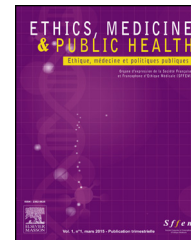




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DISABILITY / *Studies*

The introduction of a legal framework for advance directives in the UN CRPD era: The views of Irish service users and consultant psychiatrists



L'introduction d'un cadre juridique pour les directives anticipées dans la convention des Nations unies : l'opinion des patients et des psychiatres consultants en Irlande

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Ireland

Summary The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) requires us to engage in new approaches to mental health decision-making and to develop a range of support strategies. Advance directives (ADs) are considered to be appropriate measures for supporting legal capacity by enabling individuals to clearly state their 'will and preferences' in a legal document and to appoint a trusted person to communicate these wishes. This article examines the issues arising in relation to the introduction of ADs from the perspective of 111 Irish service users¹ and 100 consultant psychiatrists. The aim of the empirical study was to determine the views of service users and consultant psychiatrists towards the introduction of ADs and the extent they will be supported in Ireland. This was achieved by examining the views and preferences of both stakeholder groups, and the perceived benefits and barriers to implementation. The empirical study was the first national survey exploring the introduction

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¹ In this article, the term 'service user' is used to refer to those with a lived experience of mental unwellness and involved with mental health services for treatment. The term 'consumer' is often used in the U.S. The World Network of Users and Survivors and Psychiatry use the term 'survivor'.

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of ADs for mental health decisions in Ireland. The survey found broad support for ADs among Irish stakeholders, but varying implementation preferences. Ireland currently lacks a legislative framework for ADs, but it is proposed to incorporate them into new capacity legislation in the near future. This is viewed as a key step towards Irish ratification of the UN CRPD. The article makes recommendations for the introduction and implementation of an appropriate legal framework for ADs in Ireland and other jurisdictions in the UN CRPD era.

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MOTS CLÉS

Directives anticipées ; Santé mentale ; Prise de décision assistée ; Convention des Nations unies sur les droits des personnes handicapées ; Irlande

Résumé La Convention des Nations unies sur les droits des personnes handicapées (CDPH ONU) nous oblige à engager de nouvelles approches de prise de décision en santé mentale et de développer une gamme de stratégies de soutien. Les directives anticipées (DA) sont considérées comme des mesures appropriées pour soutenir la capacité juridique en permettant aux individus de déclarer clairement leur « volonté et préférences » dans un document juridique et de nommer une personne de confiance pour communiquer ces souhaits. Cet article examine les questions qui se posent par rapport à l'introduction de DA auprès de 111 utilisateurs de services irlandais et 100 psychiatres consultants. L'objectif de l'étude empirique était de déterminer les points de vue des utilisateurs de services et psychiatres consultants vers l'introduction de ces directives anticipées en Irlande. Les opinions et préférences des deux groupes ont été examinées, et les avantages et les obstacles à la mise en œuvre perçus. L'étude empirique a été la première enquête nationale à étudier l'introduction de DA pour les décisions en santé mentale en Irlande. L'enquête a révélé un large soutien pour les DA, mais on observe des préférences de mise en œuvre différentes. L'Irlande manque actuellement un cadre législatif pour les DA, mais il est proposé de les intégrer dans la nouvelle législation sur la capacité dans un avenir proche. Cela est considéré comme une étape clé vers la ratification irlandaise de la CDPH ONU. L'article fait des recommandations pour l'introduction et la mise en œuvre d'un cadre juridique approprié pour les DA en Irlande et d'autres juridictions dans le cadre de la convention des Nations unies.

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Introduction

Advance directives (ADs) are legal statements that allow individuals to outline treatment preferences and other life choices prior to a mental health crisis. The measure is increasingly recognised as an important supported decision-making tool in mental health care. The UN CRPD requires State Parties to adopt measures that support the exercise of legal capacity. The re-conceptualisation of ADs under the UN CRPD views them as vehicles for building decision-making capacity, supporting the articulation of preferences and recovery tools. The successful implementation of a legal framework for ADs is dependent on the support of key stakeholder groups involved in development and enforcement. The aim of the empirical research is to determine the views and preferences of Irish service users and consultant psychiatrists towards the introduction of ADs. Ireland currently lacks legislative provisions for ADs but it is planned to incorporate them into the Assisted Decision-Making (Capacity) Bill 2013. This new legislation proposes to provide a modern statutory framework for those who need assistance in making decisions in Ireland and is viewed as a key step towards Irish ratification of the UN CRPD. The findings of the study will assist legislators to draft and effectively implement a framework for ADs. The Irish legal framework provides an

opportunity to implement UN CRPD compliant ADs in mental health decision-making and to reduce barriers to implementation.

Methods

The empirical study used a mixed methods design to synthesise both quantitative and qualitative data to provide a robust understanding of preferences and choices in relation to ADs [1]. The study was approved by the Research Ethics Committee (REC) at the National University of Ireland, Galway and partially funded by the Irish Mental Health Commission. All participants were provided with information sheets and provided written consent to the survey.²

The participants in the survey were 111 mental health service users and 100 consultant psychiatrists based in Ireland. Service users ranged in age from 18 to over 61 years old and included 60 female and 49 male participants.³ Over a quarter (25.5%, 28/110) of service user participants

² Incentives such as book prizes and book tokens were used for service user and consultant psychiatrist participants.

³ Two participants did not specify their gender.

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