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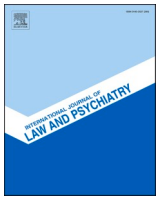
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Research Paper



Comparing mental health and mental capacity law data across borders: Challenges and opportunities

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ABSTRACT

The island of Ireland is partitioned into Northern Ireland and the Republic of Ireland. In both jurisdictions, there have been important developments in mental health and mental capacity law, and associated policies and services. This includes an emphasis on developing more comprehensive approaches to collecting data on outcomes and so there is an opportunity to align these processes to enable comparison and shared learning across the border. This article explores: legal and policy developments; international approaches to mental health outcomes; and the type of data that would be helpful to collect to better understand the use of mental health and mental capacity laws. It is argued that an inclusive strategy to developing a comprehensive, integrated and aligned approach to collecting and analysing data would benefit citizens, policy makers and professionals.

1. Introduction

The island of Ireland was partitioned by the Government of Ireland Act 1920, which was implemented in 1921. Northern Ireland, made up of six counties in the North-East of the island, remained part of the United Kingdom, and has a population of approximately 1.9 million. The 26 counties of the Republic of Ireland (often just referred to as Ireland), became independent of British rule, and has a population of approximately 5.1 million. Having two jurisdictions, on a relatively small island with similar geography, population needs and structures for the provision of health and social care, presents opportunities for comparing data that could help understand and inform the development of health and social care law, policy and services. Political conflict, however, especially in Northern Ireland during the period from 1969 until the Good Friday Agreement in 1998, inhibited cooperation and comparison. Over the last 25 years structures and efforts to build relationships and facilitate cooperation have been developed.[1] It should be acknowledged, from the start, however, that it is important to be cautious about comparison between jurisdictions, sometimes referred to as natural experiments (Medical Research Council, 2011), as there may be many variables involved. Comparison, nonetheless, does have the potential to identify similarities and differences, and so, at the very least, raise questions about what might be causing these patterns.

A specific opportunity for comparison is that there have been important, parallel, recent developments in mental health and mental capacity law in the Republic of Ireland and Northern Ireland. The use of compulsory or non-consensual intervention under mental health and mental capacity laws facilitates service provision to certain people, but also raises concerns about: infringements of rights; the potentially negative impact of compulsion; possible discriminatory variations in

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[1] For example, the current Shared Island Initiative, a partnership between the Irish Government, the British Government and the Northern Ireland Executive, which is supporting research to explore strategic challenges on the island of Ireland.

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implementation; and the effectiveness of the intervention. There are also much wider, international debates, often in relation to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), about the use and impact of compulsory intervention (Szmukler, 2017; Wilson, 2018; Wilson, 2021). Article 31 of the UNCRPD also requires states to collect the information needed to enable the implementation of states' obligations under the Convention. In order to monitor, explore and address these issues, data are needed about the use, experience and effectiveness of mental health and mental capacity laws. Compulsory intervention under mental health and mental capacity law is usually based on high levels of 'mental disorder' and/or impaired decision-making ability, and often concerns about risks of harm to the person and/or other people. These issues, especially of ability to consent and of risk of harm, mean that traditional experimental designs used to explore possible variations and effectiveness, where there is an opportunity to allocate participants, ideally randomly, to intervention and control groups, can present considerable ethical challenges (Dawson, 2002; Dawson & Sim, 2015). An alternative approach is to collect data on the use of compulsory powers, and other potentially relevant variables, and then compare within and between countries.

On the island of Ireland there have also been important developments in mental health and mental capacity law, policy and practice. These appear to have largely happened in parallel with very limited, direct communication or collaboration between the relevant governments' departments but these changes encourage opportunities for comparison. In the Republic of Ireland, the current Mental Health Act 2001 was implemented in 2006. Following a review of the Mental Health Act published in 2015, a Draft Heads of Bill to amend the Mental Health Act were published in 2021, although progress on the legislation has been slow. The Assisted Decision-Making (Capacity) Act 2015 was fully commenced in 2023. In Northern Ireland, the Mental Health (Northern Ireland) Order 1986 and the Mental Capacity Act (Northern Ireland) 2016, which has only been partially implemented, provide the legal framework. The partial implementation of the Mental Capacity Act (Northern Ireland) 2016 provides a legal framework when people, despite support, are unable to make the relevant decision/s and are deprived of their liberty in circumstances not covered by the Mental Health (Northern Ireland) Order 1986. It is proposed that, when the Mental Capacity Act (Northern Ireland) 2016 is fully commenced it will replace the Mental Health (Northern Ireland) Order 1986 for those aged 16 and over but that is dependent on the necessary resources being available and it is uncertain when that will happen.

Further drivers for comparison across the border include recent policy developments in both jurisdictions. In the Republic of Ireland, the Department of Health's (2020) *Sharing the Vision: A Mental Health Policy for Everyone* stated that "To establish targets, allocate resources and set mental health priorities, standardised performance indicators (PIs) and targeted service outcome data are required." (p. 75). These objectives were further elaborated upon in the *Implementation Plan 2022–2024* (Health Services Executive and Department of Health, 2022) which provided an organising framework for collecting data on outcomes. In Northern Ireland, the *Mental Health Strategy 2021–2031* (Department of Health, 2021) identified outcomes for each of the planned service developments and included a specific action to "develop a regional Outcomes Framework in collaboration with service users and professionals, to underpin and drive service development and delivery…To ensure we have the right services that meet the needs of the population, we must have data to measure outcomes…This will help in the evaluation of what works and will ensure services are provided that deliver good outcomes for people while providing value for money." (p. 87). The need for more robust data was also identified by the Office of Statistics Regulation (2021) which completed a *Review of mental health statistics in Northern Ireland*, concluding that: "There is a scarcity of robust mental health data in Northern Ireland. This has hindered the development of official statistics, meaning that there are significant and fundamental data gaps. For example, statistics cannot tell us how many people are accessing mental health services in Northern Ireland and whether their needs are being met. This means it is also difficult to evaluate the delivery of mental health services and understand the outcomes for individuals." (p. 5).

This article aims to address three main questions:

1. What information is currently available to enable exploration and comparison of the law, policy and practice relevant to mental health and mental capacity law on the island of Ireland?
2. What should be included in outcomes frameworks that would enable the routine presentation and comparison of the key variables relevant to mental health and mental capacity law?
3. What specific data on the use of mental health and mental capacity law should be collected on both sides of the border to enable comparison and joint learning?

2. Methods

The first question, on current law, policy and practice was addressed through the delivery of a Working Paper (Farrell et al., 2022) which used a traditional narrative review approach (Greenhalgh, Thorne, & Malterud, 2018) to provide a critical analysis of mental health and mental capacity laws, policies and practices across both jurisdictions. This included analysis of the wider contemporary policy and practice landscapes, as well as the potential implications for future research.

The second question, on what should be included in outcomes frameworks to enable analysis and comparison of the key variables relevant to mental health and mental capacity law, was addressed through a rapid review. A rapid review involves a systematic approach to searching the literature but then allows a selective approach to include the most relevant literature (Tricco, Langlois, & Straus, 2017). The review was completed as part of the implementation of the *Mental Health Strategy 2021–2031* (Department of Health, 2021) in Northern Ireland but includes consideration of the related developments in Ireland. It is organised in three parts: existing international approaches; what an outcomes framework should include; and issues to be considered for implementation (Davidson & McCartan, 2021, 2022a, 2022b).

Finally, although the Working Paper and the outcomes rapid review had highlighted the need for better and directly comparable data specifically on the use of mental health and mental capacity law, they did not explore how that should be done and so the third question was explored through a focused narrative review (Greenhalgh et al., 2018) which identified and analysed some of the previous attempts to collect and present comparable international data specifically on the use of mental health law.

3. Results

3.1. What information is currently available to enable exploration and comparison of the law, policy and practice relevant to mental health and mental capacity law on the island of Ireland?

The Working Paper (Farrell et al., 2022) explored similarities and differences in the structures of health and social care, legal frameworks and the policy context across and between the jurisdictions and then provided some suggestions for a joint research agenda on mental health law and policy.

It found that the structures for health and social care are similar across both jurisdictions. They are underpinned by mostly publicly funded services although there is a greater reliance on private health insurance and charging in the Republic of Ireland when compared to Northern Ireland where most services are free at the point of delivery. Interestingly, in contrast to Great Britain (England, Scotland and Wales), both jurisdictions use integrated forms of health and social care services, albeit with different, often changing models of organisation and delivery. In terms of oversight, in the Republic of Ireland two key

government bodies inspect and quality assure services. The Health Information and Quality Authority (HIQA) oversees health and social care provision whilst the Mental Health Commission has quality assurance responsibility for mental health services. Across its wide remit, the Commission has oversight of the use of the Mental Health Act 2001, and, more recently the Decision Support Services which has a key role in implementing the Assisted Decision-Making (Capacity) Act 2015. In Northern Ireland, there had been a separate Mental Health Commission but, under the Health and Social Care Reform (Northern Ireland) Act 2008, its functions transferred, in 2009, to the Regulation and Quality Improvement Authority (RQIA), the equivalent of HIQA.

The Mental Health Act 2001, in the Republic of Ireland, and the Mental Health (Northern Ireland) Order 1986 can both be described as traditional 'mental disorder' and 'risk' based legal frameworks, which define the procedures by which people may be detained in in-patient settings. For example, the criteria for compulsory admission in the Mental Health Act 2001 are that the person is experiencing 'mental disorder', which is defined, in Article 3(1), as "mental illness, severe dementia or significant intellectual disability" and, as specified in Article 3(1)(a), "because of the illness, disability or dementia, there is a serious likelihood of the person concerned causing immediate and serious harm to himself or herself or to other persons" or, as detailed in Article 3(b) " (i) because of the severity of the illness, disability or dementia, the judgment of the person concerned is so impaired that failure to admit the person to an approved centre would be likely to lead to a serious deterioration in his or her condition or would prevent the administration of appropriate treatment that could be given only by such admission, and (ii) the reception, detention and treatment of the person concerned in an approved centre would be likely to benefit or alleviate the condition of that person to a material extent." In the Mental Health (Northern Ireland) Order 1986 the criteria for compulsory admission, as set out in Article 4 are that the person is (a) "suffering from mental disorder of a nature or degree which warrants his detention in a hospital for assessment (or for assessment followed by medical treatment); and (b) failure to so detain him (sic) would create a substantial likelihood of serious physical harm to himself or to other persons." They also provide similar safeguards including requirements for the assessment process and for review by a Tribunal.

The Assisted Decision Making (Capacity) Act 2015 (ADMCA) and the Mental Capacity Act (Northern Ireland) 2016 (MCANI) are also broadly similar in providing a framework of support for decision-making and procedures for when a person, even with support, is unable to make the relevant decision. They both set out similar guiding principles and adopt a functional approach to the assessment of capacity. The ADMCA applies to everyone aged 18 and over, and the MCANI to those aged 16 and over. The ADMCA introduces a more structured approach to support for decision-making with the Decision Support Service and specific roles, but the general approach is similar under the MCANI. Two key differences are that the ADMCA does not provide a framework for the deprivation of liberty of those who lack the relevant decision-making ability and there are proposals for a separate framework for those safeguards (Donnelly & Gleeson, 2021) whereas that is arguably, and certainly currently, the main focus of the MCANI. The other key difference is that the ADMCA is intended to work in parallel with the Mental Health Act 2001 but the MCANI is intended, when fully commenced, to replace the Mental Health (Northern Ireland) Order 1986 for everyone aged 16 and over.

There are also clear similarities in the current policies, *Sharing the Vision: A mental health policy for everyone* (Department of Health's, 2020) and the *Mental Health Strategy 2021–2031* (Department of Health, 2021). Both are ten-year strategies which embrace the recovery approach as the foundation of mental health policy and focus on: population level mental health promotion and prevention across the life course; the central importance of involving service users and carers; and the need for a data-informed outcomes based approach to mental health care.

In conclusion, the Working Paper highlighted the opportunities that the recent development of these legal and policy frameworks creates, leading to three main implications. The first is the need for an agreed mental health dataset to facilitate comparison of the need for services, the provision of services, and outcomes for service users and carers. The second is the opportunity to develop an agreed approach to the evaluation of the implementation of the relatively new capacity-based laws. Finally, the review identified the potential benefits of the development of a wider joint research agenda which could address a number of key priorities including:

> "(i) the legal frameworks and service provision for children and young people; (ii) the implementation and effectiveness of the new capacity-based laws; (iii) the development and effectiveness of approaches to support autonomy and reduce the need for compulsory intervention; (iv) the provision of specialist services and opportunities for all island cooperation." (Farrell et al., 2022, p. 42).

These conclusions therefore raise the immediate question, if an agreed approach to data and outcomes is to be developed, what should that include and how should it be done? This was then addressed though a rapid review of the literature completed as part of the implementation of the *Mental Health Strategy 2021–2031* which is considered next.

3.2. What should be included in outcomes frameworks that would enable the routine presentation and comparison of the key variables relevant to mental health and mental capacity law?

The rapid review of the literature on mental health outcomes was organised in three parts which explored international exemplars of approaches to mental health outcomes, the main areas that should be covered in an outcomes framework and some of the issues to be considered in its development and implementation (Davidson & McCartan, 2021, 2022a, 2022b).

The exploration of international exemplars focused on selected countries: Australia, Canada, England, Ireland, Finland, France, Germany, New Zealand, Norway, Scotland, Sweden and Wales. In the process a number of key, common themes for developing an outcomes framework were identified. These included the importance of the use of language and selection of outcomes, moving away from a narrow focus on symptoms and deficits towards including measuring 'wellbeing' and quality of life. Another theme considered how outcomes should reflect a holistic view of wellbeing (at an individual, family, community, population level) and that it is important to acknowledge the social, economic and environmental context of health and wellbeing. A common, repeated finding across countries was that co-production should be central to the approach including the need to identify what issues people, including service users and carers, feel are important to measure. The international exemplars also highlighted the importance of identifying what data are already available, and any data gaps, so that only data that are needed and will be used are collected. It was also noted that some frameworks are narrowly focused on clinical outcomes and do not provide information on context, inputs, processes or wider outcomes which may limit how the clinical outcomes can be understood.

In terms of what a comprehensive approach to a mental health outcomes framework should include, six main areas were identified: the social determinants of mental health; population needs; resources and inputs; activities and processes (for example, the number of therapy sessions provided, the length of inpatient admissions and regularity of Tribunal hearings); professional reported outcomes; and service user and carer perspectives on outcomes. At present, data about the use of mental health and mental capacity laws tends to focus mainly on activities and processes and there is much less exploration of people's experiences of these processes and their impact over time. There have been previous, important efforts to bring together and review relevant mental health outcome measures, including for specific populations (Kwan & Rickwood, 2015; Thornicroft & Tansella, 2010). Flake and Fried (2020) have highlighted some of the challenges in identifying,

defining and measuring mental health outcomes, including the variety of approaches (they mentioned there are at least 280 scales for measuring depression). There are also several important, international initiatives that seek to encourage and support the greater alignment of approaches to gathering mental health data although these tend to relate to specific outcomes rather than wider population level and services data. The initiatives include: the International Consortium for Health Outcomes Measurement (ICHOM) www.ichom.org; the Core Outcome Measures in Effectiveness Trials (COMET) Initiative www.comet-initiative.org; and COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) www.cosmin.nl.

The key messages for implementation that arose from the rapid review included the acknowledgment that data collection involves time and effort, the process needs to be streamlined, accessible and of clear importance and use to the people collecting the data. It also emphasised the imperative to identify what data is already routinely collected and useful, but also what information is currently collected but perhaps not as useful and should be stopped. A theme throughout the examination of the international exemplars and evidence considered in the rapid review was the requirement to involve service users, carers and service providers in agreeing the data that should be prioritised and how it should be collected, analysed and presented. The importance of leadership, training and support for implementing a more comprehensive approach to data and outcomes was also emphasised. The potential of technology, specifically information systems, to facilitate the collection and standardisation of data was also reported. Interestingly, this was also a theme in the important and influential work of the Steering Group on Health Services Information in the UK, chaired by Edith Korner, which produced six reports in the 1980s which still inform the data that is routinely collected today. A King's Fund report based on the initial workshops in March 1982 presciently highlighted that "Information technology is only exploited to the full when developments are information led, so that the information requirements must be identified first and only then a choice made from the wide range of technology available" (Black, 1982, p. 1228). Finally, reinforcing the main theme in this article, the findings of the rapid review highlighted the potential and benefits of developing an approach to collecting data that would facilitate comparison within and between countries.

3.3. What specific data on the use of mental health and mental capacity law should be collected on both sides of the border to enable comparison and joint learning?

In both jurisdictions, data about the use of mental health and mental capacity law tends to focus on quantifying the use of powers, for example, the numbers of assessments, involuntary admissions and Tribunals, with some limited analysis by gender and age. This data provides an important baseline which enables some comparison across the border and over time. There is, however, a lack of an agreed approach which would allow direct comparison of these metrics and other related data to better understand the wider context and, crucially, the experiences and outcomes for service users and carers when these powers are applied and their impact over time.

There have been a number of attempts to explore the use of mental health, and more recently mental capacity law within and between countries which might provide these additional, necessary insights into the Irish context. An early example by Szmukler, Bird, and Button (1981) compared the social and clinical characteristics of 150 people who were compulsorily admitted to hospital in London to 100 people who were admitted voluntarily. They reported significant differences in the characteristics between these two groups and subsequent engagement with follow-up services. Riecher-Rössler and Rössler (1993) identified the variation in the use of compulsory powers between 22 countries, all in Europe except the US, and also between regions within countries referring to Lander in Germany and states in Austria as examples. They also highlighted the challenges of comparison due to the differences in the definitions of compulsory intervention and routinely collected administrative data.

Zinkler and Priebe (2002) examined data on compulsory admissions from areas of Austria, England, Finland, Germany and Italy, identifying substantial variations. Thus, rates reported in Finland were nearly 20 times higher than those reported in Italy. They acknowledged that, in only two of the included studies, data were collected at the same time using the same method. Despite this, there was a nearly 10 times difference found between two neighbouring and similar areas in the Alpe-Adria region of Austria and Italy. One limitation reported in their research was the lack of agreed definitions of compulsory intervention or internationally agreed approaches to routine data collection. Nonetheless, this level of variation was unlikely to be explained by differences in service users' needs or minor differences in the law highlighting the need for data on: wider sociodemographic variables; professionals' attitudes and approaches; and the wider services and societal context.

More recently, Rains and colleagues found large, unexplained variability in annual involuntary hospitalisation rates across jurisdictions (Sheridan Rains et al., 2019). They compared rates across 22 European countries, Australia and New Zealand and reported that, wealthier countries and those with higher number of inpatient beds, tended to have higher rates but these factors could not explain the level of variation between countries and so noted the need for more work on this topic.

4. Discussion

Given the high levels of variation previously found there is a clear rationale to shape the collection of data about the use of mental health and mental capacity laws and other relevant variables to enable these variations within and across borders to be explored.

In order for this to happen there need to be agreed definitions of the associated terms and concepts and a common dataset for the use of mental health and mental capacity law developed including the need for considering the social, economic and environmental context of settings.

As Farrell et al. (2022) have highlighted, there are already important opportunities to compare law, policy and practice across the border on the island of Ireland. Even without alignment in the specific data collected, the similarities and differences in the legal framework, the policy focus on recovery and outcomes, and the delivery of services are all useful areas for comparative research and mutual learning. Without alignment of the specific data being collected there are limitations to direct comparison.

The rapid review of international approaches to mental health outcomes (Davidson & McCartan, 2021, 2022a, 2022b) suggested that to understand any specific aspect of mental health data, such as the use of mental health and mental capacity laws, it is important to have a wider, integrated framework which enables the use of these laws to be better understood. That includes; information at the population level, in terms of demographics and the social determinants of health; accessible information about funding and service provision; as well as professional, service user and carer perspectives on outcomes to provide some understanding of the impact and effectiveness of these interventions. It is therefore suggested that, in addition to the standard clinical outcome measures of mental health, there should be routine collection of data on subjective experiences of services, social functioning, and quality of life. The rapid review acknowledged that for this to be effectively implemented the amount of data requested needs to be manageable for those involved, demonstrably useful to them and once collected, used. It does appear that, at present, and across countries, there is a great deal of information which is routinely collected by mental health services but is not effectively used to inform policy and service development.

It would take considerable effort and resources to fully engage all stakeholders involved in developing and implementing a comprehensive, integrated and aligned approach to mental health data on the island of Ireland. On the other hand, there is already considerable time

and expenditure devoted to collecting data which often does not facilitate routine analysis and comparison. A process of supporting all involved to better understand the importance and utility of data, and accessing their perspectives on the data and data systems which would be the most accessible, efficient and useful, does have the potential to better inform many aspects of mental health law, policy and practice.

A process of engagement, and ideally co-production, with all stakeholders could also help explore what specific data on the use of mental health and mental capacity law should be collected on both sides of the border to enable comparison and joint learning. The traditional focus on gathering numbers of assessments, involuntary admissions and Tribunals, along with some limited demographics is an important start to this task, but there remain some difficulties of alignment of information across jurisdictions. As the legal frameworks develop to implement safeguards for deprivation of liberty across all settings it will be important to ensure that there is sufficient data collected to understand these wider uses of compulsory intervention. It would also seem important that this would include some routine data collection about service users', carers' and professionals' experiences of the use and effectiveness of these laws which is a relatively neglected but fundamental aspect of the data needed. There would be practical and ethical issues to consider in developing the process for seeking information about people's experiences of these laws, but this is possibly the most important data to collect. This would also have the potential to better inform the ongoing international debates about how these laws should be reformed or replaced in the future.

5. Conclusions

Given the recent developments in mental health and mental capacity law and policy, including the welcome focus on outcomes, there is an opportunity to develop a comprehensive, integrated and aligned approach to collecting and analysing data across the island of Ireland. Ideally this would be an inclusive process, which would require time and resources, but it does have the potential to enable greater understanding of the current implementation and future development of law, policy and services. This could also involve annual reporting of key, directly comparable data and perhaps making the anonymised datasets open for further analysis. The identified potential benefit of aligning data on the island of Ireland raises the possibility of seeking wider international consensus about a core, common data set about the use of mental health and mental capacity law across other countries which would enable further comparison and learning. This type of cross-border cooperation and comparison also has the potential to demonstrate the benefits of aligning data for other areas of law, policy and practice.

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CRediT authorship contribution statement

Gavin Davidson: Writing – original draft, Writing – review & editing. **Elizabeth Agnew:** Writing – original draft, Writing – review & editing. **Lisa Brophy:** Writing – original draft, Writing – review & editing. **Jim Campbell:** Writing – original draft, Writing – review & editing. **Mary Donnelly:** Writing – original draft, Writing – review & editing. **Anne-Maree Farrell:** Writing – original draft, Writing – review & editing. **Trisha Forbes:** Writing – original draft, Writing – review & editing. **Rhiannon Frowde:** Writing – original draft, Writing – review & editing. **Brendan D. Kelly:** Writing – original draft, Writing – review & editing. **Claire McCartan:** Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

None.

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