



Mapping the availability of services for adults with cerebral palsy

Information Leaflet

We are conducting a survey to map available services for people with cerebral palsy who are aged 18 years and older.

Before we share the survey widely, we want a small number of people to complete it in order to see if it is easy to complete and if we get the information we need from it.

We are looking for adults with cerebral palsy, parents/family members/partners of adults with cerebral palsy, and people who provide services to adults with cerebral palsy to complete the survey. You must be 18 years or older to complete the survey.

We only want to know about services in your area or services you are aware of. The survey is anonymous. Your response will help us to create a list of existing services and to improve the survey so that we can share it more widely.

This survey is part of the Ignition study, which aims to improve the process of transitioning from children's to adults' services for young people with cerebral palsy in Ireland. More details about the Ignition study and this survey can be found on our website:

www.ignitionstudy.com

If you have any questions about this research, you can contact:

Dr. Jennifer Fortune by emailing ignitionstudy@rcsi.ie or calling 0877196661

You can find out more about the study and the research team by visiting our website www.ignitionstudy.com

Why is this study being done?

Transition is the process of planning for the needs of young people as they move from child-centred to adult-oriented health services. We examined how transition is managed for young people with cerebral palsy in Ireland and explored the views of young people, their families and health professionals on how to improve this process in the Ignition study. Young people, families, and health professionals told us that they want a list of services that are available to adults with cerebral palsy. The aim of this survey is to map available services for people with cerebral palsy. Before we share the survey widely, we want a small number of people to complete it in order to see if it is easy to complete and if we get the information we need from it.

Who is organising and funding this study?

This research is being conducted by researchers in the Royal College of Surgeons in Ireland (RCSI). This research is funded by the Health Research Board (HRB) and Central Remedial Clinic.

Why am I being asked to take part?

We are looking for adults with cerebral palsy, parents/family members/partners of adults with cerebral palsy, and people who provide services to adults with cerebral palsy to complete the survey. We have invited you to take part because we think you meet these criteria.

How will the study be carried out?

We will collect information about services in Ireland that are available for people with cerebral palsy who are aged 18 years and older using an online survey.

What will happen to me if I agree to take part?

If you want to take part in this study, you can complete the survey online. Completion of the survey indicates that you consent to take part. You can decide to stop completing the survey at anytime; the answers you provide will not be recorded unless you submit the survey by pressing finish.

We would also like to find out how easy you found the survey to complete. When you finish the survey there will be an option to follow a link to provide feedback on the survey. You can leave

feedback anonymously or you can leave your contact details to provide feedback. Any contact details you provide will be recorded separately and cannot be linked to your survey responses ensuring the survey is anonymous.

What are the benefits?

There are no direct benefits to you taking part in this research. However, we hope that this research will improve the process of moving from child to adult health services for young people with cerebral palsy in Ireland and will support adults with cerebral palsy to find services.

What are the risks?

The study will take up some of your time, which might be an inconvenience. We have included the minimal number of questions so the survey should take 5 minutes or less.

Will it cost me anything to take part?

It will not cost you anything to take part in this research. If you want to complete the survey with a researcher over the phone, please contact us by email or telephone.

Is the study confidential?

The survey is anonymous and confidential. We will not collect any personal information.

The research team

Dr. Jennifer Ryan (RCSI) is leading this research. You can contact Jennifer Ryan by emailing jenniferryan@rcsi.com or phoning **01 402 2413**. Dr. Jennifer Ryan is also the data controller as she decides why and how your information is processed.

Thank you for taking the time to read this and considering taking part in this study.