disabilities and the challenges that they may face on public and private transport.

It would be good if the Government or the transport companies developed **an awareness campaign** of the challenges such as the use of wheelchair space on a bus and fear of intimidation.

#### **Local Authorities and Rail/Bus Stations should:**

- Examine how accessible approaches to their stations are and see if their dished kerbs are working well at pedestrian lights, taxi ranks and buses stops.
- Examine **pathways around the stations** to make sure that poles, lights and other objects do not present any barriers to people with disabilities.

#### The Government should:

 Review their Transport Plan for People with Disabilities and talk and listen to people with disabilities about their experiences and learn from them.

#### **Final Message**

This research project seeks to highlight the lived experiences of people with disabilities in respect to housing and transport.

The lived experiences described in this book shows that real challenges exist for people with disabilities in respect to housing and transport.



The research participants constantly said that they did not want special treatment just their rights to access to housing and transport.

They also highlighted that these issues while experienced by them were issues that many others in society experience such as older people, parents and carers.

It is hoped that the lived experiences that have been shared will ensure that people with disabilities have:

 A say in the planning, design and operation of transport services and facilities in the future.



- A say in the planning, design and development
   of housing and the community supports that are developed around new
   housing development.
- The benefit of the **rights** that are written down in international and national laws and policies, including the UN Convention which should be ratified by the Government of Ireland.

#### References

Census 2011, Profile of Health, Disability and Carers in Ireland.

Centre for Disability Law and Policy (CDLP) Business Plan July 2011 – June 2014.

Disability Act 2005 and Equal Status Act 2000.

National Housing Strategy for People with a Disability 2011 – 2016

National Platform of Self Advocates (NPSA) Strategic Plan January 2015 – December 2017.

Sectoral Plan for Accessible Transport under the Disability Act 2005.

UN Convention on the Rights of People with Disabilities.