A Research Report: Getting the Views of Persons with Disabilities on Respite Services in Ireland

This is a Plain English Report

Údarás Náisiúnta Míchumais
National Disability Authority

ACE

What is this research about?

This research is about the experiences of adults with disabilities of respite services in Ireland.

The research looked at information on respite from Ireland and around the world.

Over 40 adults with disabilities took part in interviews and talking groups.

These adults were from different counties in Ireland.

Each person made a choice to take part in the research and to give their views.

We talked to adults with disabilities using different types of respite services.

Traditional respite services in this research was a person staying overnight in a respite house or centre.

Alternative respite services in this research was daybreak, evening groups, or weekend groups. Some people also had experience of respite with a family in the family’s home.

We talked to adults that could use respite services but chose not to.

We talked to adults waiting on a respite service.

We talked to adults with different types of disabilities.

This research could help the Government and disability services to plan respite services in the future.

Having your say on respite

This research was a chance for persons with disabilities to give their views on respite.

There is very little information on what persons with disabilities think about respite.

Most of the research looks at the views of parents and carers.

It is very important to hear what persons with disabilities have to say about respite.

What persons with disabilities said about respite services in Ireland

Overall people were very happy with their respite service.

People taking part in this research agreed with many of the views of persons with disabilities, families and carers in other studies.

There was no major difference between the experiences of persons using traditional respite or alternative respite.

There was no difference between the views of men and women.

Persons with physical and sensory disabilities said that respite was like a holiday or short break. Persons with intellectual disabilities said respite was part of their supports.

Some people did not want to stay overnight at respite houses and centres.

Most people said they liked to go to respite with friends or people they know.

The good things about respite

People said they are happy at respite and do not feel homesick.

Most respite houses and centres are nice and the bedrooms are comfortable. They are like a ‘home away from home’.

The food is good.

People said they have a good time at respite but might feel tired or a bit sad when it is over.

People enjoy having time for themselves. They like the peace and quiet in respite.

Young adults said respite is a break from their family and a chance to be more independent.

Respite gives families a break and a chance to do their own thing. People said this was very important for mothers and older parents.

Respite helps you spend time with friends, catch up with old friends and meet new people.

Respite is fun. It is a chance to do different activities and to try new things.

People said they enjoy watching TV and movies, going for meals, and going out with friends to the pub, cinema or concerts.

Most people get to choose what they do at respite.

Things that help respite to work well

Staff that do a good job. They listen and are kind, helpful and funny.

Getting on well with the staff.

Good information about respite. Information that everyone can understand.

Getting on well with the other people at respite. Some people said they would prefer to go to respite with women only or men only. Some said they did not want to go to respite with a person with behaviour problems. Some individuals said they want to go to respite with people with the same type of disability.

The bad things about respite

If staff are rude, angry or give out.

Some centres or groups have too many rules.

Staff can sometimes stop you from being independent. For example, if they do things for you that you can do for yourself.

Sometimes it can be hard to communicate with staff. For example, if they do not speak your language.

If there is not enough staff. Sometimes this means that you cannot go out or do the things you want to do.

When there is no transport. For example, if there are not enough wheelchair spaces on the bus.

Staff that cannot drive cars and buses. This can mean that people might have to stay in the house.

When houses and centres are too far away from the local town, or it is too hard to get there. This might be because paths are bad or roads are dangerous.

The barriers and challenges to respite

There are not enough respite services. It can be hard to get a place.

If you move from children's services to adult services, you might have to wait for a respite place.

There is not much choice about the type of respite you get.

People said they are not sure why some people get more respite than others.

There is not enough information about respite services. Sometimes the information goes to families and not to the person themselves.

Persons with disabilities are not given a chance to have their say about respite services. They do not get to make decisions about respite services.

Persons with disabilities need more support to speak up for the respite services they want and need.

They need more control over the dates and times of their respite stays.

Ideas for the future

Respite services should be more person-centred. This means they are about each person and what they want and need. They are less about what a group wants and needs.

There should be information about respite that persons with disabilities can understand.

Service providers should talk to persons with disabilities and their families about respite.

Persons with disabilities should have a say in the design of respite services.

It should be easier to move from children’s respite services to adult respite services.

Respite centres and houses should be near a local community.

Transport should be available.

There should be a policy for respite in disability services in Ireland.

There should be different types of respite available.

We need to think about how personalised budgets work with respite services. This is money a person can get from the Government to pay for their own services and supports.

NDA
Údarás Náisiúnta Míchumais
National Disability Authority

The National Disability Authority asked for this research to be carried out.

ACE

The research was carried out by ACE Communication.

This Plain English report was put together by ACE with experts by experience.