



Údarás Náisiúnta Míchumais
National Disability Authority

Information Leaflet on a Research Study

The journey from wardship to a new decision-making support system



This is an Easy to Read leaflet

Invitation to take part in research



THE National Disability Authority, or NDA, are running a research study.



You are invited to take part in this study.
You have been asked to take part because you are a person who is a Ward of Court or a Committee that acts for them.



You can make a choice to take part or not.



Please read this information leaflet carefully before you decide.

You can talk about your decision with a family member, advocate, or your Committee.

Invitation to take part in research



Risks and benefits are the good and bad things about taking part in research.



You should understand the risks and benefits of taking part in this research study.

This will help you to make the decision that is right for you.



This is called 'informed consent'.



You can change your mind about taking part at any time during the interview.

You can drop out up to 3 months after the interview.

You don't have to give us a reason.

If you want to opt out of the study just let us know.

About the research



The Wards of Court system started in 1870. When a person is made a Ward of Court other people make decisions for them.



This system does not fit with the United Nations Convention on the Rights of Persons with Disabilities.

This is also known as the UNCRPD.



The UNCRPD says that persons with disabilities are equal before the law.



Each person should get the support they need to express their choices and make their own decisions.

About the research



The Wards of Court system will stop when a new law starts, called the Assisted Decision Making (Capacity) Act 2015.



This is expected to start in 2023.



The Decision Support Service, or DSS, will start working when the Act starts.

This will mean changes for all adults that are Wards of Court.



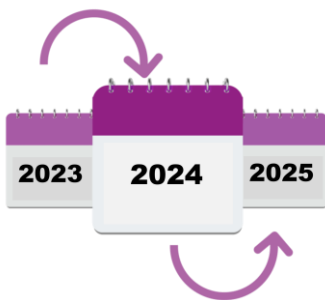
The DSS will make sure that people who are chosen to help others with decisions do their job properly.

About the research



The High Court will do a review.

It will say what supports each adult needs to make decisions.



Once the Act starts, these changes must happen within 3 years.



This research will look at how the Wards of Court system is ended in Ireland.



It will look at the experience of adults moving from the Wards of Court system to the new decision-making support system.

Who is doing this research study?



Údarás Náisiúnta Míchumais
National Disability Authority

The NDA are organising this research study.



The NDA are paying for this research study.



The NDA gives the Government advice on things that are important to the lives of people with disabilities.

Who will take part in this research study?



We plan to talk to people who are Wards and the people that act for them, called Committees.



We will talk to people working in the Wards of Court system and in decision-making support services.



We will talk to other people who can tell us how the move to the new decision-making service is going.



We will get their views on how the Wards of Court system ended, and how life is after they leave this system.

How will the research study be carried out?



If you agree to take part in this research study, we will meet you at two different times.

1

The first meeting will be before you leave the Wards of Court system.

2

The second meeting will take place at least 6 months later.



The meetings will be at times and dates that suit you.

How will the research study be carried out?



The meetings will be in a place that suits you.



You could choose your family home, the NDA offices, a day or community centre, or a residential care setting.



The place you choose should give you privacy. It should not be too noisy.



We would prefer to do face-to-face interviews but we can also do interviews by phone or on Zoom.

How will the research study be carried out?



You can be interviewed on your own, or with a family member, a friend, or an advocate.

If you wish to have a supporter, we think it is better that you do not choose your Committee.



At the first interview, we will ask questions about your experience of the Wards of Court system.

We will ask about the information you have been given.



You can tell us any worries you have about moving to a new decision-making support system.



We will ask if you think there will be changes with the new system.

How will the research study be carried out?



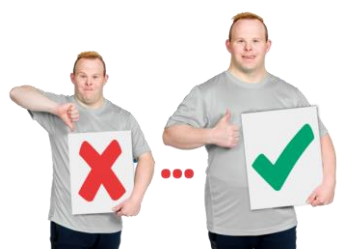
In the second interview, we will ask questions about your experience of moving to the new decision-making support system.



We will ask if the move has changed your life in any way.



You will have a chance to tell us about any worries you have about the new system.



You can tell us if you think anything could be made better.

What happens during the interviews?



A trained researcher will carry out the interview.



If you agree, we will record the interview using a digital audio recorder.



If you do not agree to an audio recording, the interviewer will take notes.

They may bring a second person with them to take notes.



We will only collect the information we need to answer our research questions.

What happens during the interviews?



You can ask for a break at any point in the interview.
You can leave or ask for the interview to be stopped.



Each interview will take about 45-60 minutes.
Some interviews may take a little longer.

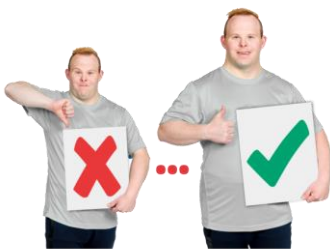
The benefits and risks of taking part in this study



The benefits and risks are the good and bad things about taking part in a research study.



You might feel happy that you shared your experiences as part of this research study.



This study might bring good changes to the new decision-making system.



There is a very low risk that people taking part in this research will be harmed.

The benefits and risks of taking part in this study



Some people might be upset talking about their lives.

The research team will give people the right supports if this happens.



The information collected for a research study is called data.

All data will be managed carefully and in line with the law.



There is always a small risk of a data leak.

This might be upsetting for some people.



If there is a leak, your personal information is kept separate from the record of what you tell us.

No-one will be able to match your name to what you said.

Is this research study confidential?



All information that you give us will be kept private.



Only the NDA research team will see the data collected for this research study.



The data will be stored safely on our IT system.

Is this research study confidential?



The Court has given permission for wards to take part in this research study.



The people taking part will be given a code or number on our data.

We do not use their names.



We may use something you said in the research report but nobody will know who said it.

Is this research study confidential?



Copies of consent forms will be kept for two years after the research study is finished.



All other personal data will be destroyed when the final report is published.



If you tell us something that makes us worried about your safety or the safety of others, we may need to share this information.



We will talk to you about this first.

We will only share information with people that can help you.

Ethical approval



Ethics means making sure that a research project has the right values and ways of working.



The NDA makes sure that the highest standards are followed in all its research activities.



The NDA's Research Ethics Committee has given their agreement for this research study.



Agreement has also been given by the Health Research Consent Declaration Committee.

Results



The results of the study will be published in reports. There will be no names or personal information in the reports.



The reports will be on the NDA website. There will be an Easy to Read version of the report. You can be sent a copy of the report if you wish. We will have to keep your contact details if you want us to send you a copy of the report.



The results may be presented at meetings, conferences, and in journals.



Data collected during this study may be used for further research. There will be no names on this data.

Where can I get more information?



If you have any questions you can get in touch with us by phone or email.



Dr. Caroline O’Nolan is the manager and lead researcher for this study.

01 608 0400



You can email the research team at:

wardsresearch@nda.ie



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The Data Protection Officer is Mr. Stephen Patten
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the National Disability Authority.



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together.

Experts by Experience helped with this
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