

Name: James Quintin

Degree: Masters of Science in Health Informatics

Title: Lost in translation: towards a standard hospital health passport for people with Intellectual Disability, an exploration of minimum data sets

Supervisor: Dr. Bridget Kane

Abstract

The health needs of people with intellectual disability (ID) are complex. People with ID are more likely to use hospital services than the general population yet there is evidence that hospital professionals lack the knowledge and experience to take care of them. The lack of knowledge and understanding of hospital professionals is one of the many obstacles faced by people with ID when accessing hospital services. Hospital health passports are increasingly being used by people with ID to overcome some of the barriers in accessing hospital services. Currently, there are different hospital health passports being used nationally and internationally.

The purpose of this study is to identify the minimum data requirements of doctors and nurses for a standard hospital health passport. Several research questions are stated to guide the study.

- Do doctors and nurses find taking care of people with ID more difficult compared to people without ID?
- Do doctors and nurses require more background information to care for people with ID?
- What are the implications of a standard hospital passport in relation to future hospital information systems for people with ID?
- Is there a difference between the information required by doctors and nurses for the hospital health passport for people with ID?

This study uses both qualitative and quantitative data to resolve the research questions and achieve the aim of identifying the minimum data requirements of doctors and nurses for a standard hospital health passport. Case scenarios using an ethnographical observation method is used to explore the challenges of hospital doctors and nurses when people with ID access the hospital. A survey questionnaire

was fielded to collect the opinions of hospital doctors and nurses which are measured and allow triangulation of data.

This study explores the idea of a minimum data set for a standard hospital health passport for people with ID. The content of hospital health passports from national and international sources are analyzed to form a list of items of information presented to hospital doctors (n=8) and nurses (n=35). Overall, 42 items of information are aggregated from 6 hospital health passports. All 42 items are ranked by nurses with moderate to very high importance while doctors rank 38 items with moderate to very high importance. The study shows a difference in opinion to some items of information, but more importantly, the study shows that both doctors and nurses find a majority of items to be similarly important. This is a step towards developing a standard hospital health passport for people with ID.