

# **A Qualitative Study of the Role of Advocacy for People with Disabilities**

**Nuruddeen Busairi**

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**Waterford Institute of Technology**  
INSTITIÚID TEICNEOLAÍOCHTA PHORT LÁIRGE

**Department of Health, Sport and Exercise Sciences  
School of Health Sciences  
Waterford Institute of Technology**

**Statement of originality and ownership of work**

**Department of Health, Sport and Exercise and Science**

**B.A. (Hons) Health Promotion**      ✓      (please select one)

**BA (Hons) Exercise and Health Studies**      \_\_\_\_\_

Name (block capitals): NURUDDEEN BUSAIRI .....

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Signed.....

Date: 28<sup>th</sup> April, 2014 .....

Student Number: 20039742 .....

Address: 38 Rocksprings.....  
.....Clarinwood, Tramore, .....  
.....County Waterford.....  
.....

Word processor word count.....

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## LIST OF ABBREVIATIONS

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1. AGM === Annual General Meeting
2. BILD === British Institute of Learning Disability
3. CIB ===== Citizen Information Board
4. CRPD == UN Convention on the Rights of Person with Disability
5. Dept. === Department
6. Dev. === Developmental
7. DFI ===== Disability Federation of Ireland
8. Estab. == Established
9. GPs === General Practitioners
10. HSE == Health Service Executive
11. IIDC == Indiana Institute of Disability and Community
12. IWA == Irish Wheelchair Association
13. ICTU == Irish Congress of Trade Unions
14. Mgt. === Management
15. NAS === National Advocacy Service
16. NCBI == National Council for the Blind Ireland
17. NCG ===== Nordic Consulting Group
18. NDA ===== National Disability Authority
19. NORAD= Norwegian Agency for Development Cooperation
20. (n=7) === Number of Participants = 7
21. Org. ===== Organisation
22. Rep. ===== Representative
23. UK ===== United Kingdom
24. UN ===== United Nations
25. UNICEF = United Nations Children's Fund
26. USICD == United States International Committee on Disability
27. WHO === World Health Organisation
28. WRD === World Report on Disability
29. Yrs. ===== Years

## ABSTRACT

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Persons with disabilities regularly experience powerlessness in their lives, particularly when taking life decisions about where and with whom to live, or where to work. Being unable to make decisions regarding their lives leaves people with disabilities at the mercy of professionals such as advocates, carers and family members (National Disability Authority, 2003). The purpose of this study was to explore the role of advocacy service for people with disabilities, with the view to know the issues and challenges associated with this role.

**Method:** It was a semi-qualitative study involving seven participants (n=7), four women and three men who work as advocates for people with disability were interviewed about what the role of advocates working for people with disabilities involve, what are the issues associated with the role and what are the challenges facing the advocates working for this population.

**Results:** Findings revealed that the role of advocacy for people with disabilities is quite essential as it is the means by which this population can attain their rights and entitlements. It was also gathered that major issues facing this population are violation and denial of basic human rights and entitlements such as health inequality, discriminations and exclusion from taking part in decisions that affects their lives (Feldman et al., 2012). Findings also showed that advocacy services have not performed up to required standard as a result of various challenges posed to the service by bureaucracy, funding, role conflicts, public attitudes etc.

**Conclusion:** In addressing these problems part of the solutions suggested is mainstreaming, this is the process by which governments and other stakeholders address the barriers that exclude persons with disabilities from participating equally in any service intended for the general public (World Report on Disability, 2013).

## CHAPTER 1: INTRODUCTION

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It is indeed disheartening that people with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. This is mainly due to the lack of services available to them and the many obstacles they face in their everyday lives (World Health Organisation, 2011). According to the Irish disability Act (2005) disability is a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment (NDA, 2006).

Surprisingly, after four decades of community inclusion movements, there is a growing recognition that people with disabilities still are not treated as equal citizens and their rights are routinely violated (Owen et al. 2003). The United Nations (UN) Conventions on the Rights of Persons with Disabilities (CRPD) aim to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities. However, many recent literatures attested to the fact that the rights of people with disabilities to health and social determinants of health are still persistently violated (NDA, 2003; Emerson et al., 2011). Evidence shows that the world comprises more than 1 billion persons with disabilities, approximately 15% of the global population. They constitute a significant group that can contribute to development and society, and yet their potential has not always been realised because of the existing barriers (United States International Councils on Disabilities, 2013). Ireland has approximately 600,000 (13% of the country's population) people living with disabilities. Despite the fact that the world has moved away from the medical model to social model (UN-Enable, 2014), it is unbelievable to know that Ireland has approximately 4,000 people with disabilities still living in institutions or psychiatric hospitals (Disability Federation of Ireland, 2012).

However, considering the vulnerability of people with disability, it has been established that an important way that their rights are brought to light is through genuine advocacy efforts (Rappaport et al., 2006; & Chambers, 2007, as cited by Brolan et al., 2012). This belief led to the

emergence of various advocacy groups fighting for the rights of people with disability. In line with this positive development, the Irish Human Rights and Equal Opportunity Commission Act (1986), was established to address the inequalities faced by people with disability among other issues (Goodbody, 2004). Also, the National Advocacy Service (NAS) was set up by Irish government in 2004 as a pilot project and subsequently in 2011 became a full national service that provides free independent representative advocacy services for people with disabilities (Citizen Information Board, 2013). Nonetheless, the emergence of various advocacy groups has not brought the desired change in health inequality and other socio-economic problems for this cohort (Brolan et al., 2002; & Fieldman et al., 2012). This undoubtedly, informed the need to explore the role of advocacy for people with disabilities in Ireland, with the view to know the issues and challenges associated with this role, which has hindered much needed change for this vulnerable population.

## CHAPTER 2: LITERATURE REVIEW

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### Introduction

People with disability experience health inequality compared with the non-disabled general populations (Emerson et al., 2011). A major factor responsible for this inequality is disparities in social determinants of health (Emerson et al., 2011). Despite the enactment of United Nations (UN) Convention on the Rights of Person with Disabilities in 2006 and its subsequent adoption by the UN General Assembly in same year; there is still strong evidence that this vulnerable group are, from time to time, marginalised and deprived of certain rights and benefits in the society (Emerson et al., 2011). Evidence shows that people with disabilities are poorer than other citizens of the EU. Fewer of them have jobs, their opportunities to enjoy goods and services such as education, healthcare, transport, housing, and technology are more limited (European Commission, 2013). However, this vulnerability is not an inevitable consequence of having a disability. Rather, it is a product of society and thus can be changed by society through genuine advocacy (Jenkins and Northway, 2002; as cited by NDA, 2003).

### Disability

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual involvement in life situations (World Health Organisation, 2013). Disability is therefore, not just a health problem, it is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. People with disabilities have the same health needs as non-disabled people; for immunization, health screenings etc. They also may experience a narrower margin of health, both because of poverty and social exclusion, and also because they may be vulnerable to secondary conditions, such as pressure sores or urinary

tract infections (WHO, 2013). Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings (WHO, 2013).

### **Brief History of Disability**

Unlike today, the Ancient Era had no historians recording the lives of persons with disabilities. Disability was seen as a mark of inferiority. The Greeks referred to people with intellectual deficiencies as idiots. Until this time, people who had seizures, or "fits" as they were called, were often said to be "touched by the finger of god" and considered sacred. Hippocrates (460-357 B.C.), the "Father of Medicine," challenged this notion by speculating that seizures were the result of physical causes, not intervention. One of the greatest philosophers: Aristotle (384-322 B.C.), believed as did most others in Ancient Greece that man was the most highly evolved being, and that woman was one giant evolutionary step below, representing "the first step along the road to deformity". Aristotle also recommended that there should be a law "to prevent the rearing of deformed children".

### **Christianity and Disability**

With the rise of Christianity, there was a gradual influence on how persons with disabilities were treated. In line with biblical belief of Jesus Christ, St. Paul directed Christians to "comfort the feeble-minded." By the fourth century A.D., the rise of Christianity led to more humane practices toward persons with disabilities. Infanticide (the practice of killing children) ceased and helping "the afflicted" became a sign of strength. During the middle Ages, the Roman Catholic Church provided refuge to those in need, and in 787 A.D., Datheus, archbishop of Milan, founded the first asylum for abandoned infants.

### **Moral Management**

Philip Pinel (1745-1826), the leading French psychiatrist of his day, was the first to say that the "mentally deranged" were diseased rather than sinful or immoral, using gentle treatment and patience rather than physical abuse and chains on hospital patients.

### **New Categories of Intellectual Deficiency**

The first major change in the 19th century regarding the concept of intellectual deficiency came from Jean-Etienne Dominique Esquirol (1782-1840), a student of Pinel's and a famous psychiatrist in France. Esquirol divided intellectual deficiency into two levels: idiocy and imbecility.

### **Parole and Sterilization**

Because of the threat of the "moral menace," persons with mild to moderate disabilities who lived in the community were labelled morons and viewed with suspicion. These individuals were sterilized and castrated before being released. Vasectomies were performed on men and tubal ligations on women. By the middle of the 19th century, society was much more aware of persons with disabilities.

### **First Advocacy Movement 1980 in USA**

US in 1980 witnessed the first self-advocacy civil rights movement that represented individuals of all races, who have been systematically neglected, abused, incarcerated, and misunderstood for most of history. Self-advocacy is both part of the larger disability rights movement and a separate movement that concentrates on major issues of concern for persons with developmental disabilities. (Excerpt from: *Parallels in times: A History of Developmental Disabilities*).

### **Rights and Empowerment**

As mentioned above, the UN conventions on the rights of persons with disabilities (CRPD) aim to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities. However, many recent literatures attest to the fact that the rights of people with disabilities to health and social determinants of health are persistently violated (NDA, 2003; Emerson et al., 2011). In spite of equal employment rights among other rights, statistics show

many disparities between disabled and non-disabled populations in employment figures across the globe. It was found that the United Kingdom (UK) has 10 million persons with disabilities. Of the 10 million persons with disabilities, 6.8 million are of working age, only one-fifth of this total are in employment, even though it was established that improving the employment rate of persons with disabilities would boost the economy by £13 billion (Disability Rights Commission, 2007).

Recent findings in Ireland also indicate that there are growing concerns over the tough challenges being faced by people with disabilities. There have been crises in service provision for the disabled population in some parts of the country owing to the state cut on funding (Inclusion Ireland, 2013). Similarly, seventeen years after Congress enacted the Americans with Disabilities Act (ADA), Americans with disabilities still do not have an equal opportunity to fulfil the American Dream. In 2006, working-age Americans with disabilities were almost three times more likely to live below the poverty line than those without disabilities (Obama & Biden, 2007).

In addressing this problem a conference of States parties to the Convention on the Rights of Persons with Disabilities was held in New York in July 2013. It was agreed in that conference that measures to foster the participation of persons with disabilities in decent employment, reduce poverty and enhance income security are among the core elements of strategies that should be adopted by countries as they take action to implement their commitments. Strategies need to be developed and implemented in consultation with persons with disabilities so that their voices are heard and their concerns appropriately addressed (United States International Council on Disabilities, 2013).

### **Advocacy**

According to the Oxford dictionary the term advocacy originated from the Latin word ‘advocatia advocare’ meaning summon, call to one’s aid. It means a public support for or recommendation of a particular cause or policy (Online Oxford Dictionary, 2013). However, in the context of this dissertation advocacy involves speaking, acting, writing with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and

defend the welfare of individuals or groups, in a fashion which strives to be emphatic and vigorous (Wolfensberger 1992; as cited in Brolan et al., 2012).

### **Types of Advocacy**

Due to heterogeneous characteristics of all people, their needs for support are different, and may change during their life time. In view of these differences, a variety of advocacy has developed (British Institute of Learning Disability, 2013). The British Institute of Learning Disability (BILD) identified six types of advocacy, namely: case advocacy, self-advocacy, peer advocacy, paid independent advocacy, citizen advocacy, and statutory advocacy. Nonetheless, in Ireland the following six types of advocacy are practised most often: Policy Advocacy, Representative Advocacy, Self-Advocacy, Parent Advocacy, Peer Advocacy, and Citizen Advocacy (Inclusion Ireland, 2014).

### **National Advocacy Service (NAS)**

The National Advocacy Service (NAS) was set up in Ireland by the Irish government in 2011 to provide free independent, representative advocacy services for people with disabilities. It is organised and managed on a regional basis by the Boards of five Citizens Information Services and is supported by the Citizens Information Board. People with disabilities may get in touch with the advocacy service directly. Enquiries from family, friends or services on behalf of people who may be unable to make a request for support from the NAS are also welcomed.

### **Advocacy and Disabilities in Ireland**

Mccoll and Boyce (2002), in their study believed that there has been a remarkable success for people with disability in the West as emergence of various Acts and Legislations in countries such as United States, UK, and Australia have paved the way for awareness about the disabled population. This development, has in turn, led to various advocacy groups fighting for the rights of people with disability. In line with this positive development, the Irish Human Rights and

Equal Opportunity Commission Act (1986), was established to address the inequalities faced by people with disability among other issues (Goodbody, 2004). Also, in keeping with the global trend it was found that the National Advocacy Service (NAS) was set up in Ireland to provide independent, representative advocacy services for people with disabilities (Citizen Information Board, 2013).

However, Mccoll & Boyce concluded that despite the successes outlined above, there have been suggestions that disability advocacy has become stalled recently. The National Disability Authority (NDA) (2003) in their findings also concluded that advocacy organisations in Ireland have emerged with few resources, and as a result they could not perform effectively. In line with this claim, it was found that Ireland is one of just three EU member states that are yet to ratify the UN Convention on the Rights of People with Disabilities, since its inception in 2006, the other two being Finland and the Netherlands (Irish Congress of Trade Unions, 2013).

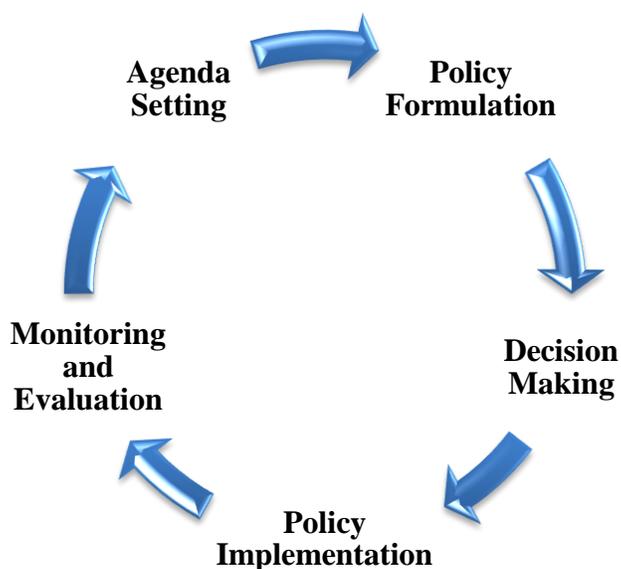
In Ireland records show approximately 600,000 are people living with disabilities, equivalent of 13% of the country's population (Central Statistics Office, 2011). At least one in ten adults of working age (15-64 years) has a disability (CSO, 2011). Only 5% of adults with an intellectual disability are in employment. Approximately 4,000 people with disabilities still live in institutions or psychiatric hospitals (CSO, 2011; DFI, 2012). People with disability experience high levels of consistent poverty (13% compared to 2% of those at work). Also, people with disabilities have poorer educational outcomes. Among people with disabilities, 43% have not progressed beyond primary education. This compares to 19% of all adults, and many more (CSO, 2011; DFI, 2012).

From the statistics above, it is quite obvious to comprehend some of the difficulties people with disabilities are facing in Ireland in spite of various advocacy services available for this population. However, in addressing the aforementioned problems, most of the literature reviewed agreed that the ratification and implementation of UN convention on the rights of persons with disabilities is a vital framework for creating legislation and policies around the world that embrace the rights and dignity of all people with disabilities (Obama & Biden, 2007; USICD, 2013; & WHO, 2013).

## Policies and Legislations

Hogwood and Gunn (1984) described policy as a field of activity (e.g. foreign or health policy, a general intent, a specific proposal (usually target driven), something that requires formal authorisation or legislation implementing a programme of action (Wellcome Trust, 2013). Policy is closely linked to a problem and the strategies needed to solve it. It is important to understand that 'policy' is not a single outcome or event and is usually seen as a cycle, which moves from agenda setting to implementation, monitoring and evaluation, as shown in Figure 1 below:

*Figure 1 Policy Cycle*



Policy in broad terms has been explained above, however, in the context of advocacy and disabilities it could be linked to health. That is a clear guidance of how to attain optimal health in a given population irrespective of their ability or disability (WHO, 2013). It is a foundation requirement to have a policy statement on any good initiative before it is planned, implemented and evaluated. Thus, findings revealed that in promoting health of a group or population, it is always a good practice to build healthy public policies as outlined in Ottawa health summit in 1986. This summit invariably plays a pivotal role in creating specific health related policy for specific population such as people with disabilities.

In view of the above on policy, the following paragraphs explored some of the policies around advocacy and disabilities in Ireland and beyond.

It was found that the Universal Declaration of Human Rights (UDHR) is generally agreed to be the foundation of international human rights law (UN, 2013). Adopted in 1948 in Paris, the UDHR has inspired a rich body of legally binding international human rights treaties. Also, the World Health Organisation (WHO) Constitution enshrines the highest attainable standard of health as a fundamental right of every human being (WHO, 2013). This right to health includes access to timely, acceptable, and affordable health care of appropriate quality. The right to health means that States must generate conditions in which everyone can be as healthy as possible (WHO, 2013). However, across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities (WHO, 2013).

With the aim to improving the quality of life of people with disabilities, the Council of Europe Disability Action Plan (2006-2015) was developed (Council of Europe, 2006). The plan provides a framework to which policy makers in member states can refer when designing, implementing and evaluating disability policies and strategies. According to the provision member states are obliged to ensure that all policies embrace the principle of accessibility and consideration be given to a barrier-free built environment. It also establishes that all people with disabilities, regardless of age, gender or impairment have equal access to healthcare services including access to specialised services if required, among other provisions (Council of Europe, 2006).

### **Disability Policies in Ireland**

The UN Rules on Equal Opportunities for People with Disabilities was the springboard for action, highlighting as it did the plight of people with disabilities, who were clearly seen to be at risk of having their rights denied or ignored at the level of social policy making and led to the development of new policies, supported by disability and equality legislation (Government of Ireland, 1996).

### **Irish equality and disability legislation**

The Irish Disability Act 2005 (Government of Ireland, 2005), among other provisions, gives statutory force to the mainstream responsibility. The Government's broad-ranging National Disability Strategy, reaffirmed by the social partners in towards 2016, sets out an agenda for every Government Department and public body, including detailed statutory Sectoral Plans for 6 key Departments, and including the health service. Equality legislation has been enacted in Ireland to outlaw discrimination in the provision of goods and services, on a number of grounds, including disability, in the Equal Status Acts 2000 and 2004. However, the Strategy does not specifically reference maternity services for people with disabilities (Government of Ireland, 2000, 2004).

### **Issues Addressed by Advocacy**

The literatures under review explored some of the major issues facing people with disabilities; these include violation and denial of fundamental human rights and entitlements such as health inequality, education, employment, discriminations and exclusion from taking part in decisions that affects their lives (Knight & Oliver, 2007; Brolan et al., 2012; and Feldman et al., 2012). Other issues affecting this population include powerlessness, lack of voice among others (Gilmartin & Slevin 2009). It was established that the world report on disability (2011) is the first of its kind, providing global guidance on implementing the UN Convention on the Rights of Persons with Disabilities (CRPD). It gives a broad picture of the situation of people with disabilities, their needs and unmet needs, and the barriers they face to participating fully in their societies. As emphasised in the previous studies above it also highlights health; rehabilitation; assistance and support; enabling environments; education; and employment as some of the issues confronting this cohort (DFI, 2012).

### **Environmental Barrier**

While the general belief is that the society has moved away from a medical model towards a social model (DFI, 2003), research shows that generally, people with disabilities face widespread barriers in accessing services. These include inadequate policies and standards, negative

attitudes, lack of service provision, inadequate funding, lack of accessibility, inadequate information and communication and lack of participation in decisions that directly affect their lives (World Report on disability, 2013). Disability arises from the interaction between people with a health condition and their environment. The CRPD reflects this emphasis on removing environmental barriers which prevent inclusion (World Report on disability, 2013).

### **Disability and Access to Mainstream Systems and Services**

According to World Report on Disability mainstreaming is the process by which governments and other stakeholders address the barriers that exclude persons with disabilities from participating equally in any service intended for the general public. This requires changes to laws, policies, institutions and environments. They argued that mainstreaming not only fulfils the human rights of persons with disabilities, it can also be more cost effective (World Report on Disability, 2013).

### **The Challenges of Advocacy**

The previous paragraphs had discussed various issues confronting people with disabilities; however this paragraph reviewed some of the challenges being confronted in performing advocacy service. In a study conducted by Llewellyn and Northway (2007) to investigate the advocacy role of learning disability nurses in Wales. It was found that nurses also perform an advocacy role for clients, and part of the challenges they faced were conflicts of interest. It was also found that nurses require education and training to perform their advocacy role effectively. In another qualitative study conducted by Knight and Oliver in 2007, they concluded that advocating for a group which has traditionally been undervalued by society is a challenge in itself. They believed that advocates working with severely learning disabled young people must tread a line between advocating for the young person and acting in their best interests. They argued for the need for advocates to be equipped with necessary skills like communication skills to work with young people with learning disabilities and communication impairment efficiently.

In a study which used an intervention and control group to provide a preliminary evaluation of the health rights training, the participants were people with intellectual disabilities recruited from Community Living Associations in Ontario, Canada. It was a randomized control design with pre, post and up to six months follow-up to evaluate the health self-advocacy training program for persons with intellectual disability. Training involved teaching participants to recognise and redress health rights violations in the context of respect and responsibility. They found that persons with mild or moderate intellectual disability can learn generalised health self-advocacy skills, through training. They however, concluded that health self-advocacy training may help fight existing health inequalities and access of person with intellectual disability. However, the size of the sample and loss to follow-up data made the authors to conclude that the result should be considered preliminary.

A similar study conducted in Ireland (2009) established how important and valued self-advocacy group are, as it empowered the un-powered, and makes real differences to people's lives. It also increases awareness of self-identity, social networks among others. They however concluded that services need to listen to the voices of people with disability and carefully consider the need to roll out of self-advocacy groups across all services. Other challenges include inadequate resourcing and lack of a person-centred approach, bureaucracy, community attitudes and ignorance (Brolan et al., 2012, as cited by Gilmartin & Slevin, 2009).

### **Advocacy Model in Australia: A Comparison with Irish Model**

In Australia the model is quite similar to the Irish model as advocacy takes the form of: Family advocacy, Self-advocacy, Peer advocacy, Citizen Advocacy, Systemic advocacy, Individual advocacy and use of Peak bodies. Peak bodies are 11 voluntary National Disabilities Organisations who have mandate to undertake advocacy for their specific disability type (Goodbody, 2004).

### **Funding**

It was found that in Australia most advocacy programs are funded by the Commonwealth Government (the Federal Government) and the government at this level does not directly provide

services (Goodbody, 2004). Advocacy organisations are therefore, moderately; free to criticize services that are generally state funded.

### **Training for Advocates**

It was found that in Australia training is quite essential for advocates. Advocates undertake some formal training programs offered via Technical and Further Education (TAFE) and advocacy organisations as in-house training for members of the organisation (Goodbody, 2004).

### **Who Receives Advocacy in Australia**

It was equally found that most advocacy organizations set their own criteria for people to access their service. The demand for advocacy services far exceeds the ability of advocacy organisations to meet these needs, so selection and referral criteria need to be established simply in order to make decisions and set priority areas (Goodbody, 2004).

### **The way forward**

Although, Ireland is yet to ratify the Conventions on the Right of Persons with Disability (CRPD), findings revealed that they have taken a step close to its actualisation, as Decision-Making Capacity Bill 2013, presented in July 2013, has been identified as a key step ahead of ratifying the Convention on the Rights of People with Disability (Irish Congress of Trade Unions, 2013).

## Conclusion

This chapter has explored various literatures on issues and challenges associated with advocacy role for people with disabilities. Key concepts such as disability, history of disability, rights and empowerment, advocacy, advocacy and disabilities were all part of the areas reviewed. Other areas explored include policies and legislations around people with disabilities, issues and challenges associated with advocacy role and comparison of advocacy model in Ireland with another developed country. It was found that people with disability are still experiencing difficulties in living a normal quality life (Brolan et al., 2012; and Feldman et al., 2012). This is due to the lack of implementation of adequate policies and constraints in access to public services and goods. Evidence shows that advocacy services have not performed up to required standard as a result of various challenges posed to the service by bureaucracy, funding, conflicts of interest, communication and many more.

## CHAPTER 3: METHODOLOGY

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### Research Design

This study involved using semi-structured qualitative interviews of seven (n=7) advocates or advocacy officers working with/for people with disabilities in different disability organisations across Dublin, Midlands and South East region of Ireland. Of the seven participants three advocates were based in Dublin, two in Midlands (Carlow and Tullamore) and two in Waterford. The researcher had considered these three regions to allow for diverse and quality data. One participant was recruited from each of the following disability organisations; namely Enable Ireland, Deaf Hear.ie, Inclusion Ireland, Irish Wheelchair Association, National Advocacy Service (NAS), Region 3, Offaly, National Advocacy Service (NAS), Region 4, Waterford, and National Council for Blind Ireland. The seven participants represented the four main categories/types of disabilities. That is developmental, intellectual, physical and sensory disabilities.

### Study Population and Sampling Method

The population of interest for this study were advocates or advocacy officers working for people with disabilities in Ireland. Seven adults (four women and three men) who were either employed as advocates for people with disability or advocacy was part of their job requirements were selected as representative samples for this study. Emails and phone calls were used to invite each participant to the study. The participants granted permission to the researcher to participate in the study and agreed to be interviewed at a mutually convenient place and time. The researcher also sought for permission from each participant to record the interview on an audio-tape device which was granted.

The sampling method that was used to select the population for this study was non probability convenient sampling. A non-probability sampling has to do with a basic assumption about the

nature of the population under study. In non-probability sampling, there is an assumption that there is an even distribution of characteristics within the population. This is what makes the researcher believe that any sample would be representative and because of that, results will be accurate (Statistics Canada, 2013). One of the limitations of non-probability sampling is, since elements are chosen arbitrarily, there is no way to estimate the probability of any one element being included in the sample (Statistics Canada, 2013). The researcher also used convenient sampling in choosing the participants for the study as time and logistics constraints would not allow for random probability sampling. The obvious advantage is that the method is easy to use, but that advantage is greatly offset by the presence of selection bias (Statistics Canada, 2013).

### **Study Setting and Site of Data Collection**

Four of the seven advocates agreed to be interviewed at their respective offices as it was mutually convenient for both the participants and the researcher. Hence, the data was collected by recording the interview at the office of each of the four advocates who had agreed to be interviewed. The other three advocates requested to send their responses to the research questions via email, as it was not convenient for those participants to be interviewed.

### **Data Collection Methods**

All the participants were given a topic guide prior to the interview to inform them about what the study involves. The interviews were conducted in Carlow, Dublin, Tullamore and Waterford between February and March 2014, using already prepared questions (see Appendix 3) adapted from a similar accredited study (NDA, 2003). The questions were designed into six sections for clarity of purpose and to facilitate understanding for the participants. Section one asks questions which measure the demographics of the participants, Section two asks questions which measure the profile of the organisation the participant works for. Section three asks questions which assess the issues being addressed by advocates, Section four, asks questions that explore the challenges facing the advocates and Section five asks questions that did not fall under any of the

previous sections. In all 31 questions were asked, and the researcher chose to use open questions to allow the interviewee to speak more. The researcher also used some key prompts to reflect and probe further on the response of the interviewee to gather more information. Each interview lasted for an average of one hour, five minutes. An android mobile phone with voice recorder was used to record the interviews and the data recorded was clear and audible enough for analysis.

### **Data Analysis**

To analyse the data collected and provide answers to the research questions, thematic content analysis was used. The researcher's choice of thematic content analysis was informed by the fact that it is the most appropriate tool for qualitative study analysis (Lewis-Beck & Iryman, 2004).

The researcher transcribed the recorded interviews on a word document; leaving double spacing between each sentence and a wide margin on each side to write on. The transcribed text from each interview was read over and over until relevant codes or main themes emerged. The emerged themes were grouped under similar pre-determined themes or headings namely; the role of advocates, the issues, the challenges and attitudes and behaviours. Different font colours were used to clearly identify each participant's quotes as applicable to each heading. Also some quotes were clearly highlighted under applicable themes. The researcher went further to break down the main codes into sub-codes, and made note of each code as linked to the main theme. The pattern is similar to leadership hierarchy or a big tree with small branches. As the researcher read and re-read over the text, new code(s) emerged and these codes were placed on the appropriate level on the hierarchy. Comparisons were made between codes or themes to maintain consistency in applying the codes. Based on these codes, the researcher collated all the findings into relevant sub-sections/themes and presented the findings in a final word document supplemented with quotes where appropriate.

### **Ethical Consideration**

In line with normal research protocols and owing to the fact that some of the information gathered during the study could be quite sensitive, consequently, the researcher addressed the ethical consideration by implementing the following measures:

- Detailed information about the research including the aims and objectives of the study was made available to all the participants; to give them a good background of what is involved in the study and what is expected of them (Please see Appendix 1).
- Informed Consent Form was made available to all the participants to obtain their informed consent before involving them in the study (Please see Appendix 2).
- The participants were informed that their participation in the study was voluntary and that they were under no obligation to take part in the study, and they reserve the rights to discontinue with the study at any stage.
- The participant' rights to anonymity in the study were equally maintained as their personal details; such as name and address are not mentioned for confidentiality reason. Each participant was assigned a pseudonym to protect their real identity.
- The potential risks and benefits associated with the study were outlined to all the participants, and equally, the right of the participants to withdraw their permission to use the data obtained, in which case the material will be deleted, was also outlined.
- Ethical approval for this study was obtained from the Department of Health, Sports and Exercise Science Ethics Committee before the commencement of the study.

## CHAPTER 4: RESULTS

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### Introduction

This chapter presents the qualitative results which were gathered through interviews with the participants (n=7) who are advocates, who work with people with disability in Ireland. The content of this chapter is structured into a number of sections. Section A, B, C, D and E. The findings are presented in table format and supported with direct quotes from the participants where applicable.

### Section A: Profiles of the Disability Organisations

Seven disability organisations were recruited for the study from three geographical areas of the country namely Dublin, Midlands and South Eastern part of Ireland. The organisations include Deaf Hear.ie, Enable Ireland, Inclusion Ireland, Irish Wheelchair Association (IWA), National Advocacy Service (NAS) Region 3, Offaly, National Advocacy Service (NAS) Region 4, Waterford, and National Council for the Blind Ireland (NCBI) (see table 1). All the seven organisations perform advocacy role for people with disability in Ireland and they all represent the main categories of disabilities; that is developmental, intellectual, physical and sensory disabilities. Five of the organisations were established between 1931 and 1964, whilst the remaining two organisations were both established in 2011. The organisations were recruited across three different geographical areas of the country to allow for any possible variations in the data collected. Apart from the National advocacy Service, Region 3, Offaly and the National Advocacy Service, Region 4, Waterford which provide national advocacy services in Ireland, all other organisations are privately owned and they provide services to their registered members only. Although virtually all of them are partly funded by the government through Health Service Executive (HSE), nonetheless, their service is quite fragmented, that is limited to their members.

The following table 1 illustrates the profile of the organisations used in the study.

**Table 1 Detailed Profile of the Disabilities Organisations**

No	Name of Organisation	Statutory Status	Location	Year Estab.	Category of Disability Catered for
1.	Deaf Hear.IE	Not for profit charitable org.	Dublin	1964	Sensory Disability: for deaf & hard of hearing people
2.	Enable Ireland	Not for profit charitable org.	Dublin	1956	Developmental and Intellectual Disability
3.	Inclusion Ireland	Not for profit charitable org.	Dublin	1961	Intellectual Disability:
4.	Irish Wheelchair Association (IWA)	Not for profit charitable org.	Carlow	1964	Physical Disability
5.	National Advocacy Service: (NAS) Region 3	Independent free national advocacy service	Offaly	2011	Intellectual disability
6.	National Advocacy Service: (NAS) Region 4	Independent free national advocacy	Waterford	2011	Intellectual Disability
7.	National Council for Blind Ireland (NCBI)	Not for profit charitable organisation	Waterford	1931	Sensory Disability: for people experiencing sight loss

Table 1 above shows that one organisation represented the physical disability category (people with limited mobility), two from sensory disabilities (deaf and hard of hearing people and people with sight loss) and four represented developmental and intellectual disabilities (people with autism, down syndrome etc.) . Five of the seven organisations were ‘not for profit’ charitable organisations, whereas the other two were established by the Irish government to provide free independent national advocacy service for people with disability in Ireland.

Table 2 below illustrates the organisations source of funding and the number of advocates employed by each organisation.

**Table 2 The Organisations Source of Funding and the Number of Advocates**

<b>No.</b>	<b>Organisation</b>	<b>Source of Funding</b>	<b>No. of Advocates in the Org.</b>
1.	Deaf Hear.IE	HSE (80%), Others: Fundraising, Enterprise	All the staff perform some form of advocacy role
2.	Enable Ireland	HSE (85%), Others: Fundraising	5
3.	Inclusion Ireland	HSE, Fundraising	4
4.	IWA	HSE, Fundraising	The organisation promotes self- advocacy and independence
5.	(NAS) Region 3	Dept. of Social Protection through (CIB)	8
6.	(NAS) Region 4	Dept. of Social Protection through (CIB)	7
7.	NCBI	HSE, Fundraising and Enterprises	Most of the staff perform some form of advocacy role

Table 2 above shows that five organisations out of the seven involved in the study are being funded by Health Service Executive (HSE), while the other two organisations are funded by the Department of Social Protection through the Citizen Information Board. Four organisations gave the number of advocates employed by their organisations, while the other three organisations regarded advocacy as part of their job requirements. Five organisations engage in fundraising and donations as part of their source of funding.

Table 3 below illustrates the organisations, their categories of disability and the types of advocacy services they provide.

**Table 3 The Organisations, Category of Disability Service and Types of Advocacy**

No.	Organisations	Category of Disability	Self-Advocacy	Rep. Advocacy	Independent Advocacy
1.	Deaf Hear.IE	Sensory Disability	✓	✓	
2.	Enable Ireland	Intellectual /Dev. Disability	✓	✓	
3.	Inclusion Ireland	Intellectual/dev. Disabilities	✓	✓	
4.	IWA	Physical Disability	✓	✓	
5.	(NAS) Region 3	Intellectual/dev. Disabilities		✓	✓
6.	(NAS) Region 4	Intellectual/dev. Disabilities		✓	✓
7.	NCBI	Sensory Disability	✓	✓	

Table 3 above shows that four of the seven organisations are in the category of intellectual/developmental disability; two of the organisations are in the sensory disability category, while one organisation belongs to physical disability category. All the seven organisations provide representative advocacy, five promote self-advocacy and two provide independent advocacy service.

Table 4 illustrates the organisations and the population group they provide their service for

**Table 4 The Organisations and their Target Population**

<b>No.</b>	<b>Organisations</b>	<b>Service for people with limited mobility</b>	<b>Service for deaf and hard of hearing</b>	<b>Service for blind and people with impaired vision</b>	<b>Service for people with intellectual disabilities</b>
1.	Deaf Hear.IE		✓		✓
2.	Enable Ireland	✓			✓
3.	Inclusion Ireland				✓
4.	IWA	✓			
5.	(NAS) Region 3	✓	✓	✓	✓
6.	(NAS) Region 4	✓	✓	✓	✓
7.	NCBI			✓	

Table 4 above shows that five organisations provide services to people with intellectual disability, four organisations provide services to people with physical disability (wheelchair users), three organisations provide services to people with sensory disability (deaf and hard of hearing people) and three organisations provide services to sensory disability (blind and people with impaired vision).

Table 5 below illustrates the organisations, the services they provide and the type of care setting in which those services are provided.

**Table 5 The Organisations and The Care Services Offered**

<b>No.</b>	<b>Organisation</b>	<b>Independent/ Semi- independent living</b>	<b>Residential/Respite care service</b>	<b>Supported living</b>	<b>Service for children with disability</b>	<b>Support services for adults with disability</b>
1.	Deaf Hear.IE				✓	✓
2.	Enable Ireland	✓	✓	✓	✓	✓
3.	Inclusion Ireland					✓
4.	IWA	✓		✓		✓
5.	(NAS) Region 3					✓
6.	(NAS) Region 4					✓
7.	NCBI			✓		✓

Table 5. above shows that seven organisations provide support services to people with disabilities. Three organisations provide supported living care services, two organisations provide independent and semi-independent living care services, two provide services for children with disability and one organisation provides residential and respite care services.

## Section B. Profiles of the Participants

The following table 6 illustrates the profiles of the seven participants.

**Table 6 Profiles of Participants (n=7)**

No	Pseudonym	Gender	Age Range (Yrs.)	Organisation	Position
1.	Brit	Male	45-55	Deaf Hear.ie	Head of Information and Policy
2.	Carol	Female	34	(NAS) Region 3	Senior Advocate
3.	Klive	Male	38	Enable Ireland	Disability Coordinator/Self-advocate
4.	May	Female	45-55	NCBI	Community Resource Worker
5.	Mate	Male	43	Inclusion Ireland	Advocate
6.	Nick	Female	30-45	(NAS) Region 4	Senior Advocate
7.	Pat	Female	45-55	Irish Wheelchair Association (IWA)	National Development officer

Table 6 above shows the names of the participants (pseudonyms were used to protect the real identity of the participants). Four of the participants were females (n=4), three were males (n=3), and their age range is between 30-55 years. The participants include two senior advocates, one advocate, one self-advocate, one community resource officer, one national development officer, and one management staff (head of information and policy). The common attribute among all these participants is that they all perform advocacy role.

### Profiles of Participants Continued

Table 7 illustrates the educational qualifications of the participants, their years of experience and how they became advocates.

**Table 7 Participants Qualification and Experience as Advocate**

No.	Pseudonym	Qualifications	Years of experience with the organisation	How they became advocates
1.	Brit	MSc. Health Services Mgt.	20 years	Part of the job requirements
3.	Carol	B.A. Applied Social Study History	7 years	Work experience with people with disability
2.	Klive	Degree in front line management in the disability sector	11 years	Personal experience with disability
4.	May	BA. Applied Social Care	8 years	Part of the job requirements
5.	Mate	BA. in Applied Social Care and Certificate in Advocacy Course	2 years	Personal experience with a child with disability
6.	Nick	Master's Degree in Criminology	3years	Master's Degree in Law and got advocacy job
7.	Pat	HD in Disability Studies	8 years	Work experience with people with disability

Table 7 above shows that all the participants (n=7) have attained third level educational qualifications, their years of experience as advocates range between 3-20 years. Five of the seven participants have got some experience prior to their advocacy role, while two became advocates through job experience as it was part of their job requirements.

## Section C: Roles of Advocates

The following table 8 illustrates the themes that emerged under the heading ‘The Role of Advocacy’.

**Table 8 The Role of Advocacy**

		<b>The Roles within Advocacy</b>						
<b>No</b>	<b>Pseudonym</b>	<b>(1) Promote Independence</b>	<b>(2) Represent/ Lobby</b>	<b>(3) Educate</b>	<b>(4) Communicate</b>	<b>(5) Provide Information</b>	<b>(6) Writing Submission/ Report</b>	<b>(7) Influence Policy</b>
1.	Brit	✓	✓	✓	✓	✓	✓	✓
2.	Carol	✓	✓	✓	✓	✓	✓	
3.	Klive	✓	✓	✓	✓	✓		
4.	May	✓	✓	✓	✓	✓	✓	
5.	Mate	✓	✓	✓	✓	✓	✓	✓
6.	Nick	✓	✓	✓	✓	✓	✓	
7.	Pat	✓	✓	✓	✓	✓	✓	✓

Each theme in the table 8 above is illustrated in detail below and supported with quote from the participant as applicable.

### **Promote Independence**

As indicated in the table 8 above, it was found that all the participants (n=7) believed that promoting independence is a key part of their roles. This is illustrated by quote from one of the participants: *“Like our mission statement, it’s about empowerment. Yes, we are supporting*

*people to reach their full potentials and to retain as much independence as they can. So in terms of empowerment that is it.” (May)*

The following figure 2 illustrates some of the themes that emerged during the interviews with the participants in relation to the roles of advocates as they ‘promote independence.’

**Figure 2: The Roles of Advocates: Promote Independence**



Figure 2 above shows that advocates promote independence by providing useful information to service users. After gaining information, the service users become well informed, they are empowered, and as a result they can make informed choice(s) and take decision.

### **Represent or Lobby**

The study revealed that all the participants (n=7) represent and or lobby in performing their roles. This is evident in the participant’s quote below:

*“Role is to listen, objective at all times, professional, confidential, liaising on behalf of the client with professionals, parents, siblings, organisations, carers. Keeping within in the guidelines of the policy and procedures of the organisation that I represent” (Klive).*

The following figure 3 illustrates some of the sub-themes that emerged during the interviews with the participants in relation to the roles of advocates as they represent and lobby.

**Figure 3: The Roles of Advocates: Represent and Lobby**



Figure 3 above shows that part of the roles of advocates is that they represent individual and group with the aim to promoting the will and preference of the service user(s).

### **Educate**

It was gathered from the study that an important part of advocacy role is to educate and raise people's awareness on issues as it relates to the needs of service users. All the participants (n=7) believed that they educate the service user as part of their roles. The following quote is from one of the participants.

*“The most important thing, the members must do for themselves, they must gain the experience, they must gain knowledge and therefore they are empowered then to make a choice.” (Pat)*

The following figure 3: illustrates some of the themes that emerged during the interviews with the participants in relation to the role of advocates: ‘educate service user’

**Figure 4 The Roles of Advocates: ‘Educate’**



Figure 4 above shows that advocates educate, create awareness and promote empowerment as part of their roles. When service users are educated, they are aware of their needs, rights and entitlements and thus, they are better informed.

### **Communication**

According to the findings in table 8 above communication was found to be one of the key roles performed by all the participants (n=7) as evident in the quotes below.

*“You also need to know what people’s rights are in many situations. You also need excellent communication skills. You need to be determined and committed to the person using your service.” (Mate)*

*“Basically you listen to the client’s views and wishes and then you translate it in their words to whom they want you to Advocate to.” (Klive)*

The following figure 5 illustrates some of the themes that emerged during the interviews with the participants in relation to the role of advocates: ‘communication’.

**Figure 5 The Role of Advocates: Communication**



Figure 5 above shows that communication is an integral part of the roles of advocates. Communication takes the form of listening to the service users, the advocate then provides the needed information to the service users and the service users become more aware of their needs and rights. Therefore, they can demand for those rights.

### **Providing Information**

Information is also a key part of advocacy roles, the study found. All the participants (n=7) agreed that providing information is essential to their role.

*“The person has to be making the decision, we don’t make the decision for people, and we just give the information support the person to make an informed choice.” (Carol)*

Figure 6 below illustrates some of the themes that emerged during the interviews with the participants in relation to the role of advocates: ‘providing information’

**Figure 6: The Role of Advocates: Providing Information**



Figure 6 above shows that providing useful information leads to empowerment and people are better informed. Been informed would enable service users to take decision, make informed choices and take responsibility for their action.

### **Writing Submission**

Almost all the participants (n=6) were found to be involved in writing submissions or reports as part of their roles, as evident in the following quote.

*“My first brief is representative advocacy, and as I was saying to you, at the AGM people bring forward what the issues are, but we also run consultation sessions down the country. We accumulate what the issues are and we submit them to the government department, or we may get invite from GPs, or Dentists, or even shops as to what the issues are for people with disabilities. But mostly, is around the Sectoral Plan in Disability issues about that a time we lobby the government, so we used them as lobbying the government on what the issues are. So you write the submissions and then you go and lobby.” (Pat)*

The following figure 7 illustrates some of the themes that emerged during the interviews with the participants in relation to the role of advocates: ‘writing submission’.

**Figure 7 The Role of Advocates: Writing Submission**



Figure 7 above shows that advocates write submission/report, then they represent and lobby to influence policy and change towards a better access to rights and services for people with disability who have been marginalised and excluded from the mainstream of activities.

### **Influence Policy:**

From the table 8 above three participants acknowledged that their role involve influencing policy, as stated in the following quote.

*“I graduated over the years into management, now into the post primarily involves in advocacy, doing the submission report, looking at policy, looking at research, as part of our strategy to advocate and succeeding in getting better access, getting better service for deaf and hard hearing people.”(Brit)*

The following figure 8: illustrates some of the themes that emerged during the interviews with the participants in relation to the role of advocates: ‘influence policy’.

**Figure 8 The Role of Advocates: Influence Policy**

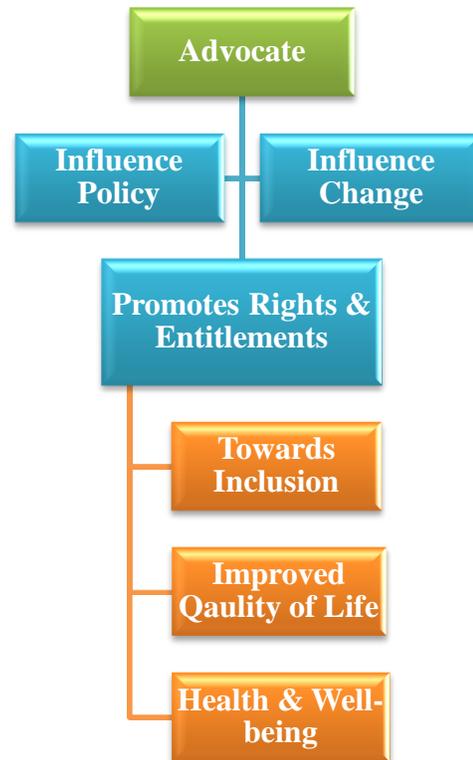


Figure 8 above shows that advocates influence policy, influence change, as a result they promote rights and entitlements and this actions leads to social inclusion. Invariably, social inclusion would lead to improved quality of life, health and wellbeing of the service users.

## Section D. Issues

The following table 9 illustrates some of the issues being addressed by the participants during their advocacy practice.

**Table 9 The Issues Being Addressed During Advocacy**

No.	Pseudonym	Issues						
		(1) Access to Service	(2) Health	(3) Rights & Entitlements	(4) Transport	(5) Housing/ Appropriate Accommodation	(6) Employment	(7) Education
1.	Brit	✓	✓	✓	✓	✓	✓	✓
2.	Carol	✓	✓	✓		✓		
3.	Klive			✓				
4.	May	✓	✓	✓		✓		✓
5.	Mate	✓	✓	✓		✓	✓	✓
6.	Nick			✓		✓		
7.	Pat	✓		✓	✓		✓	

### Access to Service

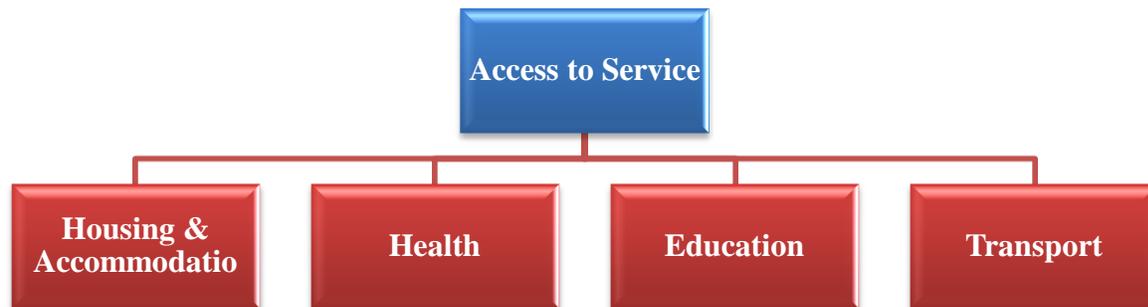
Table 9 above shows five (n=5) out of the seven participants (n=7) have come across or addressed the issue of access to service. The following quotes are from the participants:

*“I could mentioned that if am a deaf person and I use sign language and I’m sick, I go to the hospital, I will be lucky if I get an interpreter. I will be lucky if get a good service the same as other people.” (Brit)*

*“The main issue when you talk about advocacy is the same as chestnuts. It would be employment, housing, access as in environmental access and income, cost of living, because cost of living for disability is considered a bit higher. They would be the four main issues that come up.” (Pat)*

The following figure 9 illustrates some of the themes that emerged during the interviews with the participants in relation to the issues being addressed during advocacy: ‘issue of access’.

**Figure 9 The Issues Being Addressed During Advocacy: Issue of Access**



The above figure 9 shows the issues that emerged under access to service. People with disability are deprived of appropriate accommodation due to lack of funding. People with disability are denied access to health service due to lack of interpreter in some GPs and clinics. Access to education also emerged as special needs schools are either not adequate or far away from some service users. Access to transport is an issue especially those living in rural areas.

### **Health**

Table 9 shows that four participants (n=4) acknowledged health as one of the issues they have come across. The following quote is from one of the participants:

*“Many people have difficulty accessing therapy services for children.” (Mate)*

The following figure 10 illustrates some of the themes that emerged during the interviews with the participants in relation to the issues being addressed during advocacy: ‘issue of health’.

**Figure 10 The Issues Being Addressed During Advocacy: Issue of Health**

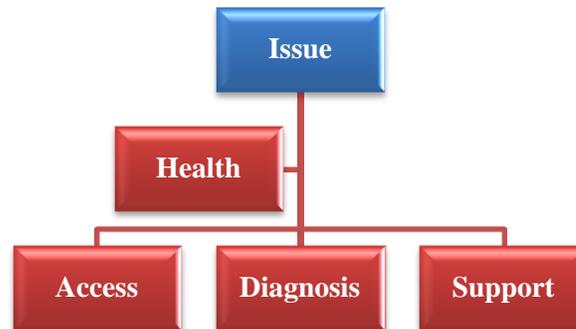


Figure 10 above shows that people with disability experienced difficulty in gaining access to health service (e.g. inadequate speech therapist). Findings revealed that people with hard of hearing hardly do not get interpreter in the hospital, as a result it could lead to wrong diagnosis. Also, it was found that people with disability sometimes lack after clinic support.

#### **Rights and Entitlements:**

All the participants (n=7) agreed that the issue of rights and entitlements is one of the main issues being addressed by advocates according to table 9 above. The following quotes are from the participants.

*“Housing is the main issue. **H**ousing is the biggest and benefit would have been another one.”*  
(May)

*“At present this cohort of people cannot get married. People also have difficulty in having a relationship. Many sexual relationships are even outlawed by the (Criminal Justice Sexual Offences Act). People with disability who have children are more likely to have their child taken into care.”* (Mate)

The following figure 11: illustrates some of the themes that emerged during the interviews with the participants in relation to the issues being addressed during advocacy: ‘issue of rights and entitlements’.

**Figure 11 The Issues Being Addressed During Advocacy: Rights and Entitlements**

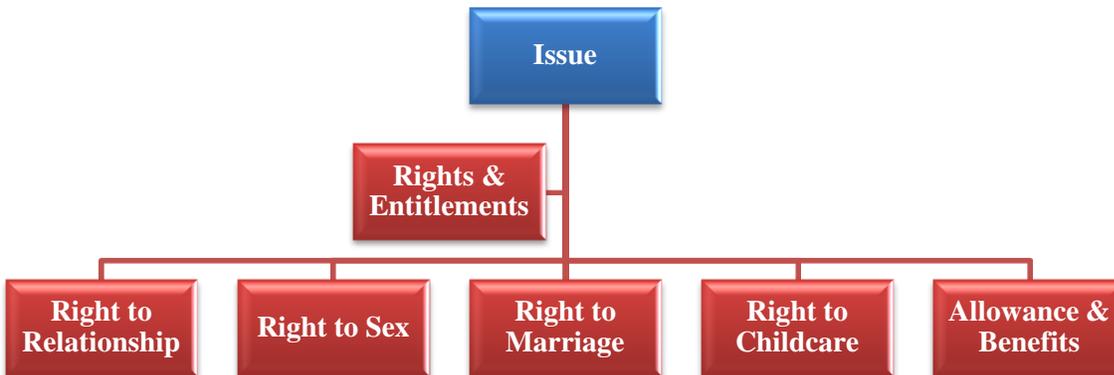


Figure 11 above shows that under rights and entitlements issue, the issue of right to relationship, right to sex, right to marriage and right to childcare emerged as those rights that are not allowed for people with disabilities. Findings also, revealed that this cohort sometimes experience difficulty in getting their allowance and social benefits.

#### **Transport:**

Table 9 above shows two participants (n=2) who have come across transport as one of the issues in their advocacy practice. The following quote is from one of the participants: *“Again, accessible taxi is difficult, that is extra cost. So the average thing you trying to go to the Dentist, trying to go to hospital appointments prove pretty tricky and expensive. So your options are extremely limited as to how you can get access.”* (Pat)

The following figure 12: illustrates some of the themes that emerged during the interviews with the participants in relation to the issues being addressed during advocacy: ‘issue of transport’.

**Figure 12 The Issues Being Addressed During Advocacy: The Issue of Transport**

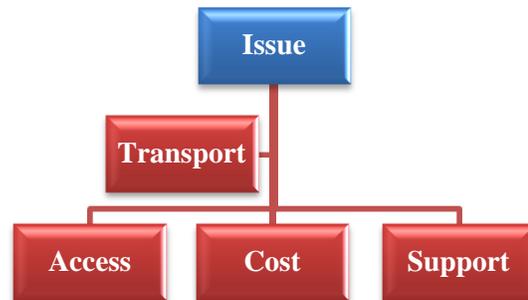


Figure 12: above shows that people with disability experience difficult accessing transport, especially those living in rural areas due to high cost and lack of care support needed.

#### **Housing/ Appropriate Accommodation:**

Table 9 above shows six participants (n=6) who acknowledged the issue of housing and appropriate accommodation as part of the issues being addressed during their advocacy role.

*“Inappropriate accommodation will be one issue where somebody may be inappropriately placed. May be where they were living in nursing home at young age, and they really should be living in an apartment or somewhere more appropriate.” (Carol)*

*“The biggest one, funning enough is the housing adaption grant. There is shortage because often the grant is run out very, very quickly, and it’s quite expensive to adapt your house.” (Pat)*

The following figure 13: illustrates some of the themes that emerged during the interviews with the participants in relation to the issues being addressed during advocacy: ‘issue of housing’.

**Figure 13 The Issues Being Addressed During Advocacy: The Issue of Housing**

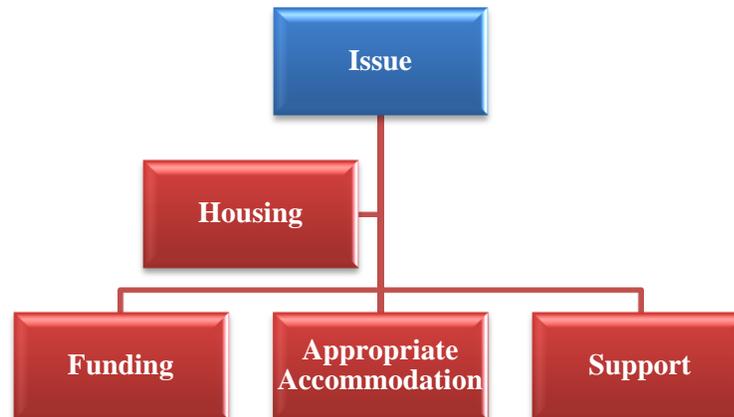


Figure 13: above shows that housing is one of the issues being addressed during advocacy. People with disability experience difficulty in getting appropriate accommodation due to lack of funding, and also sometimes there is no support staff due to cut in number of hours by disability organisations.

### **Employment**

According to the table 9: above three participants (n=3) acknowledged employment as one of the issues being addressed as part of their advocacy role.

*“People with physical, limited mobility come back to us and say they found that the hardest is to find meaningful employment.” (Pat)*

The following figure 14: illustrates some of the themes that emerged during the interviews with the participants in relation to the issues being addressed during advocacy: ‘issue of employment’.

**Figure 14 The Issues Being Addressed During Advocacy: The Issue of Employment**

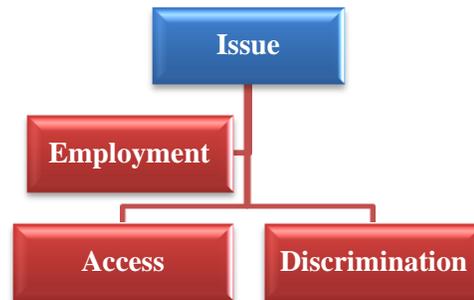


Figure 14: above shows that people with disability experience difficulty in getting employment. Findings revealed that this cohort cannot gain access to employment as they are discriminated against.

**Education**

Three participants (n=3) agreed that education was part of the issues they have come across.

*“Education has many issues. Children have difficulty getting an appropriate school place. Access to special need assistant support or resource hours is an issue. The use of isolation rooms in schools is also an issue.” (Mate)*

The following figure 15: illustrates some of the themes that emerged during the interviews with the participants in relation to the ‘issue of education’.

**Figure 15 The Issues Being Addressed During Advocacy: The Issue of Education**



Figure 15: above shows that the issue of education is one of the issues that are being addressed during advocacy. This includes access to mainstream education (e.g. distance or transport problem) and the necessary support needed by the service user (e.g. special need assistant support or inadequate special education teacher).

## Section E. Challenges

The following table 10 illustrates the challenges the participants face in performing advocacy role.

**Table 10 The Challenges Facing the Advocates**

No.	Pseudonym	Challenges					
		(1) Funding	(2) Policies & Legislation	(3) Bureaucracy/ Red Tape	(4) Workload	(5) Conflicts of Interest	(6) Public Perceptions/ Behaviour
1.	Brit	✓	✓	✓		✓	✓
2.	Carol	✓	✓	✓	✓	✓	✓
3.	Klive	✓	✓			✓	
4.	May	✓	✓	✓		✓	✓
5.	Mate	✓	✓	✓			✓
6.	Nick	✓	✓	✓	✓	✓	
7.	Pat	✓	✓	✓			✓

### Funding:

Table 10 above indicates that all the participants (n=7) acknowledged funding as one of their major challenges. The following quote is from one participant.

*“So there can be difficulty around that when you trying to advocate for change for the person, that control of problem, lack of funding for services, you know, you are advocating time and time again for people who have needs and the funding is not there to meet those needs.”* (Carol)

The following figure 16: illustrates some of the themes that emerged during the interviews with the participants in relation to the challenges facing the advocates: ‘funding’.

**Figure 16 The Challenges Facing the Advocates: The Issue of Funding**

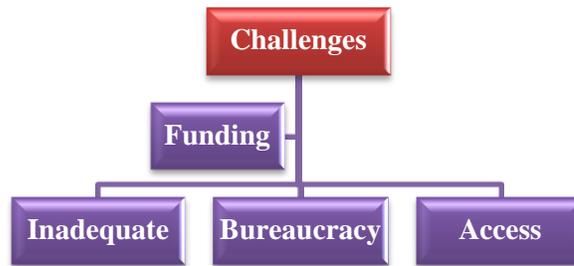


Figure 16: From the figure above the issue of funding is linked with inadequate funding, problem of bureaucracy in the public office and the problem of gaining access to the required funding for interventions needed by people with disabilities. Also people with disability do not have direct access to their fund due to Irish legislations.

#### **Policies and Legislations:**

Table 10: above indicates seven participants (n=7) believed that policies and legislations are part of the challenges they are facing in performing their role.

*“At present this cohort of people cannot get married. People also have difficulty in having a relationship. Many sexual relationships are even outlawed by the (Criminal Justice Sexual Offences Act). People with a disability who have children are more likely to have their child taken into care” (Mate).*

*“The UN convention on the rights of people with disability is not yet ratified in Ireland, that’s a big issue, yeah in terms of rights. The fact that is not ratified and also for the fact that we have poor legislation in relations to mental capacity and decision making, that bill is being looked at the moment so, until when that is enacted and when UN Convention is ratified things should improve.” (Carol)*

The following figure 17: illustrates some of the themes that emerged during the interviews with the participants in relation to the challenges facing the advocates: ‘policy and legislations’.

**Figure 17 The Challenges Facing the Advocates: Policy/Legislation**

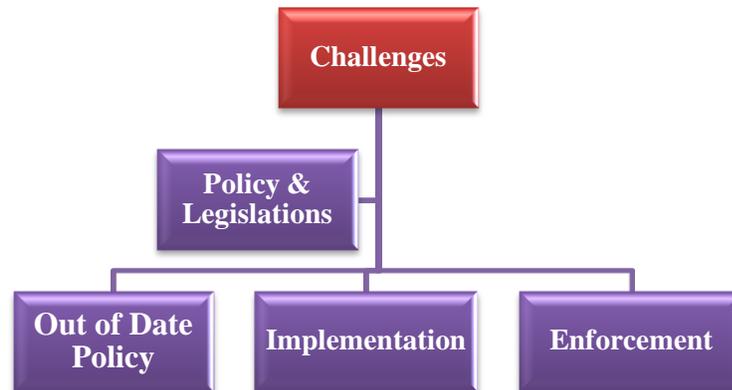


Figure 17: above shows that policy and legislation are part of the challenges facing advocates in performing their role. Implementation and enforcement of applicable legislations were seen as part of the challenges. Even some of the policies are old and out of date.

### **Bureaucracy or Red Tape:**

According to table 10 above, almost all the participants (n=6) acknowledged bureaucracy as one of the challenges facing advocates in performing their role. Participants said the following quotes:

*“I think you know, most systems are kind of and it can be guilty of that, you know, simple term of red tape, sometime it’s so bureaucratic in written, you know, is like a wall you are trying to get through (Pat).*

*“Trying to access key decision makers and experiencing delays in the process.” (Nick)*

*“You can write to eight particular persons over eight specific issues on an individual for housing, and you might write four letters and never get reply. You can then email and you never get reply. You are trying to advocate on this person’s behalf and getting nowhere or you might have a meeting with the housing representative and the service user and something that might be said in that meeting is changed immediately you have the door”. (May)*

The following figure 18: illustrates some of the themes that emerged during the interviews with the participants in relation to the challenges facing the advocates: ‘bureaucracy or red tape.’

**Figure 18 The Challenges Facing the Advocates: Bureaucracy/Red Tape**

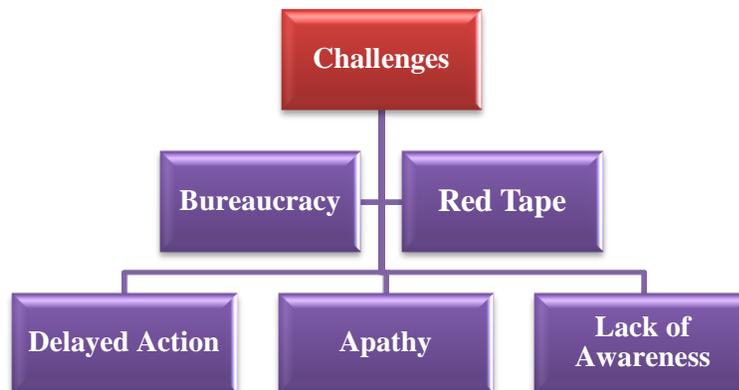


Figure 18 above shows that due to bureaucracy/red tape, there are delays in action, sometimes apathy is noticed on the part of the public office, and probably was due to lack of awareness and education about people with disability.

### **Workload:**

Two participants (n=2) identified workload as one of the challenges the advocates were facing. The following quote is from one of the participants.

*“Meeting the level of demand can be a challenge as well, that we do have a waiting list that kind of thing. So in relating to service that it’s just one advocate for an area, so it can be challenging in that sense. That is high demand for the service.” (Carol)*

The following figure 19 illustrates the theme that emerged during the interviews with the participants in relation to the challenges facing the advocates: ‘workload’.

**Figure 19 The Challenges Facing the Advocates: Workload**

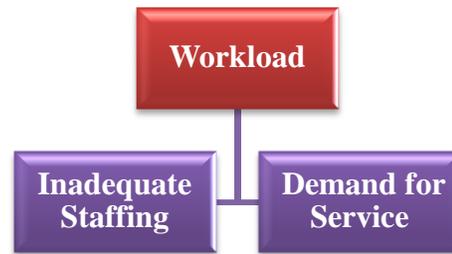


Figure 19 above shows that advocates face the challenge of workload due to inadequate staffing, especially at the NAS service, and as a result the limited number of advocates could not cope with the increasing demand for advocacy service.

### **Conflicts of Interest**

Table 10: above shows that part of the challenges advocates face is conflicts of interest with family or carer. The quotes below are from the participants.

*“Family and parents, you know, typically overprotect, they are often over protect their child as they are growing up in terms of their deafness and that’s often can end up in a conflict of interest, you know, interest.” (Brit)*

*“A client wanting to move out of home and the family not understanding why they want to move.” (Klive)*

The following figure 20: illustrates the themes that emerged during the interviews with the participants in relation to the challenges facing the advocates: ‘conflicts of Interest’.

**Figure 20 The Challenges Facing the Advocates: Conflicts of Interest**

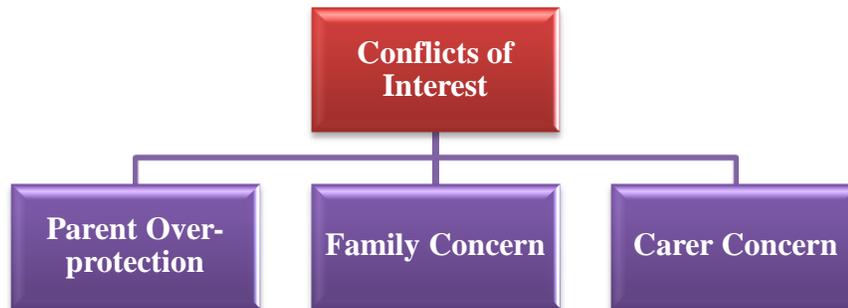


Figure 20 above, shows that under the challenge of conflicts of interest, advocates experienced this challenge as a result of parent being over-protective of the service user or family and carer showing concern about what the advocates have agreed with the service users to be carried out.

### **Public Attitudes and Behaviours**

The challenge around public attitudes and behaviours was also acknowledged in the findings. Table 10: above shows five participants (n=5) believed that people's attitudes and behaviour is one of the challenges facing advocates.

*"A client wanting to move out of home and the family not understanding why they want to move."* (Klive)

*"From my experience it's like lack of communication with the housing department. The issue with people with sensory disabilities doesn't seem to be a priority with that person in the department of housing section, and you very rarely get response from them which is very frustrating. Lack of interest before the stories: I don't really want to have... And if you talked about legislation, if you do find information about disability (equal rights) yeah and put it forward, they don't, they interpret it the way they want to interpret it."* (May)

The following figure 21: illustrates the themes that emerged during the interviews with the participants in relation to the challenges facing the advocates: 'public attitudes and behaviours'.

**Figure 21 The Challenges Facing the Advocates: Public Attitudes and Behaviour**



Figure 21 above shows that public attitudes and behaviours towards disabilities is a major challenge for advocates. Findings revealed that lack of education and understanding and lack of proper awareness about people with disabilities posed a big challenge to advocacy role. Public officers, carers or families sometimes do not act in the interest of this populace due to their ignorance.

## Conclusion

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This chapter has presented in details the results of the qualitative research conducted on the Role of Advocacy for People with Disabilities in Ireland. The findings gathered from the interviews with seven participants (n=7) explored in-depth the issues and challenges associated with the role of advocates working for people with disabilities as presented above in tables and complemented with quotes from the participants. The findings from this study are quite sufficient to answer the three research questions as evident in sections C, D, and E above. The results from this study is based on the opinions of the participants recruited for this study which centred on their experience as advocates or advocacy officer who work for people with disabilities. Due to the small numbers of participants (n=7) and other limitations identified in this study these results cannot be generalised. Nonetheless, the findings from this study are discussed in details in the next chapter.

## Chapter 5: Discussion

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### Introduction

This chapter seeks to draw together and discuss in detail the key findings that emerged from the previous chapter. The findings are based on qualitative interviews of seven participants (n=7) who work as advocates for people with disabilities in Ireland. Thus, the discussion will centre on the findings in relation to the purpose of this study which was to explore the role of advocacy for people with disabilities. Despite the limited number of participants in the study (n=7), the findings gathered from the seven interviews conducted are quite sufficient to answer the outlined research questions. Comparison of the findings with other studies will be carried out with a view to draw similarities, differences and limitations from this research. Thereafter, a conclusion and recommendations will be presented.

### Results Overview

The purpose of this research was to explore the role of advocacy service for people with disabilities in Ireland. Like most of the literatures reviewed, overall it was gathered from the study that the role of advocacy for people with disabilities is quite essential as it is the means by which this population can attain their rights and entitlements. Similar to a couple of previous studies, it was also gathered that the role of advocacy entails quite a number of responsibilities which would require some distinctive attributes to perform optimally. The findings also established that advocacy role for this vulnerable cohort can be quite broad and highly demanding in such a way that it would necessitate a strong and passionate commitment to a result-oriented practice in order to achieve the much desired change for this population. Rappaport et al., (2006) & Chambers (2007), as cited by Brolan et al., (2012) also supported this view as they found in their studies that an important way that the rights of people with disability are brought to light is through genuine advocacy efforts. Similarly, Indiana Institute on Disability and Community (2006) corroborated this view as they affirmed that knowledge alone does not make an effective and good advocate, interpersonal skills are essential in order to create and

maintain a good working, collaborative relationship (IIDC, 2006). However, surprisingly, this study has found that only two advocates out of the seven participants have attained a 'formal advocacy training' prior to their role. Although, it was gathered that this is not peculiar to the participants alone, as findings revealed that most advocates in Ireland do not necessarily acquire advocacy training to perform their role. Having basic skills such as communication, ability to read, write and understand the client or service user, and having some knowledge around policy and legislations as applicable to the service would suffice. Even a comparison of models carried out between Ireland and Australia revealed a number of similarities, except for the fact that it is a requirement in Australia for advocates to acquire advocacy training (Goodbody, 2004). Nonetheless, all the participants appeared to know what the job entails as they had all attained third level education and acquired years of experience over time.

The finding also reveals that all the seven participants acknowledged that their roles involve acting on behalf and for the interest of their service users. That is the primary goal of the advocates to promote the will and preference of the people with disability. Similarly, this is outlined in one of the reviewed literatures which stated that what is common to all types of advocacy is that the person who it is for (in this instance the person with disability) is always at the centre of the advocacy process (BILD, 2013).

Another key area of interest for this study was to investigate the issues around people with disabilities being addressed through advocacy role. The study explored in depth to establish some of the key issues being presented by people with disabilities to the advocates. Findings show that there are quite a variety of issues being addressed through advocacy as human needs are endless. Nonetheless, this study has found that most of the issues facing people with disabilities include access to service, health issue, the issue of rights and entitlements, transport issue, housing, employment and education. Some of the reviewed literatures also support the findings as they affirmed that the major issues facing people with disabilities include violation and denial of fundamental human rights and entitlements such as health inequality, discriminations and exclusion from taking part in decisions that affects their lives (Knight & Oliver, 2007; Brolan et al., 2012; and Feldman et al., 2012). Other issues affecting this population include powerlessness, lack of voice among others (Gilmartin & Slevin, 2009). Findings revealed that these issues can be overwhelming for advocates working with this cohort

as they battle with a number of challenges in their effort to attain basic rights and entitlements for people with disabilities.

The challenges facing the advocates in performing their roles were equally explored, and the findings show similar results to what has been found by Brolan et al., (2012), as cited by Gilmartin & Slevin, (2009). These include inadequate resources (e.g. funding and inadequate staffing), bureaucracy, community perceptions and ignorance. Other challenges found are policy and legislation, workload and conflicts of interest. Similarly, a study conducted by Llewellyn and Northway (2007) to investigate the advocacy role of learning disability nurses in Wales found that nurses also perform advocacy role for clients, and part of the challenges they faced were conflicts of interest. In addition to aforementioned, it was also established that education and training could pose some challenges to advocacy role as established by Llewellyn and Northway in their research. They concluded that nurses require education and training to perform their advocacy role effectively. This view is nonetheless, supported by Australian Department of Health as they assert that the effectiveness of a person's advocacy activities can be increased through acquiring knowledge, clarifying attitudes and values, and learning specific skills and strategies.

### **The Role of Advocates Working for People with Disabilities (RQ1)**

Interestingly, both the reviewed literatures and findings from this study have acknowledged the significance of advocacy role for people with disabilities. This is because people with disabilities have been subjected to persistent health inequality compared with the non-disabled general populations due to disparities in social determinants of health (Emerson et al., 2011). Persons with disabilities regularly experience powerlessness in their lives, particularly when taking life decisions about where and with whom to live, or where to work. Being unable to make decisions regarding their lives leaves people with disabilities at the mercy of professionals and family members (NDA, 2003). These growing concerns, no doubt have necessitated the increasing numbers of advocacy organisations we have today. This study has found that Ireland has over 160 disability organisations and virtually all of them perform one form of advocacy or the other for this vulnerable group. Findings also show that virtually all the participants in this study

agreed that they have performed the basic roles of advocacy which is representing, lobbying, speaking and acting on behalf of their service users to promote their will and preference. However, this study has revealed, like most reviewed literatures, that people with disabilities are excluded from the mainstream of activities in Ireland.

Despite the Irish disability Act 2005, and the UN convention on the rights of persons with disabilities, of which Ireland is a signatory member, it was found that approximately 4,000 people with disabilities still live in institutions or psychiatric hospitals (CSO, 2011; DFI, 2012). In actual fact, five of the seven participants in this study agreed that this cohort have been marginalised and discriminated against. In view of these findings, the question of why the role of advocates has not brought the needed change for this cohort came to mind. Not surprising, the answers found from this study are quite similar to those in all the reviewed literatures. Some of the participants agreed that the problem of ineffectiveness of the role of advocacy is due to the way the Irish system is structured. They believed that the system is faulty and the culture is quite resistant to change. Furthermore, the participants equally identified quite a number of challenges facing the advocates in performing their roles such as bureaucracy, failure to implement right policies or legislations, funding, conflicts of interest and public perceptions which are discussed in details in the subsequent paragraphs.

Nonetheless, the Norwegian Agency for Development Cooperation (NORAD) in their evaluation of Norwegian support to promote the rights of persons with disabilities gave some recommendation which perhaps might be helpful. They identified one of their major problems to be a failure to translate policy into action and gave the following reasons: 1. Lack of political priority, 2. Lack of understanding of disability as an important human rights and poverty reduction issue, 3. A belief that inclusion of persons with disabilities is difficult, expensive and not viable and 4. Weak advocacy by the disability organisations. They however, made some recommendations, but for this dissertation only one recommendation is discussed. They recommend that the country should take a political, high level decision to include disability as a key human rights issue in the international engagements of Norway around the world. They believed that when Norway has ratified the Convention on the Rights of Person with Disability (CRPD) it will be a legal obligation to do so (CRPD: Article 32) (Nordic Consulting Group, 2012). The problem identified in the Norway evaluation is quite similar to one in Ireland, as it

was gathered from both the reviewed literatures and this study that one of the major problems hindering the advocacy service in Ireland is legislation. Findings show that some of the legislations in place are either out of date or not properly implemented, and more so Ireland is yet to ratify the UN convention (CRPD), which most of the literatures reviewed agreed to be the catalyst to address the whole issues around disabilities and mainstreaming (Obama & Biden, 2007; Irish Congress of Trade Unions, 2013; USICD, 2013; WHO, 2013).

### **Issues Being Addressed During Advocacy (RQ2)**

This research has investigated in details some of the issues being addressed during advocacy and the findings revealed eight main issues that are associated with the needs of people with disabilities. These include access to service, health, rights and entitlements, transport and housing. Others include appropriate accommodation, employment and discrimination. These results are in agreement with the findings from studies conducted by Knight & Oliver, (2007), Feldman et al., (2012) and Gilmartin & Slevin (2009). Due to human nature and their particular needs, the issues facing any group or population can be quite diverse. However concerning the people with disabilities it has been summarised under one solution by the World Health Organisation (WHO) which is ‘mainstreaming’ (WHO, 2013).

Mainstreaming according to the (WHO) (2013) is the process by which governments and other stakeholders address the barriers that exclude persons with disabilities from participating equally in any service intended for the general public. This requires changes to laws, policies, institutions and environments. They argued that mainstreaming not only fulfils the human rights of persons with disabilities, it can also be more cost effective (WHO-World Report on disability, 2013). Even though it is generally believed that there has been a pattern shift in approaches to disability. Recent decades have witnessed the move has been away from a medical understanding towards a social understanding (DFI, 2003). Evidence shows that disability arises from the interaction between people with a health condition and their environment. Therefore, the convention on the rights of person with disability (CRPD) (2006) reflects the emphasis on removing environmental barriers which prevent inclusion of this cohort (World Report on Disability, 2013).

It is quite fascinating to see all these policy statements, enactment of legislations and promulgation of various laws in the society. However, it is really disheartening and worrisome to know that most of these initiatives appear to be mere theories without practicality. That is failure to translate policy into action which is believed to be responsible for all the issues facing the people with disabilities (Nordic Consulting Group, 2012).

The Norad Evaluation Report (2012) in their evaluation where they identified ‘failure to translate policy into action’ as one of the problems preventing the desired change for this cohort identified one of the reasons to be ‘weak advocacy by the disability organisations’. This view is quite striking as this study also found that, of the seven participants in this study only three have engaged in influencing policy in their advocacy role. Perhaps this may explain ineffectiveness of advocacy by the numerous disability organisations in Ireland.

In a move to revitalise the old promises and show more commitments to the plights of people with disability in Ireland, it was found that the Irish government launched the new plan for the National Disability Strategy, which was prepared and agreed by the National Disability Strategy Implementation Group (NDSIP) and submitted to Government on July 2013. The plan is described as a whole-of-Government approach to advancing social inclusion of people with disabilities. The idea is a welcome one, however quite a number of flaws have been identified by a concern group called Disability Federation of Ireland (DFI). They argued that overall it lacks ambition, and does not include many of the priority actions which DFI have suggested since the start of the drafting process for the Plan. They went further to say that what is underpinning this whole process is inadequate public service reform which is crucial for the successful implementation of the National Disability Strategy. They believed that there is a conflict between the actions stated in the NDSIP and the reality of Government decisions that have been taken over the past number of years. They equally argued that there has been a ‘chipping away’ at both disability specific supports and mainstream supports representing a complete lack of understanding of the challenges faced by people with disabilities trying to live an ordinary life with health and well-being in their own communities. They however, concluded that fulfilling the commitment made in the Plan to cross-departmental and cross agency working will require new approaches and in many cases, a cultural shift in ways of working. They believed that a robust implementation will be required if Ireland is to fulfil its obligations under

the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (NDSIP, 2013).

### **The Challenges Facing the Advocates (RQ3)**

This study and finding from a reviewed literature affirmed that advocating for a group which has traditionally been undervalued by society is a challenge in itself (Knight and Oliver, 2007). In investigating the challenges being faced by advocates in performing their roles, the findings from this study show great similarities to the studies conducted by Llewellyn and Northway, (2007), Brolan et al., (2012), as cited by Gilmartin and Slevin, (2009). However, some of the reviewed studies identified communication skills, training and education especially in working with people with intellectual disabilities as some of the challenges for advocacy role. On the other hand, funding, policy and legislation, bureaucracy, conflicts of interest and public perception and behavior are the major challenges found in this study. Surprisingly, only two participants who work for National advocacy Service (NAS) identified workload as part of their challenges. Possibly, this could be understood as they were the only organisations in Ireland that provide 'Free Independent National Advocacy Service' for people with disabilities. Furthermore, this study has found that the NAS are located in five regions of the country with one advocate covering a county in some cases. So no doubt, the NAS is grossly understaffed to cope with the volume of work demand. Perhaps this may be part of the explanation why advocacy service is ineffective as expected.

### **Public Attitudes toward Disabilities**

It is quite disturbing for the advocates to know that the public attitudes and behaviours toward people with disability in Ireland are still short of what it should be. Findings show that advocates do have conflicts of roles with family and carers due to inability to understand and lack of duty of care on the part of some families and carers for this population. For instance, the challenges of bureaucracy or red tape and policy could as well be seen as lack of understanding and respect for people with disabilities. The United Nations Commitment to Advancement of the Status of

Persons with Disabilities (UNCASPD) (2004) support this findings as they argued that disabled persons often suffer from discrimination, because of prejudice or ignorance, and also may lack access to essential services. Access to essential services can be made available via allocation of funds. All the participants did not mince word in saying funding for the service is one of the major challenges they faced in performing their roles. It is quite pertinent to reiterate that all the disability organisations in Ireland are funded by the Irish government through the Health Service Executive (HSE). Even the National Advocacy Service (NAS) is equally funded by same government, but through Department of Social Protection. In view of the aforementioned, one could have thought of the impact of the economic recession on most services. However, it was gathered that the resources for disabilities organisations have not been adequate even before the advent of the economic crisis as National Disability Authority (NDA) (2003) claimed. The NDA (2003) in their study alleged that advocacy organisations in Ireland have emerged with few resources, and as a result they could not perform optimally.

Even recently a statement credited to UK shadow Transport Secretary Mary Creagh equally affirmed the on-going trend of inadequate resources for people with disabilities service, as she said that the Government was failing to make more stations accessible. She said, on buses and railways, the government is cutting costs and failing to act to improve travel for people with disabilities (Independent News Paper, April 13, 2014). Apart from the fact that funding for disability service has never been adequate, it is also noted from this study that people with disabilities under the present provision in Ireland; lack the capacity to manage their own fund. That is the funding from government goes directly to the service or the organisation and not to the service user.

This is a "silent crisis" which affects not only disabled persons themselves and their families, but also the economic and social development of the entire societies, where a significant reservoir of human potential often goes untapped. Considering that disabilities are frequently caused by human activities, or simply by lack of care, assistance from the entire international community is needed to put this "silent emergency" to an end (UNCASPD, 2004). Even recent research by National Disability Authority (NDA) attest to the fact that Public attitudes to people with disabilities can be a key facilitator or a serious barrier to their inclusion and participation in

society (NDA, 2011). The NDA has conducted a series of national surveys of public attitudes to disability since it was established in 1999. However, the findings of their study in 2011 show a hardening of attitudes across all types of impairments, less positive attitudes towards children with disabilities in mainstream education, which challenges the improvements that were achieved between 2001 and 2006 (NDA, 2011). They therefore, concluded that the findings in their 2011 survey indicate the importance of ensuring that Irish society and all its stakeholders recognised the need to address the negative attitudes that exist if they are to achieve real and meaningful inclusion of people with disabilities in Irish society (NDA, 2011).

### **Limitations of This Study**

While it has been acknowledged that all studies have limitations (University of Southern California, 2007), it is the wish of the researcher to identify some of the perceived limitations of this study, with the view to making suggestion(s) or recommendations for further research. Thus the following have been identified as some of the limitations of this study:

#### **Sample**

The small number of participants (n=7) in this study could be a limitation as this size cannot be considered a representative distribution of the population and to be considered representative of groups of people to whom results will be generalised or transferred.

#### **Method of Sampling**

The participants were not randomly selected to give equal chances to all the disabilities organisations in Ireland. This is also seen as a limitation as all the participants were volunteers and selected based on the main categories or types of disabilities.

### **The Spread of the Participants**

The participants were selected across three geographical areas (Dublin, Midland and South Eastern Regions) of the country due to distance and logistics constraints. This could limit the data gathered.

### **The Self-Reported Data:**

In conducting a qualitative research study and gathering the data, self-reported data is limited by the fact that it rarely can be independently verified. In other words, one has to take what people say, whether in interviews, focus groups, or on questionnaires, at face value. However, self-reported data contain several potential sources of bias that should be noted as limitations e.g. (1) selective memory, (2) exaggerations and many more (USC, 2007). Based on the fact that the data was gathered through interviews of the participants could be a limitation as they may have given their subjective views rather than objective.

### **Difficulties in getting participant**

It was quite difficult to get volunteers to participate in the study which left the researcher to use those who showed interest. This could be a limitation as those participants who were not willing to participate may have different views that could influence the results. Also, some participants could not be available to be interviewed; hence answers to the research questions were sent via email to the researcher. This is also a limitation as the researcher had no opportunity to probe further on answer supplied by those participants.

### **The Findings:**

The findings were based on the views of advocates working with people with disabilities. With respect to research question two (RQ2) ‘What are the issues associated with the role of an advocate for people with disabilities in Ireland?’ The aim of this question was to explore the issues or problems facing the people with disabilities from the view point of the advocates. This

could be another limitation as the advocates may not be able to give full details of the problems, as situations are best explained by those in that situation.

**Time and Fund**

This study was conducted by a student within a short time frame. Due to the limited time and lack of fund this could be a limitation to explore more widely to get quality data.

**Fear of losing their job:**

Most of the participants wanted to remain anonymous due to the fear of losing their job. This could be a limitation as the participants may not be 100% comfortable divulging some key information on the questions asked.

## Conclusion

This study has explored the role of advocacy for people with disabilities in Ireland with a view to examine the issues and challenges associated with this role. However, this research, through semi qualitative interviews has found that, due to the vulnerability of people with disabilities, advocacy role is quite important for this population to attain their basic human rights and entitlements in the society. Some of the rights and entitlements issues people with disabilities were experiencing are identified in this study. This study has also established that due to the emancipation of human rights movements and the subsequent emergence of various Acts and Legislations in Ireland, quite a number of disabilities organisations have emerged. In line with this positive trend a variety of advocacy groups and types have equally sprang up speaking and fighting for the attainment of rights and benefits for people with disabilities. Based on this positive development, one would have assumed that these vulnerable individuals would be enjoying the same rights as those non-disabled populations. Nonetheless, evidence revealed that despite the numbers of advocacy groups in Ireland, this cohort are yet to be fully included in the mainstream of activities in the society and they are consistently marginalised. In view of these negative outcomes, the study has found that, in addressing those numerous issues facing people with disabilities, the advocates were confronted with a number of challenges that hinders the effectiveness of their role. These include policy and legislations, funding for service, public attitudes and behaviours toward people with disabilities, among others.

Part of the solutions found however, is the need to pursue development strategies that include social, economic and environmental policies to empower excluded social groups (USICD, 2013). That is measures to foster the participation of persons with disabilities in decent employment, reduce poverty and enhance income security are among the core elements of strategies that should be adopted by countries as they take action to implement their commitments, including the Millennium Development Goals and the Convention on the Rights of Persons with Disabilities. Nonetheless, the Irish society and all its stakeholders ought to recognise the need to address the negative attitudes that exist if they are to achieve real and meaningful inclusion of people with disabilities in Irish society (NDA, 2011). Although, Ireland is yet to ratify the Convention on the Rights of Persons with Disabilities (CRPD), however, the presentation of

Decision Making Capacity Bill in July 2013 has been acknowledged has a positive move towards the actualisation of the convention, which is hoped to usher in an all-inclusive society.

## Recommendations

### **For Further Studies:**

Based on this study, the researcher has made the following recommendations for further studies and for policy makers who truly believe in promoting an all-inclusive Irish society that would be a model for others to emulate.

1. This study has found a number of issues facing people with disabilities from the view point of the advocacy officers working for this group. It is however recommended that a further research involving the people with disabilities should be conducted to explore their real-life situations and experience of this cohort.
2. It is also the wish of the researcher to recommend that further research involving the advocates working with people with disabilities should be conducted, but the participants should be randomly selected across the five regions of the country to see whether there would be difference in the results.
3. Perhaps to know the effect of advocacy role in promoting the rights of people with disabilities it is recommended that a research involving parents or family of person with disabilities be carried out to compare the findings from parent/family view point.
4. Based on the difficulties experienced by this researcher in recruiting the participants, it is however, recommended that more time should be given for future research and perhaps, participants should be incentivised to motivate a good number people.

### **For policy makers and stakeholders:**

1. Based on this study the researcher recommends that policy makers should ensure that policies are followed with genuine actions.
2. From this study, there is a need to address the negative attitudes that exist in the society toward people with disabilities by creating a good awareness and promoting the positive side of this cohort to sensitise the public towards understanding of this group.

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## Appendices

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- 1. Appendix A: Information Sheet**
- 2. Appendix B: Informed Consent Form**
- 3. Appendix C: Email Message to Brit**
- 4. Appendix D: Email Message to Carol**
- 5. Appendix E: Email Message to Klive**
- 6. Appendix F: Email Message to May**
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- 9. Appendix I: Not documented verbal conversation with Nick**
- 10. Appendix J: Topic guide (List of questions used for the interviews)**

**Appendix A:****INFORMATION SHEET**

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***Purpose of the study:*** As part of the requirements for Bachelor Honours degree in Health Promotion at Waterford Institute of Technology, I have to carry out a research study. The study is concerned with the issues and challenges associated with the role of advocacy in Ireland. The purpose of this study is to explore in-depth the issues and challenges that the advocates for people with disability encounter in performing their role.

***What will the study involve?*** The study will involve the use of semi-qualitative interviews of advocates working for people with disability in the South Eastern Region of the country. Questions relating to the research topic will be asked, and the interview is expected to take 25-30 minutes.

***Why have you been asked to take part?*** As an Advocacy Officer/Advocate you have been asked because you are specifically suitable to provide the required data for this study based on your role and experience with people with disability.

***Do you have to take part?*** No! Your participation is voluntary, you are at liberty to or not to participate in this study, and you have the option of withdrawing before the study commences (even if you have agreed to participate) or discontinuing after data collection has started. You can equally withdraw your permission to use the data, in which case the material will be deleted.

***Will your participation in the study be kept confidential?*** Yes! - I will ensure that no clues to your identity appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

***What will happen to the information which you give?*** The data will be kept confidential for the duration of the study. My supervisor and I will have access to the data, and on completion of the thesis, they will be retained for a further six months and will then be destroyed.

***What will happen to the results?*** The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal.

***What are the possible disadvantages of taking part?*** I don't envisage any negative consequences for you in taking part. However, it is possible that talking about your experience in this way may cause some distress.

***What if there is a problem?*** I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, you should contact your GP for help.

***Who has reviewed this study?*** The Department of Health, Sports and Exercise Science Ethics Committee has given approval for this study.

***Any further queries?*** If you need any further information, you can contact me: Nuruddeen Busairi on 0899588850, or email: [naabusairi@gmail.com](mailto:naabusairi@gmail.com)

If you agree to take part in the study, please sign the consent form overleaf.

**Appendix B:****INFORMED CONSENT FORM**

I..... (Print name) agree to participate in Nuruddeen Busairi's research study.

The purpose and nature of the study has been explained to me in writing and I am participating voluntarily.

I give permission for my interview with Nuruddeen Busairi to be tape-recorded: Yes  No

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

Please tick one box:

I agree to quotation/publication of extracts from my interview

I do not agree to quotation/publication of extracts from my interview

Signed.....

Date.....

**Appendix J:****TOPIC GUIDE**

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**Section 1: Introduction Advocate:**

1. Could you please tell me about yourself? (Please include your name and age)
2. Please tell me how you became an advocate for people with disability?
3. Please tell me about your education and training

**Section 2: Organisation:**

4. Please tell me about the organisation you work for
5. When was your organisation established and for what purpose?
6. Please tell me how is your organisation structured?
7. How is your organisation funded?
8. How many advocates are employed by your organisation?
9. Would you say your organisation is achieving its set objective(s)?

**Section 3: Role:**

10. What are your roles/duties and responsibilities as an advocate?
11. Could you please tell me how many clients do you attend to in a day?
12. What does your role as an advocate working for people with disabilities involve?
13. What has helped you as an advocate to perform this role?
14. Has your role been hindered anyway?
15. How would you describe your role with your client's family or carer?

**Section 4: Issues:**

16. What issues have you come across in your role as an advocate for people with disability?
17. Would you say the rights of people with disability have been met in Ireland? Please elaborate further. For example: the Rights to vote, Access to education, Access to

- good housing, Access to public services and transport, Access to health, even Rights to marriage?
18. Have you had or dealt with issues of marginalisation with people with disability?
  19. How would you describe people with disability rights to make informed choice or informed consent in Ireland
  - 20.
  21. Of all the issues you have come across, which ones have been quite challenging for you?
  22. How are those issues solved or dealt with?

**Section 5: Challenges:**

23. What would you describe as your major challenges as an advocate?
24. How have you overcome these challenges?
25. Have you had any challenges around communication with your client?
26. Have you experienced any conflicts of role with client's family or carer?

**Section 6: Others:**

27. Could you please tell me how many advocacy services that works with people with disability?
28. How would you describe people with disability involvement in policy and decision making in Ireland?
29. How would you describe the future of advocacy for people with disability in Ireland?
30. What advice would you give to potential advocates for people with disability?
31. Is there any other thing you would like to say or add?

Thank you very much for your time and assistance. I really appreciate this.

Nuruddeen Busairi

4th Year Health Promotion student, Waterford Institute of Technology

Contact: Phone: 0899588850, Email: naabusairi@gmail.com