

Athlone Institute of Technology

A study on the care of people with Intellectual Disabilities in general hospitals in  
Ireland

Marie Mc Donnell


Submitted in part fulfilment of the MA in Advanced Social Care Practice)

12<sup>th</sup> July 2017

Word count: 13, 024

Signed declaration

I declare that this dissertation and the research involved in it are entirely the work of the author. This work, or part of it, has not been submitted for a qualification to any other institute or university.

Signature: 

Date: 12<sup>th</sup> July 2017

## Acknowledgements

This research project would not have been possible without the support and encouragement of many people. The student would like to express her gratitude to her supervisor, Brigid Delemere, for her approval, support and guidance in undertaking the research study.

I wish to thank my fiancé James Nolan for his unconditional love, understanding and patience during the completion of this study and over the last three years while undertaking this course.

I would also like to thank my beloved family for their continual support, especially my parents for their words of encouragement and faith in me at pivotal times.

Finally, I would like to acknowledge and sincerely thank all those who participated in the study. Thank you for being so abundantly generous with your time, knowledge and in sharing your personal and professional experiences with me. I hope that the present work gives you and your experiences the positive recognition they deserve.

Table of contents	Page
Abstract	5- 6
Literature Review	7- 15
Method	16- 22
Results	22- 32
Discussion	35- 44
References	45- 48
Appendices	49- 63

## Abstract

The current study examined the care of people with intellectual disabilities in general hospitals in Ireland. Participants of the study were purposefully selected to reflect the aim of the study. The aim of the study was to provide an insight into the care of people with intellectual disabilities in general hospitals, from an advocacy and service-user perspective. The sample compiled of two professionals in the disability sector, two family members and two people with an intellectual disability (ID). The study was important because it established an optimal model of hospital care in general settings for people with ID. Data collected contributed to the wider understanding of the challenges that may be encountered by a person with an ID and of the conditions for success to positive experiences in local hospitals.

Literature reviewed on the subject area suggested that there was little research on the personal experiences of people with intellectual disabilities of care received in Irish general hospitals. The literature review outlined a synopsis of relevant policy and procedure applicable to people with intellectual disabilities in Australia, United Kingdom (UK) and Ireland. The implications of the Mencap report on 'Death by indifference' was examined in the context of its influence on service provision in general hospital settings in the UK since its publication in 2007. The study employed a qualitative approach in the format of interviews. Six participants took part in the study; carers, family members and people with intellectual disabilities. All participants had an experience in the past of care of people with intellectual disabilities in general hospitals, either from a service-user or advocate perspective. A summary of the findings were: effective communication between medical staff and service-users was identified as an important feature of a positive hospital experience, conflicts of interest between care staff and hospital staff occurred over issues about discharge of patients and the lack of training on disability observed in hospital staff practices, positive experiences in hospital were reported to be occurring where careful considerations have been implemented in the provision of care, and people with intellectual disabilities benefited from special accommodations such as the tailoring of appointments and procedures to meet the individual needs of the person with ID. Recommendations were made in relation to the actions required to achieve an

optimal model of care, the introduction of specialised training to enhance the confidence and competency of hospital staff, and the benefit of conducting future studies to include the views of medical staff.

## Literature review

### Introduction

This is a small scale study that proposes to explore the care of people with intellectual disabilities in general hospitals. The overall aim of the study is to gain an insight into the lived experiences of people with intellectual disabilities about their the care received in general hospitals. This will be achieved by listening to their stories directly and through the lens of care-givers and supporting family members of people with intellectual disabilities. On completion of the study, it is hoped that the study will contribute to a wider understanding of the challenges that may be encountered by people with intellectual disabilities while in hospital and establish the conditions for success to a satisfactory hospital experience for vulnerable adults.

Census records from 2011 showed that there were 44, 952 people in Ireland who were recognised as having an intellectual disability (Central Statistics Office, 2012). People with intellectual disabilities (ID) can often present with complex health conditions subject to the characteristics of their individual diagnoses. Associated health care needs may include, but are not exclusive to, constipation, risk of aspiration, sensory impairments, recurrent chest infections, diabetes, epilepsy, hepatitis B, dysphasia and heart defects (Blythe & Buchan, 2017). In situations whereby people with ID are presenting with multiple health conditions and have intricate care needs, poly-pharmacy is a likely feature of treatment in institutions and residential services. Poly-pharmacy is a generic term which describes the use of a broad range of prescribed medications, of varied class, in managing health conditions. For example, a concoction of non-steroidal anti-inflammatory drugs, antipsychotic medication, sedatives and analgesics could typically form an individual's regular daily prescription. Poly-pharmacy can negatively impact on one's health as a direct result of side effects and complications linked to medications (Bhaumik, Branford, Barrett & Gangadharan, 2015). It is reasonable to assume that people with intellectual disabilities frequent general hospitals over a life span.

This chapter will examine literature to date on similar studies in order to establish existing research relevant to the subject area and to provide a theoretical background to the discussion. By the end of the chapter, scope for further investigation will be identified. Four topic areas will be discussed. Firstly, significant differences between the Health Service Executive (HSE) in Ireland, the National Health Service (NHS) in the United Kingdom, and the State funded health care system Medicare in Australia are identified in the context of legislation affecting the healthcare provision to people with disabilities. Then, the 'Death by indifference' report published by Mencap in the UK in 2007 will be acknowledged for how it has influenced positive change for the experiences of people with intellectual disabilities receiving care in hospitals in the UK (Mencap, 2012). Mencap is a charity set up in the UK which works with and on behalf of people with intellectual disabilities, their families and carers in advocating for a better quality of life. Mencap were responsible for uncovering the inequalities experienced by six people with ID in receipt of State healthcare which resulted in their untimely death. Death by indifference documents the investigation. Thirdly, the fundamental role that communication plays in hospitals is outlined in the context of its impact on the experience of a person with a learning disability in a hospital. Finally, the gap in research on experiences of people with learning disabilities in Irish hospitals is explored. Subsequently, the foundation is set to explain the rationale of the current study.

Policy and legislation on health care provision relevant to people with intellectual disabilities across Australia, Ireland and the United Kingdom

The Australian Government commissioned a report called 'Shut Out: The Experiences of People with Disabilities and their Families in Australia; the report launched in 2009. The report, which was an account of a national discussion that took place about disability, presented the feedback from over seven hundred respondents including individuals with ID, family members and organizations in the disability sector. Participants in the discussion paper were asked to answer specific questions about barriers in the community, personal experiences of discrimination and recommendations for local and national action. Findings in the report influenced the establishment of the National Disability Strategy which is a ten-year framework in



place to improve the quality of lives of people with intellectual disabilities in Australia (National People with Disabilities and Carer Council, 2009). One story recalled in the process told of a man who reported that he was not considered as a candidate for an organ transplant because he had a disability. Reform in mainstream health services for people with ID was shortlisted as one of six key areas categorized in need of improvement. Action plans in the National Disability Strategy require that all allied health services meet the needs of people with disabilities by providing accommodations both structurally and in the form of service-user friendly information and facilities. The introduction of health initiatives specific to the health care needs of people with disabilities and dual-diagnoses was also proposed as an action. Dual-diagnoses refer to a term used to describe someone who has an intellectual disability and another diagnosis usually of mental health origin. The strategy is designed on a preventative model with the aim to prolong the life-span of people with disabilities whilst enhancing their overall quality of life (Lacono, Bigby, Unsworth, Douglas & Fitzpatrick, 2014; Commonwealth of Australia, 2011).

The Government of the United Kingdom is admirable in terms of being proactive and advanced in their approach to accessibility to healthcare services under the NHS. In particular, when contrasted with the Irish Health System (HSE); for example, all residents of the United Kingdom can avail of free medical care cover under the NHS as opposed to the means test for qualification for a medical card under the HSE in Ireland (Aspalter, Uchida & Gauld, 2012). In England, there are 1.1 million people registered as having a learning disability and as citizens of the UK they automatically have access to and benefit from free healthcare. In contrast to Ireland, the UK's publication 'Valuing People, a new strategy for Learning Disability for the 21<sup>st</sup> Century' which was published in 2001 and replaced in 2009 with 'Valuing people now: a new three year strategy for people with learning disabilities' has yet to be updated since its last conclusion date of 2012. However, the latter strategy has been influential as it made possible the recruitment of Learning Disability Liaison Nurses in general hospitals nationally in the UK. The appointment of these new roles was purposeful to facilitate better quality service and informed care for people with a learning disability whilst enhancing the effectiveness of course of treatment. Liaison nurses are specialized in intellectual disability and their appointment to the role is

envisaged to reduce any possible risks associated with misdiagnosis as a result of miscommunication (Gates & Mafuba, 2015; Government of UK, 2009). A pivotal role of liaison nurses in the UK is to avoid the ultimate risk; that is, unnecessary death in patients.

In Ireland, the National Disability Inclusion Strategy, which originated in 2004, has entered into its third and final phase of the new plan 2016- 2020. The preceding phases involved consultation with relevant parties and the development of preliminary themes and action plans. Phase three welcomes critique of proposed action plans and recommendations for implementation. Proposed actions in phase three are reported under different themed. Plans under 'Health and Well-being' envisage the mainstreaming of hospital services to enhance communication and facilitate equal accessibility to information and resources for people with ID. However, there are no specific details in the document as to how the government aim to achieve the set-out actions (Department of Justice and Equality, 2016). The long-awaited Assisted Decision-Making (Capacity) Act was passed into law at the end of December 2015. The Act replaces the Lunacy Act of 1871. It will have a positive impact on the decisions made by people with intellectual disabilities about their own medical affairs. The act provides a person with intellectual disability, whose capacity to make a decision is compromised, with a legal right to an assistant or joint assistants who will act as a catalyst in providing, explaining and interpreting relevant information. The enactment of the legislation is a stepping-stone for Ireland in ratifying the UN convention on the Rights of People with Disabilities (Inclusion Ireland, 2016).

The United Nation Convention on the Rights of Persons with Intellectual Disabilities is a universal convention which was introduced in 2006 as a movement directed towards shifting perceptions of people with intellectual disabilities from that of recipients of charity and medical treatment to equal citizens who are decision-makers and valued members of society. Australia ratified the convention into law in 2008. The convention was ratified in the United Kingdom in 2009. Ireland, although a signatory to the Convention since 2007, has yet to ratify the convention and will not

satisfy the criteria of ratification until pertinent legislation is amended at a national level.

The significance of the Mencap Report 'Death by indifference'

Charity organization and service watchdog Mencap published estimated annual mortality rates stating that over a thousand people with intellectual disabilities die unnecessarily in the care of the NHS (Blakemore, 2013). However, the Mencap report on 'Death by indifference' 2007 has been instrumental in the advancements in healthcare provision for people with intellectual disabilities in the UK. The report accuses the NHS of failing six citizens with learning disabilities over a two year period while under the care of public health services. All six people died as a result of alleged inadequate healthcare (Gates & Mafuba, 2014). In response to the controversial report 'Death by indifference', an independent inquiry into the quality of healthcare provided to people with ID in the UK was commissioned in 2008 called 'Healthcare for all'. The independent inquiry coincided with the publication of the 'Valuing people now strategy'. The key recommendations from the inquiry are included in the most recent strategy plan. Inquiry recommendations and government responses proposed the following actions for mainstream healthcare services (Department of Health, 2009):

- ✓ Educational institutions to develop and include mandatory training on intellectual disability in undergraduate course curricula for clinicians
- ✓ General health services to develop relevant assessments to determine appropriate care provision in meeting the individual healthcare needs of people with intellectual disabilities
- ✓ Implementation of an annual health-check register for people with intellectual disabilities and annual health checks are to be provided locally by individual's General Practitioners (GPs). GP's to receive specific training from liaison staff
- ✓ The department of health to increase awareness about avoidable death, such as that identified in the Mencap report, and to execute an inquiry for learning and preventative purposes

## The role of effective communication in hospitals and empirical recommendations for improvement

Blair (2013) reported how simple mistakes in miscommunication can induce clinical risk in treatment in hospitals. He warns that there is a tendency for a consultant's professional judgment to become impaired due to general misconceptions made about disability. Blair proceeds to defend the importance of hospital passports, their development and appropriate use. The hospital passport is a document devised in a traffic-light designed template to highlight valuable personal profile information, at a glance. Sections in the red include allergies and medical history, the amber allows for details on "keeping safe" and "how I communicate", and in the green section there are statements such as "things I like" and "things I dislike". Bell (2012) also comments on the useful function of the hospital passport in minimizing barriers to communication. Bell (2012) evaluated the function of the hospital passport through purposeful sampling. She found that the participants of the evaluation study, eight of whom had an ID, lamented about the impact of poor communication in the past. Informed consent, trust and information-sharing were often compromised by clinical staff in situations where communication broke-down. Understandably, the hospital passport was a welcomed communication aid by study participants. Hospital passport templates are available for families and carers from the local doctors, community disability teams and hospitals. Their use is encouraged by relevant healthcare professions to enhance communication between hospital staff and people with ID while in hospital (NHS, 2015).

Castles, Bailey, Gates and Sooben (2013) evaluated a newly established learning disability nursing liaison service within a large hospital setting in the UK, and found that the new service was beneficial to all stakeholders. The liaison nurses had received specific training applicable to supporting people with ID which assists in determining immediate health care needs promptly, accommodates moral support for colleagues who are untrained, and provides a sense of inclusion and understanding for the service-user.

There is little research on the perspectives of service-users as patients and on potential challenges faced when in receipt of care in general hospitals. However, a study carried out by Gibbs, Brown and Muir (2008) report on the experiences of people accessing general hospitals in the UK. The sample recruited for the study included adult participants with intellectual disabilities, and support-workers and family members of people with intellectual disabilities. Gibbs et al initiated the study in response to recognized gaps in research. They believed that existing research predominantly focused on accessibility to healthcare and less on actual personal experiences. Emerging themes from data gathered included feelings of fear and lack of understanding associated with hospital visits. There were mixed experiences in relation to whether the patient was directly spoken to by hospital staff or whether the hospital staff directed all communication to the accompanying family member or advocate. There were reports that the lack of easy-accessible information and little preparation for appointments and admissions form other communication barriers while in hospital. Protocols practiced on discharge of the patient were reported to be of positive experiences. However, a comprehensive handover between nursing staff on shift was not always occurring, according to the participants. A similar study completed in Australia by Webber, Bowers and Bigny (2010) reported positive experiences of effective communication. For example, if it was predetermined that a patient with ID was fearful about an upcoming procedure, the hospital would invite that person to the hospital in advance of the procedure and facilitate a tour of the hospital to familiarize the patient with the setting and also to introduce the person to clinical staff that would be involved in their care. However, in the study the positive experiences are attributed to specific hospitals who have adapted similar policies, procedures and systems to specifically accommodate people with intellectual disabilities. Howieson (2015) undertook a small study within a focus group to inquire about care experienced in hospitals in Scotland. Seven people with mild to moderate disabilities participated in the study. The nature of the study appeared to focus on the assessment of reasonable accommodations available in hospitals for out-patient appointments and admissions. The results showed that participants complained about the lack of the provision of easy-to-read information such as appointment letters, long periods of waiting to be seen and of environmental barriers such as

being an allocated a private room in isolation as opposed to admission onto a ward. The participants in the study did not indicate any positive experiences.

The experiences of people with ID of care in general hospitals- an Irish perspective

In contrast to the United Kingdom and Australia, there are minimal studies published in Ireland to represent the experiences of people with ID in Irish hospitals. One exception to this is a qualitative study carried out by Sowney and Barr (2005), of the University of Ulster, who aimed to investigate the barriers faced by hospital staff that had experience of caring for patients with an intellectual disability in a hospital setting. The study focused on the perspectives of nursing staff only. The study invited nursing staff participants from various geographic locations across Northern Ireland. One finding of the study indicated that there was a shared consensus amongst participants that service-users with ID benefit from having a family member or carer present throughout the hospital stay. Nursing staff admitted that their lack of specialized training and lack of frontline experience in the disability sector served as a disadvantage to their competency in delivering quality care in difficult circumstances, such as breakdown in communication. The nurses recalled how vulnerable and nervous they felt when exposed to unfamiliar situations involving a person with a disability.

The current study

It is evident that people with ID are vulnerable in terms of their physical and mental health status, which can vary depending on a range of demographics such as age, medical history, diagnoses and medication profile (Gibbs et al, 2008). It has been established that people with intellectual disabilities go to hospital, and that their experiences there can be varied. It is common for a typical patient to have an unpleasant experience in the hospital; thus, a patient does not necessarily need to have an intellectual disability to have a negative experience. A recent statistic that the amount of people admitted to hospital and left on trolleys in Irish hospital peaked to its highest record of 612 in January this year. This statistic shows that unpredictability of service provision can be experienced by all patients, not just prevalent to people with intellectual; disabilities (Hilliard, 2017). However, there is

little research on the personal experiences of people with ID of care received in Irish general hospitals. It is important to further investigate to explore the experiences of people with ID of health service provision in general hospital settings. The study will endeavor to identify the factors which influence a positive experience in hospitals for adults with additional needs whilst seeking to establish an optimal model of hospital care for people with an intellectual disability.

A qualitative methodology will be employed to collect data for the current study. Service users, their carers and immediate family members will be interviewed. The methodology will be discussed in more detail in the following chapter.

## Method

### Research design

The subject area of ‘the care of people with intellectual disabilities in Irish hospitals general hospitals’ was chosen as the topic area to study with the aim to gain an insight into the lived experiences of people with intellectual disabilities about their time spent in general hospitals. The researcher engaged in secondary research by gathering information from current literature, analyzing empirical data from journal articles and relevant websites. Interviews were carried out with service-users, family members and carers to explore their experiences of hospitals as either a patient or as an advocate for someone with an intellectual disability. The interviews were designed to gain an insight into the first-hand experiences of the hospital care provided to people with intellectual disabilities. A qualitative approach was employed to facilitate more personal accounts of people’s experiences. The advantages of qualitative research are detail, exploration and sensitivity (Dahlberg and McCaig, 2010). The advantages influenced the choice of interviews as the primary method of research in the following ways:

- ✓ *Detail-* Interviews facilitate the opportunity to get specific detail about experiences as to fully comprehend the overall picture.
- ✓ *Exploration-* Interviews allow scope to probe for information, particularly in areas where the interviewer may lack specific knowledge. This method is more suited to achieving the aim of the current study; whereas, a quantitative approach would require the pre-formulation of exact questions; for example, on questionnaires.
- ✓ *Sensitivity-* Interviews provide interviewers with the opportunity to build trust with participants as interaction occurs in the advance preparation stage of the interview itself such as preview of proposed questions, provision of information of study and personal introduction of the researcher to the participant. People with intellectual disabilities are naturally more vulnerable as a result of their biological profile; exposing them to reliance on service provision throughout their lives and to potential infringement of human rights



(Robinson, 2013). Therefore, the researcher was mindful of sensitivity as a deciding factor when choosing an appropriate research method.

During the research design, the researcher was conscious of the fact that the potential participants would include people with an intellectual disability. The information sheet, consent form, and questions were formulated in two versions; one in typical fashion on a word document and the other in an easy-to-read accessible version, using pictures as visuals and employing uncomplicated language. (See Appendices 1- 6)

An interview guide, established by Patton (1990), was adapted in the development of interview questions and format. Maykut and Morehouse (1994) recommend three important factors to consider when choosing a suitable interview format-

1. Experience as an interviewer
2. The number of people interviewing
3. The level of the interviewer's professional knowledge on the topic of inquiry

In choosing an appropriate interview format for the current study, the three factors as recommended by Maykut and Morehouse were interpreted as follows:

- *Experience as an interviewer*- the researcher, as a manager and a post-graduate student, has already obtained experience in the conduct of interviews. The interview schedule relies on experience in order to benefit from the freedom of asking questions spontaneously and in allowing the interviewer to go in the direction in which the interviewee is taking them; thus, maintaining the flow of the interview.
- *The number of people interviewing*- an interview would preferably require an interview guide if there were more than one interviewer involved as to ensure structure and smooth execution of questioning. The researcher was the only interviewer involved in this study.
- *The level of the interviewer's professional knowledge on the topic of inquiry*- the subject area of research is of interest to the researcher who works in the

disability sector. However, little is known about the phenomena of the experiences of people with intellectual disabilities of care in general hospitals; hence, the interview guide is a fitting format to ask open-ended and broad questions.

The overall aim of the research was to gain an insight into what it is like for a person with an intellectual disability to be in receipt of hospital care in general hospitals. The research approach allowed scope for an in-depth discussion to occur with key people in the process. The interviews were instrumental to the objectives of the research first established which were to contribute to a wider understanding of what challenges may be encountered by people with intellectual disabilities while in hospital and to establishing the conditions for success to a satisfactory hospital experience for vulnerable adults. The interviews encompassed experiences from a professional, personal and family perspective, all with the best interests of the person with the intellectual disability in focus.

#### Participant selection and recruitment

Guidelines set out by Trochim (2006) were followed when selecting a sample for the proposed study. People who are experts in the disability sector were purposively recruited. Two professionals who met the criteria were two employees who support people with intellectual disabilities and who have accompanied a service-user to hospital in the past. Both participants were recruited via an internal advertisement in the organization seeking interest in the study. The remaining four interviewees were representative of quota sampling, two service-users and two family members. The criteria for service-user participation were individuals with a mild intellectual disability, people who had no mental health issues and those who had past experiences of healthcare service provision in hospitals. The researcher asked fellow managers to act as gatekeepers in the recruitment of the both service-users. The gatekeepers identified potential participants within the service who met the criteria outlined. Once identified, it was through the gatekeeper that interest and consent was expressed to participate in the interviews. The gatekeepers were also involved in the recruitment of the family members.

## Materials

Some materials were resourced prior to the interview. The participant information sheet was comprehensive and clear in providing details of the purpose of the study, the potential risks and the benefits of participation in the study, details on the logistics of the interview, reassurance about privacy and confidentiality, and information on the participant's right to withdraw from the interview at any time. The information sheet was circulated as a tool to assist the recipients in making a decision on whether they wished to participate or not. A consent form, to take part in the interview and to be tape-recorded, accompanied the information sheet. It was made clear to participants that tape-recording was not a condition of the interview; note-taking was an alternative. Recipients were also informed that there was a one week response time-frame allocated to confirm participation or not. A service-user friendly version of both documents was made available, where applicable. The interview schedule was divided into categories, and broad questions were assigned under each heading accordingly. The interview questions were sequenced deliberately, on the expert advice of Patton (1990), being mindful to build some rapport with the participant before narrowing the focus of inquiry. The questions were also made available in an accessible version (See Appendix 3). The interview questions were issued to all consenting participants, for perusal, prior to the interview taking place. The researcher also purchased a Dictaphone to record each interview, where permitted.

## Procedure

.An application to undertake the study was submitted to the college ethics committee. An ethics approval was also required from the researcher's workplace. The ethics application required detailed information on the proposed study to show:

- That the value of the study was justified
- The benefit of the research
- That consent would be obtained (Beins, 2004).

Both bodies approved the application. It was recommended that additional safeguards were put in place for vulnerable persons, these were:

- ✓ To ensure support was available if required e.g. counseling, if memories of experiences were traumatic. This would be in addition to reminding the participant that they could stop the interview at any stage and withdraw immediately
- ✓ To provide a copy of an accessible format of the questions was made available to the participant prior to the interview taking place
- ✓ To advise that if the advance viewing of the interview questions caused trauma to the potential participant that support would be arranged and the questions reviewed accordingly

The recommendations were welcomed and acted upon immediately.

Preparation for the interview included brainstorming ideas, grouping of possible questions, deciding on the appropriate format, and practising the interview on close work colleagues to test for feasibility and approximate interview duration (Maykut and Morehouse, 1994). Gatekeepers were utilized in the recruitment process so that participants would not feel obliged to participate in the study. The study information sheets were circulated internally within the organization, and externally to prospective family members. Interviews were held at preferred locations. The interviewer travelled to all locations. The interviews lasted between 15 minutes to 1 hour in length. The interviews were recorded using a Dictaphone. The recordings were destroyed once the information was transcribed verbatim.

#### Ethical considerations

Due to the nature of the selected sample, ethical issues were carefully reflected upon throughout the process. The Belmont Report (1979) and the HSE National Consent Policy (2014) were guiding documents on the ethical decisions made in the planning and execution stages of the current research. The ethical principles outlined in the Belmont Report were reflected in abundance; primarily, in the criteria set out for service-user participation. The criteria set out for service-user participation

required individuals to have no mental health diagnosis and included those with a mild intellectual disability only. Informed consent was ensured; the format of the study was explained by familiar staff in advance of the interview. All corresponding documents were presented in an accessible version. Key-workers were asked to preview the interview guide to determine whether any of the questions would pose a threat to or upset the individual. Familiar staff members were invited to support the service-users during the interview to determine assent. Assent is a term used when seeking consent from children and vulnerable adults. As they may not fully understand what they are consenting to, assent is the process of observing for other signs such as body language to determine whether they are uncomfortable, bored or wish to withdraw from the interview. Assent was carefully considered through the invitation of key workers and familiar staff to accompany service-users while being interviewed (Department of Health and Human Services, 2016). Adherence to the National Safeguarding Vulnerable Adults at Risk of Abuse Policy 2014 ensured that participants were advised on the information sheet and reminded again at the beginning of the interview about disclosures. It was explained, that if any information was disclosed during the interview which raised concerns about the individuals safety that this information may have to be shared (Health Service Executive, 2016).

Other participants, staff and family members, were equally assured of confidentiality and other ethical considerations throughout the process. An information sheet was circulated in advance which explained that participants had the right to withdraw at any time during the interview. It gave details of the storage, transcription and reporting of findings ensuring confidentiality at all times. The option to be tape-recorded was at the discretion of each participant. Measures were taken to ensure participants of anonymity and confidentiality throughout the process. The names of participants, hospitals and organizations are not disclosed in the report. For the purpose of transcribing and analyzing of data, coding was used e.g. hospital 1, hospital 2. The use of fictitious names in the follow-up report and the use of initials for the storage of recordings were employed.

## Method of analysis

After completion of the interviews, each recording was transcribed. Findings are presented factually in the next chapter. Common themes emerged during transcription. The data will be reported according to the themes in the next chapter. Significant quotes were extracted and are included in the results section.

## Delimitations

The study was limited. It was small scale and took place over a short period of time. The sample was restricted to those in receipt of care only, and did not include people who are employed by the hospitals. In order to include hospital staff it would have been necessary to seek permissions of governing bodies. An extension of sample size would be recommended for future studies. However, the study was sufficient in achieving the proposed objectives. A detailed synopsis of challenges encountered by people with intellectual disabilities is presented and an optimal mode of hospital care provision for people with intellectual disabilities is envisaged.

## Results

Five common themes emerged during the transcription of data recorded in the six interviews. These themes were admissions and discharge, communication, training and other resources, special accommodations, decision-making. In this section, themes are reported accordingly under relevant headings. The participants are coded in reflection of the role played in hospital visits; for example, Carer 1 and Carer 2 (Support workers accompanying people with intellectual disabilities to hospitals), Patient 1 and Patient 2 (participants with an intellectual disability in receipt of hospital care), Family 1 and Family 2 (family members who have accompanied relatives with intellectual disabilities to the hospital).

### Admissions and Discharge

There was a shared feeling amongst some participants, namely carers and family members that admission to and discharge from hospitals can induce feelings of dread, panic and frustration. One support-worker, Carer 1, commented that:

It is always a case of getting the person out as soon as possible, you get the feeling of we (the hospital) do not have the time for these people, you (the patient) have a care setting in the community so go back there.

Carer 2 shared similar feelings regarding discharge procedures saying that she felt people with ID were discharged too early; in particular, if there was a situation where the person was not tolerating the hospital, was displaying difficult behaviours or was non-compliant with the medical staff team. Family 2, a mother of a child with autism and a sister to a teenager with down syndrome, said that she feels that the only function of a hospital visit is to “pump him (son) up with antibiotics and send him home because that is all they can do”. The mother said that she does her best to manage her child’s care at home so that she does not have to go back in there (hospital).

Carer 1 and Carer 2 had conflicting experiences in relation to the discharge of patients back into residential care. Carer 1 stated that adequate discharge notes are prepared but that the handover is confined between medical professionals i.e. the

notes are sent directly to the local G.P and the care staff have to request a copy from the G.P. Carer 1 also commented that the discharge protocol differs from one hospital to the next. Carer 2 stated that notes are not sent to the local GP by the hospital, and that staff always have to follow up with the hospital to ensure that a copy of the discharge notes are forwarded to the G.P. Discharge notes is a term used to describe a document containing a summary of key information about the patient's time in hospital including their presentation on admission, treatment administered, investigations carried out while in hospital, and a recommended follow-up plan on discharge. Carer 2 stated that carers rely on medical advice received on discharge of patients back into residential care "to plan for their recovery in a safe and familiar setting".

Family 1, a mother of an adult female who has complex health conditions characterised by her diagnosis, recalled a time whereby her daughter was discharged too early from the hospital post-surgery. Family 1 reported that shortly afterwards her daughter had to be rushed back into theatre because the wound had opened. She felt that the reason for her daughter's early discharge was due to the fact that her needs are higher as a result of her moderate intellectual disability. Referring to hospital staff she said:

They (the hospital) weren't as keen to discharge her the next time, they don't listen to you. I can understand the issue if they wanted her out quicker than everyone else but she is never without an accompanying carer as she cannot be left on her own

Family 1 described a recurrent feeling of dread which resonates if her daughter has to be admitted to hospital, saying that she would be "sick at the thoughts of my daughter being admitted to hospital and I just think here we go again".

Some positive experiences of admission and discharge were noted. Patient 1 remembers on one occasion when he became unwell at home, an ambulance was sent out to him to take him to the hospital and there was a nurse provided in the back of the ambulance. The nurse held his hand and reassured him on the way to the hospital.



The welcomed provision of assistive equipment was a feature in some discharge experiences with Patient 1 commenting that he arrived home after being discharged from hospital to find that a specialised bed had been delivered by the hospital. Patient 2 said she was supplied with a walking aid by the hospital to assist her with mobility while recovering at home. However, patient 2 did express her shock about one hospital experience in the past when the doctor had deemed her as fit for discharge back into care but she did not agree with this decision. Patient 2 confided in the doctor telling him that she did not feel well enough to go home. The patient had been in the hospital for one month at this time. The doctor returned to Patient 2 on the ward the following day, accompanied by a social worker, and “threatened” Patient 2 telling her that “if you don’t go home we will send you somewhere that you do not like, you will not get to see your host family again, and you will not get to travel to Medjugorie”. A host family is a family in the community who offer respite care to Patient 2 in the form of overnight stays at their family home. When asked about the significance of Medjugorie, Patient 2 explained to the interviewer that she visits there annually as part of a parishioner group excursion. Patient 2 did leave the hospital on advice of the doctor. Patient 2 met the same doctor at an out-patients appointment at a later date, and she reported that he was nice to her on this occasion.

Carer 2 remembered a time when the person she accompanied to the hospital had a panic attack on arrival as a result of anxiety associated with hospital visits. She said that the doctor who was present at the time responded by inquiring of the carer as to “how long does he (patient) have epilepsy”? Carer 2 informed the doctor that the individual was in fact having a panic attack, and not an epilepsy seizure. Carer 2 criticised the doctor for not asking the patient how they were feeling; even though, it was “obvious that the person with ID was in a cold sweat and displaying panic”.

In response to a question in relation to satisfactory discharge protocols in place in hospitals, Family 2 remarked that “they (the hospital staff) do not want people with ID in hospitals, it is like they should have their own hospital and they would like to see them separated from everyone else”.

## Communication

There were both evidence of barriers and conditions for success to effective communication experienced by people with intellectual disabilities and observed by advocates in hospitals. Family 1 described an incident where “a nurse walked in shouting and roaring at my daughter”. The nurse was asked by a family member to stop shouting and it was explained to the nurse that the person could hear what was being said and is not deaf. Patient 1 and Patient 2 provided examples of good communication with medical staff. Patient 1 reported that they have frequented the hospital regularly in the last few years, and recalls that on each occasion procedures and treatment were explained to him in a comprehensible manner; “I cannot read but they explained the lot”. However, Patient 1 added that he has often “seen people in hospital who are handicapped and there should be more done for them; half the things are not done”. When asked what would be most helpful to improve communication between people with ID and medical staff, Patient 1 replied “what I would to see in hospitals is if people do not understand what was going on for them photographs would be used”. Patient 2 linked her positive experiences of effective communication in hospitals to the fact that she is “verbal and well able to ask questions”. She has fond memories of the interaction with the nurses. Patient 2 viewed herself as fortunate when compared to a fellow resident saying that:

I feel sorry for her, she screeches, she cannot help it and it is not her fault. She cannot say I have a pain here or I have a pain there. She would need someone in the hospital with her that knows her, and someone who knows that when she is upset that she likes sweets

Carers and family members identified many barriers to effective communication while supporting a person with ID in the hospital. Common themes took issue with medical staff talking over the patient directly to the carer/ family member about the patient. Carer 2 described communication between the medical team and patient “as very poor as they (medical team) don’t explain things the way someone with an intellectual disability understands”. Parent 2 said that the care received by her child was that of a “second class citizen”, commenting that she was very lucky that her son was outspoken. On one occasion her son interrupted the doctor while the doctor

was speaking to Parent 2 to make a simple request “speak to me because you are talking about me”.

Carer 1 commented on a recent incident where she had received a contradictory account of the patient’s medical condition and progress from the medical team as to what had been communicated to family members abroad. She felt that the hospital did not respect her role as a professional, as someone who was responsible for the care of the patient in the absence of family members. The withholding of information by the medical team had implications on the inconsistency of handovers between Carer 2 and family members. Carer 2 reported that her integrity to family was compromised as a result.

The allocation of sufficient time was reported to be in short supply in general health settings with no extra support available in the treatment of people with ID. Parent 2 observed the lack of patience of clinical staff when interacting with her son, “the nurse tried to pick my son up and shove him on the bed when all he needed was a couple of seconds to do it independently”.

Parent 1 has been disappointed in the past when the medical team have not listened to the people who know her daughter best, like her siblings and carers. For example:

We know when my daughter is in the height of pain because she sobs her heart out and she cannot control the sob. Yet, when you try to explain this to the doctor, they look at you as if you are talking rubbish

Carer 1 commented that there is a need for the medical jargon to be amended to suit the individuals’ comprehension level. Carer 2 suggested that it would be helpful if medical staff received training in accessible modes of communication such as PECS which she explained is a system of picture exchange communication using visual cards as prompts and in Lámh which she describes as a form of sign language used as prompts with the use of simple language. Carer 2 suggested that doctors would benefit more from such specialised training than nurses, admitting:

I think nurses are more on a communication level with a person with an intellectual disability than doctors. Doctors seem to have an attitude of pity, they never communicate directly to the patient, in my experience.

Both Carer 1 and 2 recommended the use of the hospital passport as a communication tool for hospital staff to learn and understand the most important factors about the patient. The hospital passport is commonly developed by care staff as a visual document to accompany a person with intellectual disability on admission to hospital. Carer 2 described the hospital passport as a traffic-like system document that captures significant information about the person such as their likes and dislikes, allergies, ways in which they prefer to communicate and next of kin information. Carer 2 said that she remembers offering the passport to hospital staff as a communication aid on two occasions. The first time it was positively received by hospital staff who complemented it for detail and its effectiveness. However, in the latter experience it was deemed “silly” by hospital staff who queried the function of the hospital passport asking “why would I need to know this information when you (Carer) are here”. Carer 1 commented that the hospital passport is a useful resource but that “hospital staff should take the time to actually read it”.

Carer 1 reported that in her experience there was little support from hospital staff to carers when accompanying a patient to the hospital. She reported that “medical staff almost leave you to your devices, they forget about you (carer)”. She explained that hospital staff have to be prompted to assist carers with personal care and to administer regular medication timely to the person with ID. The impact of poor communication can result in contradictory care notes recorded about the patient. For example, Carer 1 reported that a patient she had accompanied on admission had vomited repeatedly by the hospital bed; however, their hospital care notes did not reflect this because there was no hospital staff present when the vomiting occurred or to assist in cleaning it up. Consequently, there are risks that discrepancies are occurring in the handover between nurses on duty about the wellbeing of the patient.

## Training and other resources

When asked what resources could improve service delivery in Irish general hospitals, there was a mutual response amongst carers and family members that hospital staff would greatly benefit from specific training. Family 2 reflected that “hospital staff have no training in disability, maybe they do but it doesn’t seem like they do because you feel like they don’t care. Carer 1 recommended that hospital staff receive module training in disability so that they can recognise certain mannerisms as forms of communication rather than difficult behaviours. Carer 2 acknowledged that generally there are insufficient resources available in hospitals to provide extra support to people with disabilities. However, Carer 2 stated that it would be helpful if hospitals gave careful consideration to the allocation of nurses or doctors to patients with ID; medical staff who are “fit for the job i.e. have experience or awareness in disability”.

Family 1 recognised that knowledge of disability was an important factor in satisfactory service provision in hospitals. She shared an experience where she overheard a senior doctor misinform his team of junior doctors about her daughter’s diagnosis. He described her daughter’s condition as “institutionalisation”. Her daughter has a rare genetic disorder.

Carer 2 reported that she had an experience whereby the paramedics travelling in an ambulance with the patient in her care did not have sufficient training to administer emergency medication to the patient for an underlying condition. The patient was on route to the hospital via an ambulance and Carer 2 had to travel behind in her own car. She was requested by the ambulance staff to pull in on the motorway to administer the required medication. Carer 2 was unable to clarify as to whether this training is now mandatory for paramedics.

Carer 2 commented that she senses panic in service-users on admission to hospital as some struggle to adapt to new environments; in particular, because “hospitals can be hostile places to visit”. Carer 2 recommended that every hospital should have some element of sensory input readily available such as lava lamps, low arousal lighting, weighted blankets and other sensory equipment. Carer 2 believes that such

accommodations would make for a home-from-home environment for service-users while in hospital and be less a intimidating environment.

Time was identified as a valuable resource in ensuring a satisfactory hospital experience for people with ID. Patient 2 observed times where there was only one nurse on duty responsible for six patients on a general ward, and suggested that the hospital would need somebody to help out if there were patients who required extra support, in the absence of an advocate. Parent 2 admitted that she felt that every visit to the hospital with her son was a battle “every time it is a fight, you know you are going to be trying to explain that your son has autism and that he does not like waiting”.

The necessity for the presence of a family member or carer to support a person with ID during the hospital stay was emphasised by interview participants. Carer 2 stated that “the only success a person with an ID has to visit hospital is if accompanied by someone that knows them”. Both carers and family members were asked how the people they have supported in the past would manage if they had to stay in the hospital without the direct support of an advocate. Carer 2 commented that such a situation would not be possible, as the person would display fear and anxiety in unfamiliar surroundings. Carer 2 explained that she would be fearful of this scenario too. She explained that in the absence of someone who has an awareness of disability, patients may potentially display behaviours to communicate frustration about not being understood. Such behaviours may be perceived as dangerous situations by hospital staff. In her experience, Carer 2 reported that medical staff have responded to perceived dangerous situations by “administering sedative medication unnecessarily”. Carer 1 admitted that her past experiences have indicated that there is a need for a strong advocate to ensure patients receive a good quality of care in hospitals and to play the joint role of a communicator and interpreter between the medical team and patient. Family 2 envisaged that the hospital is “a scary place to be if the person with ID does not have someone familiar there explaining things to them”.

Family 1 acknowledged that her daughter requires a familiar staff to accompany her to the hospital at all times due to her complex needs. However, she recognised that

clinical staff do not listen to carers “it is like they do not believe what carers are saying to them or else it is that they do not want to hear it”.

Patient 2 reported that over the last few years she has frequented four different hospitals. She did not require extra support while in hospital but commented that carers from her residential home visited her regularly “to check up” on her. Patient 2 rated the service provision of each hospital attended at an equally high standard.

#### Special accommodations

Patient 1 remembered a time in hospital where he had difficulty in accessing the nearby toilet. Hospital staff provided him with a commode for ease of accessibility and comfort.

Examples emerged of special adjustments to services that have enhanced hospital experiences in the past and that would improve experiences in the future. Changes to the environment proved imperative depending on individual sensitivities. It was reported that people with autism are particularly sensitive to noise and busy spaces. Carer 2 recalled a time when the hospital allocated access to a disused space to accommodate an individual being supported who was waiting for his appointment. The individual has a tendency to pace when feeling anxious. Family 2 reported that her son with autism has a low tolerance for waiting, pointing out that “waiting leads to frustration and frustration leads to outbursts and nobody wants that”. In the past, Family 2 has attempted to engage with hospital staff to inform them of the conditions that work best for her son when attending hospital appointments. However, Family 2 reports that she has always received a hostile response from hospital staff in this context because she feels that it is interpreted by hospital staff as if she “wants to skip the queue or to be seen first”. Family 2 described the process of going to an appointment in a general hospital with her son as an ordeal. In comparison, Family 2 described the experiences of accompanying her sister, who has down-syndrome, to appointments in a children’s hospital as “brilliant”. Family 2 reported that the doctor in the children’s hospital is familiar with her sister and that he has an insight into her individual preferences and triggers. “The doctor speaks directly to her, tells her exactly what it is he is going to do and the steps he will do it in. He waits for her.”

Family 1 reported that her daughter spent the first year of her life in and out of hospital. She attended a children's hospital. Family 1 stated that the time spent in the children's hospital is the only positive hospital experience that she can recall.

Carer 2 accredited the effectiveness of special accommodations facilitated by the hospital to the success of a surgical procedure experienced by an individual she supported. The hospital was informed in advance that the individual with ID deterred hospital settings. The staff team in the hospital were also made aware that the patient's mother, who was required to be present in the hospital to sign consent forms for the upcoming procedure, had a negative impact on the patient. The medical team responded proactively to valuable information received. A meeting with the patient's mother was arranged prior to the procedure taking place, to facilitate the signing of the consent forms in the hospital and to minimise the risk of the mother and son meeting each other. Carer 2 reported that on arrival to the hospital, in preparation for surgery, there were special accommodations facilitated for the person with ID "a wide and airy room with a television was provided with an adjacent toilet, a weighted blanket was on the bed to meet his sensory needs, and the patient was asked if he liked music and what his favourite song was." Carer 2 stated that the patient's favourite song was then played by the medical team during surgery. Carer 2 reported that she was aware that the same hospital is strategic in the use of available resources at a local level, to effectively meet the needs of people with ID where possible:

the distribution of case loads on the wards daily are purposeful, so if there is a patient with an ID expected for an appointment or received on admission, clinical staff who have lived experience of disability, for example have a family member with autism, are purposefully assigned to that patient

### Decision-making

The level of service-user involvement in decision-making while in hospital was a questioned during interviews. Patient 1 remarked that he was always offered choice at mealtimes. Patient 2 reported that on one visit to a hospital it was suggested that



she may need a wheelchair for a short period; she reported that she was informed and involved in that decision.

Poor decision-making practice amongst people with ID was raised as an area of concern by other participants. Carer 1 described service-user involvement in decisions while in hospital as very minimal stating that hospital staff “tend to do for rather than do with”. Carer 1 made reference to a patient who frequented the hospital recently for a period of three weeks, and surmised that “if it was his choice he would not have wanted to be there at all but how much care can be provided in the residential home?”

Carer 2 reported that it was common practice, in her experience, for nurses to come in and proceed to inject a patient with a needle without seeking consent first. Carer 2 reported that she witnessed hospital staff administering medication to patients without explaining the rationale for it. Family 2 believed that assumptions are made about her son because he has autism; she witnessed hospital staff arriving as a group of four and proceeded to hold her son down in order to take bloods. Family 2 stated that her son responds well to hospital procedures if he is involved in the process. Carer 1 reported that she had to intervene and advise hospital staff that it was unnecessary to hold a patient down to apply a gas mask. Carer 2 advised hospital staff that he had the capacity to understand what was happening and to consent once things were explained to him. She stated that she believed that “the hold was assumed necessary action by hospital staff because the patient had an intellectual disability”.

Family 2 feels that her son is not included in making decisions about his care as he is completely ignored by hospital staff “I feel that when we go into the hospital that staff speak more so to the parent than to the person who is actually ill; he has often been referred to as *these people*”.

Family 1 stated that her daughter cannot talk for herself or verbalise how she feels. However, Family 1 has witnessed hospital staff involving her daughter in basic decisions stating that they will offer choice around meals and activities which her daughter to which she will give a yes/ no answer. Family 2 noted a big difference

between the service provisions of a typical patient to that of a person with ID comparing her own hospital experiences to her daughters' "Doctors would explain everything to me. On the odd occasion the doctor would look at my daughter and talk to her about treatment but the majority of the time she is not involved".

#### Positive experiences

In response to the question asking for an example of when the participant had a positive experience in the hospital, Carer 1 reported that she has never had a positive experience, Carer 2 described a positive experience attributing the successes to a specific hospital and purposeful systems in place. Family 1 and Family 2 linked their only positive experiences to children's hospitals, Patient 1 and Patient 2 spoke about positive experiences in various hospital settings.

## Discussion

The discussion chapter recapitulates the results of the study. The findings are interpreted in the context of how they support previous research and how the current study contributes to the body of knowledge on the subject area 'the care of people with intellectual disabilities in general hospitals in Ireland'. Significant issues are discussed such as the significance of communication, the effectiveness of the hospital passport and the impact of introducing disability liaison nurses to Irish hospitals, the importance of relevant training and education in disability, and the dependency on carers and family members during hospital visits. The limitations of the study are reiterated in the context of the value added to the study if there access to a broader sample. Other suggestions for future research are recommended.

### The power of effective communication

Effective communication was perceived as one of the most important factors amongst all of the participants to the success of a positive hospital experience. The two participants with intellectual disabilities admittedly concluded that their positive experiences were due to the fact that they had a voice and could interact with hospital staff directly. However, there was a shared sense of empathy expressed for fellow service-users who are less fortunate than they are with communication skills. The two participants with an ID had a great sense of awareness that fellow residents and friends with intellectual disabilities were not all accustomed to such positive hospital experiences as they were. Simple recommendations suggested were the use of pictures as visuals to explain procedures, and hospital staff being made aware of important information about patients; particularly, likes and dislikes. The recommendations coincide with findings in Howieson (2015) where participants noted that there was a lack of easy-to-read information available in hospitals attributing to the fact that no positive experience in the hospital were recalled. The provision of easy-to-read accessible information in hospitals would be relevantly inexpensive to introduce. Pictures explaining hospital care, picture cards to empower decision-making, picture prompts to inform about treatment could form part of an effective communication system. However, inconsistencies in communication suggest that hospitals would benefit from reconsidering the current communication

aids used in hospitals and to develop a generic communication system to be rolled out nationally. Changes are required to address the unmet communication needs of vulnerable adults and to promote decision-making capacity in light of the new legislation passed in Ireland. The pending ratification of the UN Convention on the rights of people with disabilities will strengthen the rights of people with ID to equal access and fair treatment.

On the other hand, carers and family members vented their frustration about the lack of communication directed at the person in receipt of care. Participants shared their annoyance about people not being seen as the person first when in hospital. Family members and carers gave examples, in abundance, of hospital staff not speaking directly to the person with ID. The findings supports research carried out by Gibbs, Brown and Muir (2008) who reported that there were inconsistencies in communication approaches by hospital staff. The current study recommends specialized training in communication for hospital staff. Understandably, hospital staff who are untrained in effective communication skills lack the confidence to initiate conversation independently with a person with an ID. This seems particularly prevalent if there is an advocate present; interaction with the carer or family member instead makes for a more preferred option.

From experiences shared, it would be reasonable to assume that there is a reliance on the presence of an extra support person in hospitals. Consequently, it appears that hospital staff presumes incompetence of people with ID in communication skills when an advocate is present. The findings coincide with that of Sowney and Barr (2005) who reported that nursing staff recognised the benefits to patients with ID who were accompanied to the hospital by a family member or carer. However, in the case of Patient 2 who reported an incident whereby she was threatened by hospital staff when she questioned the timing of her discharge, the absence of an advocate potentially puts an individual with an ID in a vulnerable position. This was an unexpected finding. Impressively, the participant has sufficient independent skills to attend the hospital alone. However, it seems that the fact that she had an intellectual disability deemed threatening, an inappropriate method of communication, as acceptable behaviour. Hospital staff were trusted with personal information about the

patient's family arrangements and annual holidays. In this instance, the trust appears to have been abused with hospital staff opting for an intimidating approach to resolve an issue rather than involving the patient in the decision.

The level of communication between hospital staff and carers was reported to be hostile at times. The impact of non-sharing of information affected the handovers provided by staff to families and by nurses to fellow nurses. This finding coincided with a finding of Gibbs, Brown and Muir (2008) who reported that there were concerns raised about inconsistencies in the handover between nursing staff about the patient.

Family members and carers reflected that the level of communication on the discharge of patients back into residential care was very poor. The protocol on the discharge of patients requires vast improvement. There seems to be a sense of urgency on general hospitals to discharge people with intellectual disabilities. Difficult behaviours are misinterpreted as a nuisance, and early discharge seems imminent if a situation becomes unmanageable. The disability organisations and the hospitals appear to be working off completely separate protocols. There needs to be more structure in place to ensure that a safe and timely discharge is occurring. There is a risk that unreliable communication practices on discharge would impact on the quality of after-care provided by professionals in the aftermath. Re-admission for the same complaint and the redeployment of unnecessary resources were perceived as the implications of premature discharges. All professions involved would benefit from agreeing on a serviceable plan of discharge. Time wasted following up on discharge notes with G.Ps and hospitals and the allocation of extra support staff for repetitive admissions would be better invested elsewhere in the individual's recovery. The significance of comprehensive discharge practices is new information.

A major deficit noted in the findings was the poor level of decision-making practices in patients. People with disabilities seem to have assumed the role of child or pity while in hospital. The presence of a full-time carer in the hospital has, unintentionally, infringed the rights of people with disabilities. Decisions have been made without them and assumptions made based on their lack of input. The service-users may benefit from an independent person overseeing their care and level of autonomy

during hospital stays. Typically the adapted role a disability liaison officer is required, someone who can mobilise from ward to ward as needed, rather than having a 'disability section' in hospitals to avoid seclusion.

### Carers versus Nurses

The use of the hospital passport appears to be a common practice amongst care staff but its use in hospital settings seems inconsistent. The hospital passport is familiar to care staff as a fundamental document to individual communication and personal profile information. However, its advantages are not shared by all healthcare professionals. It is unclear as to whether Irish hospitals were involved in the development of the hospital passport document or whether it is a document that has been circulated within disability organisations only. In the UK, the NHS (2015) advertises the availability of hospital passports at G.P. clinics and hospitals, which by association automatically gives the document medical credibility. The use of hospital passports in hospitals in Ireland appears to be selective and tokenistic. The hospital passport template should be jointly developed by carers and medical staff. The template should reflect the professional opinions of what constitutes important patient information to ensure the delivery of high quality care. The use of the adapted hospital passport should be enshrined in relevant policy and procedure as a mandatory condition of care provision in Irish hospitals.

There seems to be an imbalance of power in respect of the relationship between the hospital staff and care staff. Family members and carers expressed their frustration at carers not being listened to or their knowledge not being respected by hospital staff; even though, information is communicated in the best interests of the service-users. From a nursing perspective, Sowney and Barr (2005) report that nurses feel inferior in their work with people with ID as they are lacking specialist training in disability. It would be beneficial if the roles and responsibilities of carers and medical staff in hospitals were clearly defined and agreed on; then, maybe professional information-sharing and support would occur naturally in respect of that.

## Special adaptations to service provision

The findings suggest that people with ID generally associate hospitals with feelings of fear and anxiety. The unfamiliarity of staff and the unsuitability of some hospital facilities were contributing factors. Flexibility of hospitals was evident in the creative use of vacant spaces. There was evidence that special requests from parents were perceived as nuisances. Requests for special accommodations for people with ID are understandable as general hospitals by name are very generic, as described in the findings- unsuitable lighting, unpredictable waiting times, and at times high volumes of noise and people. However, there could be a risk that the allocation or design of special spaces will revert to institutional practices like in the instance where a person with ID was redirected to a disused wing of the hospital. Although the gesture was accommodating to meet the needs of the patient with ID, the redirection of patients to isolated spaces can be perceived as non-inclusive care. Instead, there should be a balance in striving for an optimal model of care within the current environment. Findings in the current study surmise that the following adaptations to general hospitals would contribute to a positive hospital experience for people with intellectual disabilities:

- ✓ The availability of sensory equipment that can be offered to patients on a case-to-case basis rather than the design of a sensory room used in isolation
- ✓ The collective design and formal introduction of the hospital passport in general hospitals
- ✓ The implementation and recruitment of disability liaison nurses. The allocation of experienced staff to people with intellectual disabilities.
- ✓ The provision of training and education to medical personnel on intellectual disabilities, associated characteristics of specific diagnoses, relevant communication skills, and the interpretation of difficult behaviours.
- ✓ The implementation of assistive and accessible information to empower people with intellectual disabilities in decision-making about their treatment and care. The issue of consent needs careful consideration in practices.

- ✓ Structure to the discharge system across general hospitals to ensure that carers and hospital staff have shared responsibilities in safe and timely discharge of patients from hospital.
- ✓ A review of potential changes that could be made to hospital environments to alleviate anxiety levels for people with intellectual disabilities; in particular, to waiting times.

The current study strengthens the concept that preparation is imperative to success and time is an invaluable resource, as evidence in the research by Webber, Bowers and Bigny (2010). Similarly, the personalized details of a hospital experience for one person with intellectual disability ensured that any identified triggers or negative emotions were planned for in advance of the hospital visit. There is no doubt that the preparation, planning and careful execution of the hospital admission and procedure, as described by Carer 2, restored confidence in the individual for future hospital visits. However, the application of such careful considerations for every admission of a person with ID does not seem feasible given that some admissions are unplanned. The resources in hospitals vary and that the information in hospital passports is not always interpreted by hospital staff. The current study was enlightened by the creativity of a certain hospital who allocated staff specifically based on their lived experiences of disability. In effect, the hospital made provisions for its own version of a Disability Liaison Nurse; as implemented in the UK as a result of the Valuing people now: a new three year strategy for people with learning disabilities (2009).

#### Training and education

An exploration of the curricula of nursing and medicine graduate courses was outside the remit of the study. However, the majority of participants reported that specific training in disability was not evident in practice in Irish hospitals. The current study reports the implications that making presumptions about people with intellectual disabilities has on decision-making, the course of treatment and the way in which hospital staff approach people with an ID. The findings support an experience shared in the report 'Shut Out: The Experiences of People with Disabilities and their Families in Australia' where an individual was unconsidered for



treatment as a result of their disability status. The introduction of specific training to hospital staff seems imperative to alleviate misconceptions regarding diagnoses and to ensure that there are no barriers to the quality of care delivered to people with an ID. Awareness of the actual disability that the person presents with and how it affects the person may be an additional feature to a comprehensive version of the hospital passport. Training in how people with an ID communicate through behaviours, in the absence of verbal skills, would be helpful to hospital staff to understand the display of difficult behaviours as a form of communication. Hospital staff who have first-hand experience with people with an ID, through family or association, are a valuable resource and should be utilised more within staff teams as reported about one particular Irish hospital.

#### Limitations of study

The current study was limited to a sample comprising of family members, carers and people with an intellectual disability only. There was no access to participants to represent perspectives of hospital staff. It would be interesting to hear the experiences of hospital staff similar to that reported in the study carried out by Sowney and Barr (2005), to inquire as to whether specialist training in disability forms part of the graduate course curriculum or if there is specialist training offered internally in hospitals as part of continual professional development. Hospital staff could provide an insight into the difficulties, if any, encountered when caring for patients with intellectual disabilities. Research encompassing the views of hospital staff would contribute to a more balanced representation of hospital experiences for all involved in the care of people with ID. Family members, carers and service-users would benefit from the input of hospital staff to current research to understand the role and responsibilities of hospital staff. The views of hospital staff would help people with ID, the carers and family members to identify with the experiences of nurses/ doctors of working who work with people with ID and to discuss the implications on care provision. The hospitals would benefit from the feedback from its employees about how to improve service provision and get inspiration from practices that are effective in fellow hospitals. Future research could encompass the opinions of hospital staff on hospital passports and their views on what suffices

effective communication with people with an ID. a cross-agency approach would contribute to a vision of an optimal model of care for people with intellectual disabilities; a shared and achievable vision. The current study acknowledges that recommendations on adaptations to general hospitals to improve service provision are envisaged in the absence of hospital staff perceptions and in the absence of inside information on policy, procedure and practice.

Ethical considerations limited the sample to people with a mild intellectual disability only. One of the service-users interviewed was not dependant on a family member or carer to attend the hospital. The positive experiences described could have been influenced by the fact that she possessed strong communication skills that enabled her to communicate competently with hospital staff to ask questions and make decisions about her care. The other participant, who represented patients with intellectual disabilities, was unable to read but was able to verbally communicate independently with hospital staff about his care and treatment. The study was limited as it did not have direct access to service-users with more complex intellectual disabilities. Instead, their experiences were shared through the lens of their family members and carers.

#### Future research

Future research on the care of people with intellectual disabilities in general hospitals in Ireland would benefit from the inclusion of hospital care staff in the sample. Research in the form of focus groups, comprising of participants who are family members, carers, medical staff and people with an ID, would promote open communication and empathy amongst participants. The main objective of a potential study in the future would be to develop an action plan for a model of care that is satisfying to and reflective of all stakeholders. Gibbs, Brown and Muir (2008) and Webber, Bowers and Bigny (2010) carried out studies of similar nature in the UK and Australia respectively. A study employing a larger inclusive sample could influence policy makers and organisational bodies to introduce resources to achieve potential systems. Recommended future research would provide justification for the allocation of funding on disability services in general hospitals such as disability liaison nurses and specialist training.

Specific research into the contributing factors to positive experiences needs to be explored. A study on the policies, procedures and practices occurring in children's hospitals, and in general hospitals that are renowned for making special accommodations for people with intellectual disabilities could offer a guidance document on effective service provision for other hospitals to aspire to.

A comparative study on the experiences of people with intellectual disabilities versus that of typical patients in receipt of care in hospitals would help distinguish as to whether negative experiences are linked to the presentation of the patient or if experiences are generic in nature. The comparative study could include data to determine whether the number of readmissions experienced by people with ID is higher than that of typical patients. The study would support proposals to Government departments for change in service provision, if it could be proven that current systems were ineffective and costly in comparison. Future research in this area would not be achievable at a post graduate level.

## Conclusion

The overall findings of the current study have influenced the decision that there is an pressing need for improvement to the quality of service provision to people with intellectual disabilities in general hospital in Ireland. Two themes that emerged were interlinked: the empowering of decision-making capacity in patients, about their care and treatment, and enhancing communication approaches with the individual, to promote respect. Both findings are imperative to meeting the needs and human rights of people with intellectual disabilities. There is a requirement for cross-agency communication to occur between medical staff of hospitals and care staff of disability services. There is a responsibility on agencies to work together to achieve aims and objectives of service provision in the best interests of the person in care. The positive experiences encountered in hospitals need to be acknowledged as influential examples of how to utilise available resources efficiently. Planning and preparation were pivotal to positive experiences. However, planning and preparation require time and time is a resource that appears in short supplies in general hospitals. The current work achieved the proposed aims and objective of the study. New information was found. The study extracted an optimal model of care from data

collected and contributed to the body of knowledge about the subject area at a local level. Scope for future research at a larger scale has been identified.

## Reference list

Aspalter, C., Uchida, Y. & Gauld, R. (Eds.) (2012). *Health Care Systems in Europe and Asia*. Oxon: Routledge.

Beins, B.C. (2004) *Research Methods: A Tool for Life*. New York: Pearson.

Bell, R. (2012). Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff. *Tizard Learning Disability Review*. 17 (2), pp 57-63.

Bhaumik, S., Branford, D, Barrett, M. & Gangadharan, S.K. (Eds.) (2015). *The Frith Prescribing Guidelines for People with Intellectual Disability* (3<sup>rd</sup> ed.). West Sussex: Wiley Blackhall

Blair, J. (2013). Everybody's life has worth – Getting it right in hospital for people with an intellectual disability and reducing clinical risks. *Clinical Risk Management*. 19, pp 58-63.

Blythe, A. & Buchan, J. (2017) (Eds) *Essential Primary Care*. West Sussex: John Wiley & Sons Ltd.

Castle, A., Bailey, C., Gates, B. & Sooben, R. (2013). Experiences of the implementation of a learning disability nursing liaison service within an acute hospital setting: a service evaluation. *British Journal of Learning Disabilities*. 42, pp 272-281.

Central Statistics Office. (2012). *Profile 8 Our Bill of Health*. Available at: [http://www.cso.ie/en/media/csoie/census/documents/census2011profile8/Profile\\_8\\_Full\\_document.pdf](http://www.cso.ie/en/media/csoie/census/documents/census2011profile8/Profile_8_Full_document.pdf) . [Accessed 07th December 2016]

Commonwealth of Australia (2011) 2010-2020 National Disability Strategy Summary Document An initiative of the Council of Australian Governments. Canberra: Australian Disability Enterprise.

Dahlberg, L. & McCaig, C. (Eds.) (2010) *Practical Research and Evaluation: A Start-to-Finish Guide for Practitioners*. London: SAGE Publications Ltd.

Department of Health and Human Services (2016) *The Belmont Report* [Online]. Available at: <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>. [Accessed 05<sup>th</sup> May 2017].

Department of Justice and Equality (2016). *National Disability Strategy Inclusion Plan: Phase 3 Consultation Document*. Available at: <http://www.enableireland.ie/sites/default/files/project/National-Disability-Strategy-Inclusion-Plan-Phase-3-Consultation-Document.pdf>. [[Accessed 20<sup>th</sup> June 2017]

Gates, B. & Mafuba, K. (2015). *Learning Disability Nursing: Modern Day Practice*. Boca Raton: Taylor & Francis Group.

Gibbs, S.M., Brown, M.J. & Weir, W.J. (2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. *Journal of Intellectual Disability Research*. 52 (12), pp 1061-1077.

Government of Ireland. (2007). Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013. Dublin: Stationery Office.

Government of United Kingdom. (2009). *Valuing People Now: a new three year strategy for people with learning disabilities*. : London: Department of Health.

Health Service Executive (2016) *National Consent Policy* [Online]. Available at: [http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National\\_Consent\\_Policy/consenttrainerresource/trainerfiles/NationalConsentPolicyDOC.html](http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/consenttrainerresource/trainerfiles/NationalConsentPolicyDOC.html). [Accessed 05<sup>th</sup> May 2017].

Hilliard, M. (2017). *Record numbers of patients on hospital trolleys at 612*. Available at: <https://www.irishtimes.com/news/health/record-number-of-patients-on-hospital-trolleys-at-612-1.2924298> [Accessed 02<sup>nd</sup> July 2017]

Howieson, J. (2015). Experiences of acute hospital services among people with mild to moderate learning disabilities. *Learning Disability Practice*. 18 (9), pp 34-38.

Inclusion Ireland (2016). *Assisted Decision-Making- What does it mean?*  
<http://www.inclusionireland.ie/sites/default/files/attach/basic-page/991/assisted-decision-making-act-factsheet.pdf>. [Accessed 20<sup>th</sup> June 2017]

Lacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research*. 14 (505), pp 1-9.

Maykut, P. & Morehouse, R. (1994) *Beginning Qualitative Research: A Philosophic and Practical Guide*. London: The Falmer Press.

Mencap. (2007). *Death by Indifference: Following up the Treat Me Right! Report*. London: Mencap.

Mencap. (2012). *Death by indifference: 74 deaths and counting. A progress report 5 years on*. [Online]. Available at: <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf> . [Accessed 02<sup>nd</sup> June 2017].

National People with Disabilities and Carer Council (2009). *Shut Out: The Experiences of People with Disabilities and their Families in Australia*. Available at: [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/nds\\_report.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf). [Accessed 02<sup>nd</sup> June 2017]

Robinson, S. (2013) *Preventing the Emotional Abuse and Neglect of People with Intellectual Disabilities*. London: Jessica Kingsley Publishers.

Sowney, M & Barr, O.G. (2006). Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing*. 55 (1), pp 36-45.

NHS (2015). *Going into hospital with a learning disability*. Available at: <http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Going-into-hospital-with-learning-disability.aspx>. [Accessed 11<sup>th</sup> May 2017]

Trochim, W.M. (2006) *The Research Methods Knowledge Base* (2<sup>nd</sup> Ed.) [Online]. Available at: <http://www.socialresearchmethods.net/kb/> . [Accessed 10<sup>th</sup> April 2017].

Webber, R., Bowers, B. & Bigby, C. (2010). Hospital experiences of older people with intellectual disability; Responses of group home staff and family members. *Journal of Intellectual and Developmental Disability*. 35 (3), pp 155-164.



## Appendices

Appendix 1: Participation information sheet

Appendix 2: Participation information sheet: easy-accessible version

Appendix 3: Consent form

Appendix 4: Consent form: easy-accessible version

Appendix 5: Interview guide

Appendix 6: Interview questions: easy-accessible version

## Appendix 1



### Participation Information Sheet

#### **A study on the experiences of people with intellectual disabilities of treatment in general hospitals**

Marie Mc Donnell

[mariemcdonnell563@hotmail.com](mailto:mariemcdonnell563@hotmail.com)

(086) 0847452

Date: 19<sup>th</sup> February 2017

Dear participant,

Thank you for your interest in this study. I am carrying out this small scale study as part of my Masters programme in Advanced Social Care Practice at Athlone Institute of Technology. You are being invited to participate in this research project and I am required to provide a participation information sheet and consent form to inform you about the study. The information sheet is to convey that participation is voluntary, to explain the potential risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask me any questions you may have. If you agree to take part, I will ask you to sign a consent form. Please take your time

in reading the information sheet and I shall revert back to you in a week from the date marked on this letter to check as to whether you have chosen to participate or not. You should only consent to take part in this research study when you feel that you understand what is being asked of you and you have enough time to think about your decision. Thanks again for reading this.

## **PURPOSE OF RESEARCH**

The purpose of my research is to evaluate the care and treatment provided to people with intellectual disabilities in general hospitals. I will gather data for my research by interviewing service-users who have had an experience of hospital treatment, and by also interviewing family members and care staff who have accompanied service-users on hospital visits. I will then analyse this data in order to produce factual findings in this area.

A model of effective hospital care will be assessed on the basis of the level of satisfaction experienced in areas of communication, sensitivity of interactions between hospital staff and service-users/ carers and in relation to admissions and discharge.

## **DETAILS OF INTERVIEW**

Should you choose to participate in this study, I am willing to travel and interview you in your home, place of work or in an alternative more suitable venue of choice. The interview will last no longer than one hour. I will issue you with a copy of the interview questions prior to the interview taking place.

## **POTENTIAL BENEFITS**

Although you will not directly benefit from participation in this study, you will be contributing to a greater understanding of the experiences of people with intellectual

disabilities of care received in general hospitals and of the potential challenges faced.

In addition, I would like you to understand that you are central to this study and to the completion of same (and you will be invited to feedback on my interpretation of your words and experiences.)

### **POTENTIAL RISKS**

The potential risks of participating in this study are limited. Please understand that you are free to stop the interview at any stage and to withdraw immediately; in particular, if something comes up in the interview that you are not comfortable with. All information and topics discussed are confidential and your anonymity is assured at all times.

### **PRIVACY AND CONFIDENTIALITY**

The data for this study will be kept confidential. The interviews will be audio taped with your permission. Once the interviews are completed, the content will be transcribed and analysed. Only my supervisor, Brigid Delamere, and I will read the transcript, which is a written outline of the interview. The tapes will be destroyed once the content has been transcribed. I will securely store the information retrieved from the interview on a password protected file on my laptop which will be stored for up until 10 months. In my report I will give general information and should I give a quote from you then your name/ organisation will be kept fictitious. I will not discuss what you actually said with your colleagues or Manager.

However, as a Social Care Worker I have a duty of care under the Trust in Care Guidelines to report suspicions or reports of abuse against health service staff should there be any disclosures made during the interview.

## **YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW**

Participation in this research project is completely voluntary. You have the right to say no. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

## **CONTACT INFORMATION FOR QUESTIONS AND CONCERNS**

If you have any questions about this study, please contact myself at the e-mail address or contact number above.

## **SUMMARY**

Participation in this study is on the clear understanding that your participation is voluntary. A consent form accompanies this participant information sheet. A copy of both will be provided to you. You are required to sign a copy of the consent form should you agree to participate in this study. Thank you so much for considering taking part in this study.

Marie Mc Donnell

## Appendix 2



### Information Sheet on study about people with intellectual disabilities and their visits to the hospital



I would like to know if you would help me with research that I am doing for my course in college.



I would like to find out about your visits to the hospital in the past.



If you would like to take part, I will ask you a few questions about this. I will ask you about how the hospital staff looked after you, what you liked and disliked about the hospital, and if you understood everything that was going on during your visit.



I would like to tape the conversation. If you do not want this, that is ok. I will take notes instead. You can stop the interview at any time. If you do not want to answer some of the questions, that is ok.



When we are talking, I want you to feel relaxed and comfortable so your Key-worker \_\_\_\_\_ will sit with you while I am asking you questions.



Everything you say is between us and will only be used for my study. But if you were to say something that caused me to worry about your safety we will talk about that. I am not allowed to keep secrets. We may have to talk to another adult to make sure you are safe.

~~John~~

Your name and the names of other people will not be in the report. I might write down one or two things that you said in exactly the way you said it, but I will not write your name.



If you would like to take part, please read the consent form below and sign your name.



If you have any questions you can contact me on:

**MARIE 0860847452**



## Appendix 3



### **A study on the experiences of people with intellectual disabilities of treatment in general hospitals**

#### **CONSENT FORM:**

Marie has explained this study to me. I understand that the interview will take up to one hour and I understand that I can stop the interview and withdraw at any time during it.

Now that I have been informed about the purpose of the study, the potential benefits and risks to my participation, and the details of the interview including the receipt of a copy of the interview questions, I voluntarily give my consent to participate as planned.

Signed \_\_\_\_\_

Print Name \_\_\_\_\_

Date \_\_\_\_\_



**A study on the experiences of people with intellectual disabilities of treatment in general hospitals**

**CONSENT FORM FOR RECORDING DATA:**

Please tick relevant box based on your personal preference:

I consent to my interview being audio-taped by Marie, for the purpose of transcribing the data only. I understand that once the data has been transcribed that Marie will destroy the tape

I would prefer if Marie recorded my interview by taking notes only

Signed \_\_\_\_\_

Print Name \_\_\_\_\_

Date \_\_\_\_\_

## Appendix 4



### **Information Sheet on study about people with intellectual disabilities and their visits to the hospital**

#### **Consent Form**

I will answer questions on what I think is about my visits to the hospital. My key-worker has explained the study to me using pictures. I am taking part as long as I will not be named in the report and my organisation will not be named. I know I can change my mind and stop answering questions at any time.

Signed \_\_\_\_\_ Date \_\_\_\_\_

**Information Sheet on study about people with intellectual disabilities and their visits to the hospital**



**Consent Form to be taped**

Is it OK with you to have the session taped?



Signed \_\_\_\_\_ Date \_\_\_\_\_

## Appendix 5



### Interview Guide

#### **A study on the experiences of people with intellectual disabilities of treatment in general hospitals**

##### Demographics/ Background Information:

1. What is the nature of your relationship with a person or people with intellectual disabilities?
2. How often have you frequented the hospital on a professional/ advocacy basis?
3. Can you tell me what role you play if a person you support/ family member with ID are admitted into hospital?
4. What are your thoughts on general hospitals effectively meeting the needs and rights of people with intellectual disabilities?

##### Quality of Service Provision:

5. Can you give an example where you have felt that the quality of care provided to a person with ID/ family member differed from that of a typical patient?
6. What do you feel is the most important factor for people with ID to ensure they have a satisfactory experience in hospital?
7. What resources do you think would improve service provision in hospitals?
8. What challenges have you witnessed people with ID experience in hospital?

Personal experiences:

9. Can you tell me of a positive experience you have had while supporting a family member/ service-user in hospital?
10. What kind of recurrent feelings do you associate with supporting someone with an intellectual disability in hospital?
11. Can you ever recall a time whereby there was a conflict of interest between you as an advocate and the hospital staff?

Communication:

12. How do you feel the hospital staff manage in their approach to communicate to people with ID about their treatment and care?
13. What tools help communication between people with ID and hospital staff?
14. How are service-users involved in decision-making while in hospital?
15. What is the protocol in place between the hospital and the carer in relation to the discharge of the service-user back into care?

## Appendix 6



### Interview Guide

#### **Information Sheet on study about people with intellectual disabilities and their visits to the hospital**

##### Demographics:

1. Can you tell me about yourself?
2. How many times do you think you have visited the hospital in the past?
3. Have you stayed overnight?

##### Quality of Service Provision:

4. Can you tell me about your favourite thing about the hospital?
5. What makes you feel comfortable about being in the hospital?
6. What could make the hospital better?

##### Personal Experiences:

7. How do you feel if you have to stay in the hospital for a long time?
8. How do you feel after you have come home from the hospital?

##### Communication:

9. How do the nurses and doctors help you make decisions about your care?
10. What would help you understand more about what happens in the hospital?