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Coláiste na hOllscoile Corcaigh

Striking the balance between parental rights and children's best interests in medical decision making in cases of life-limiting illness: a social work exploration.

Roisin Cantillon

CARL Research Project
In collaboration, with
Mito Families Ireland

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

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Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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Declaration

I confirm that this dissertation submitted for examination is entirely my own work. Where I have used the work of others, it is cited appropriately. The originality report for this dissertation has been reviewed on TurnItIn prior to submission and the final document edited accordingly. This was carried out to convey compliance with UCC Plagiarism Policy and UCC Guide to Examinations for Students and Staff.

Signed:_____ **Date:**_____

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Abstract

The main objective of this study is to analyse and examine the rights of children and their families when a child suffers from a life-limiting illness, such as mitochondrial disease. The research investigates if those rights can be protected and balanced to ensure medical decisions are made in the best interest of the child. The study includes case studies, and also examines and considers relevant legislation, medical and legal decisions, end of life care and the best interests of the child. The study explores how social workers as a part of a palliative care team can support families and their children with life-limiting illness. The research undertaken for this study was secondary research. Thematic analysis was carried out drawing on the principles of constructivism and critical theory. The study found that a formal mediation process that supports parents' rights and balances those rights with the rights of the child would be preferable to changing legislation.

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Chapter 1

Introduction & Methodology

Research Title:

Striking the balance between parental rights and children's best interests in medical decision making in cases of life-limiting illness: a social work exploration.

Introduction:

This research question highlights important and complex issues regarding the rights of children and their families, both here in Ireland, and in the United Kingdom (UK), in the treatment of children with life-limiting illnesses. The research provides an important opportunity to examine, explore and discuss the issues, as well as improve my knowledge and understanding of them. The research title was designed in conjunction with Mito Families Ireland. Mito Families Ireland is a voluntary organisation, whose aim is to raise awareness and provide continued support to families affected by mitochondrial disease. Existing research into mitochondrial disease has mainly been medically focused, while less research existed in relation to the social and personal impacts the disease has on families. This research discusses and highlights the social and personal problems the disease can cause for families in Ireland. It is hoped that this research will give a voice to those affected by mitochondrial disease, while raising awareness regarding the rights of children and their families and ensuring medical decisions are made in the best interest of the child.

Background:

This research question was developed in conjunction with Community Academic Research Links (CARL) an initiative based in University College Cork, which provides "independent research support to Civil Society Organisations in the region undertaken by students in collaboration with community partners across a wide range of disciplines".

This study examines and analysis a child's right to life, compares parental rights and choices with medical decisions made about children with life-limiting illnesses, such as mitochondrial disease. The study includes case studies, and examines and considers relevant legislation, medical and legal decisions, end of life care and the best interests of the child. Irish and international sources were investigated and analysed. The research also considered the responsibilities and duties of social workers in the provision of palliative care support, as part of a multi-disciplinary team. The research examined the Charlie Gard case, as an example of parents who wanted to make decisions about the medical treatment and the right to life of their child. Charlie Gard was a child born in the UK who suffered from mitochondrial DNA depletion syndrome (Lagercrantz, 2018). There is no medical treatment for mitochondrial DNA depletion syndrome and it usually causes death in infancy. The Gard case was newsworthy because the parents and medical team argued about whether treatment in the United States was in Charlie's best interests. Mito Families Ireland suggest that there is a gap in research within this area, and want to learn more about how processes or structures can be implemented to ensure that parents are supported, and their concerns and wishes heard and considered when decisions are made about their child's life-limiting illness.

Location of Research in Current Literature:

Existing research into mitochondrial disease is mainly medically focused, with less research available about the social and personal impact that the disease has on families. The Charlie Gard case has, however, created significant media and public interest. Much of the research on the Gard case focuses on parental rights, the best interests of the child, legal and medical decisions about children with life-limiting illness. Little research exists about whether new legislation is required to provide guidance in cases like the Gard case, and on how to successfully support parental rights and choices when children are suffering from terminal illnesses.

Rationale:

I chose a CARL project, because I was interested in completing a research project that was topical, interesting, helpful and beneficial to others. I was particularly interested in the Mito Families Ireland project because I was aware of the Gard case before I commenced the research project. I was also interested because during my social work placement in early intervention, I met with families whose children had life-limiting illnesses and I noticed that the families were affected by the social and personal impacts that the life-limiting illness had on them. I felt that this research project would assist me as a social worker, and provide me with a good understanding of the issues and complexities regarding end of life care when working with children or adults with life-limiting illnesses.

The purpose of the research project was to:

- Explore and highlight issues experienced by families affected by life-limiting illnesses, informed by the Gard case.
- Review the legislation and medical decisions made that challenged or disagreed with the parental rights or wishes when it came to the best interests of the child.
- Establish if those rights should be recognised when medical decisions were made about the child's end of life care.

While this research primarily focused on the life-limiting illness mitochondrial disease, the research also considered other cases where parental rights conflicted with medical decisions when it came to the best interest of the child.

I completed this research project on behalf of Mito Families Ireland in conjunction with their liaison person, whom I met and consulted with regularly. This research will help Mito Families Ireland, social workers and other health care professionals understand the complications and issues that exist regarding legislation and medical decisions made in the best interest of the

child versus parental rights in cases of children with life-limiting illnesses. This research will be of particular interest to social workers who work in palliative care, or in disability social work settings where children have life-limiting illnesses. According to Gwyther et al (2008, p.88), "All social workers, regardless of practice setting, will inevitably work with clients facing acute and/or long-term situations involving loss, life-limiting illness, death and grief". The research also considered how social workers could support families, like the Gard family, to ensure parents' voices were heard and considered. The research will help social workers to understand and manage cases where a conflict of opinion exists about a child's best interests, and assist them in supporting families who have to make very stressful decisions about their children with life-limiting illnesses.

"The Community Academic Research Links (CARL) initiative promotes community based research, which allows for the voice of civil society not only to be heard but to inform policy in a productive way" (Meehan, 2017, p.5). The CARL initiative, together with the community organisation Mito Families Ireland, have allowed me to promote community based research by carrying out this research project on their behalf.

Aim:

This research aims to analyse and examine the rights of children and their families when a child suffers from a life-limiting illness, such as mitochondrial disease. The research will investigate if those rights can be protected and balanced to ensure medical decisions are made in the best interest of the child. The study will include an analysis of the Charlie Gard case and will also review and consider relevant legislation, medical and legal decisions, end of life care and the best interests of the child.

Objectives:

- Conduct secondary research by reviewing existing literature, legislation, policies, and media articles, on the rights of children and their families when a child has a life-limiting illness, with an emphasis on mitochondrial disease.
- Investigate if those rights can be reasonably balanced to ensure that medical decisions are made in the best interest of the child.
- Analyse other research cases of children with life-limiting illness, and compare the decisions made in those cases with the decisions made in the Gard case.
- Examine the role of the social worker from a palliative care perspective, and recommend how social workers can better support families.
- Identify, highlight and advise on any gaps or conflicts in legislation regarding a child's right to life and parental rights or choices.

Research Questions:

1. What rights do parents have in making decisions about their child's right to life when their child is suffering from a life-limiting illness?
2. Does legalisation protect a child's best interests when it comes to making decisions about children with life-limiting illnesses?
3. How can social workers best support families who have to make important decisions when their children are terminally ill?
4. Should legislative changes support parental rights?

Methodology:

Methodology is a "framework in which to organise a project, a recipe of methods and a strategy, as well as a theoretical and philosophical structure around which to support a dissertation" (Carey, 2013, p.109). The methodology section of research brings together all

aspects of the research project. For this dissertation, I used secondary research, as outlined in the CARL agreement. I identified and collected existing literature on the research topic. I then read, studied and analysed the material, carefully considering the value, significance and importance of the information for my study.

Epistemology:

"Epistemology is the theory of knowledge it relates to different forms and types of knowledge about the social world" (Carey, 2013, p.58). It focuses on how we understand reality and what shapes the source of what we know (Ritchie et al, 2014). Epistemology is a fundamental aspect of social work research (Corby, 2006). The epistemological focus of this study draws on the principles of constructivism and critical theory. "Constructivism is the view point that all knowledge and therefore all meaningful reality as such is contingent upon human practice" (Crotty, 1998, p.3), whereas "critical theory is concerned with empowering people to overcome circumstances that constrain them, it tends to be used as an umbrella term covering various research movements" (Ritchie et al, 2014, p.16). This study sought to empower parents and give them a voice to overcome issues that restricted them concerning their children with a life-limiting illness by:

- Identifying inequalities in the current legal practices
- Highlighting ways where parents' voices can be heard
- Recommending better supports and improved rights for parents
- Highlighting the experiences of families who have a child with life-limiting illness

Theoretical Perspective:

A theoretical perspective is defined as "the philosophical stance informing the methodology and hence providing a context for the process and grounding its logic and criteria" (Crotty, 1998, p.3). This research study consisted of a combinational approach, combining principles

from both critical and interpretivist approaches. A combination of theoretical viewpoints are necessary in cases such as this, "where there are questions regarding policy and practice that, require measurement of some kind but also greater understandings of the origins of the issue" (Ritchie & Lewis, 2003, p.38). The theoretical positions in this research provided a context as to how the investigation was carried out. The interpretivist approach was adopted for this study, the literature was examined to understand the experiences of the parents regarding their rights and supports when decisions were made about their children with life-limiting illnesses (Carey, 2013). A critical inquiry is a process of gathering and evaluating information, ideas and assumptions from many different contexts (Crotty, 1998). This links to the research study because the study critically evaluated the literature to understand how parents could be better supported and empowered to make decisions about their children with a life-limiting illness. It is important to mention that mitochondrial disease affects children differently, and that the actual experiences of the participants in the studies may be different, or have a different meaning. "The interpretive approach attempts to uncover the meaning and reality of people's experiences" (Carey, 2013, p.61) within the social world.

There are many social work theories relevant to the practice and framework used for this research. The *ecological systems* theory was relevant, as the research focused on the connections between people and their networks both wide and close, such as individuals, families, friends, work colleagues and communities (Teater, 2010). The *systems* theory also applied, as the research examined the role of the social worker working within a system supporting families as part of a multi-disciplinary or palliative care team. The *grief and loss* theory was also used as part of the study. According to Goldwirthy (2005, p.176) "working and recognising grief and loss in families and individuals has been long identified as one of the core skills in social work". Parenting children with disabilities, such as mitochondrial disease, means that parents need to come to terms with feelings such as loss and grief, and balance these

feelings with hope and resilience (Costantino, 2010). Costantino (2010) describes learning about the diagnosis as a storm, an unforeseen event that erupts in an instant and changes one's life course. I think this theoretical perspective assists the research in making sense of the experience of parents who care for children with mitochondrial disease.

Research Methods:

A qualitative research method was used for this dissertation. Qualitative research "within a social work dissertation seeks to analyse in detail the behaviours and experiences of social groups and individuals" (Carey, 2013, p.43). Qualitative research seeks to find meaning and add to theory and development. The research examined existing literature, legislation, medical and legal decisions on parental and children's rights, best interest principle, end of life care, life-limiting illnesses, mitochondrial disease and the Gard case. Ritchie & Lewis (2003, p.76) suggested that secondary analysis is "returning to a data set which was collected for one set of purposes, to re-examine it with a slightly different set of objectives". According to Carey (2013), there are several advantages to carrying out secondary research: secondary research saves and is cost effective, information is available and easy to assess, and research can be conducted in a timely manner. As the research literature for mitochondrial disease is limited, I also examined other cases of children with life-limiting illnesses. This dissertation also used the secondary research approach to carry out a comprehensive literature review. According to Onuwuegbuzie & Freis (2016), a comprehensive literature review is the methodological approach used to document the current state of the knowledge about the topic.

Search Strategy:

The search methods used to gather information for this research were as follows:

- UCC library books

- UCC online database to source journal articles such as JSTOR, SAGE, ProQuest, SocINDEX
- Google scholar and Google search engines
- Newspaper and media articles
- Previous Mito Families Ireland research projects

Search terms included: ethical decisions, end of life care, life-limiting illnesses, mitochondrial disease, parental rights, best interests of the child, legislation, the role of the social worker, palliative care social work, Charlie Gard, medical law, grief and loss.

Ethical Considerations:

As I completed a CARL project, the guidelines limited my research to secondary research. As the study was secondary research, the main areas for ethical consideration were plagiarism and any bias that I held on the topic. It was also very important that the work of others was not changed or misinterpreted by me, the researcher (Onwuegbuzie & Frels 2016). As a researcher, I ensured that all of the research I carried out, and all the material that I presented and published from my research, was accurate. I made sure that my research was competent, accurate, balanced and within my knowledge and skill set. Because my research was written about a very sensitive topic, I was mindful, respectful, careful and factually correct when carrying out my research and when presenting my findings. I was very conscious about how I communicated my findings and always considered the feelings of families with children who suffered from life-limiting illnesses. I had to minimise potential risks and maximise the benefit of my research for Mito Families Ireland, following advice and guidance of my supervisor. I acknowledged and referenced all material used for my research project. When the research project is completed, I will present a copy of my project to Mito Families Ireland and, subject to the approval of my supervisor, will allow the project to be published on the CARL website.

Overview of Chapters:

Chapter Two

This chapter considers relevant legislation protecting the rights of children and parents, as well as providing a brief background to the Charlie Gard case and considers comparative case outcomes.

Chapter Three

This chapter analyses key terms, it focuses on the impact life-limiting illness has on families. It considers the decision-making rights and responsibilities of parents and examines the best interest of the child.

Chapter Four

This chapter examines the role of social workers from a palliative care perspective as part of a multi-disciplinary team and also considers proposed changes to legislation following the Gard case.

Chapter Five

This chapter summarises the key findings from the research study, makes recommendations and examines the experiences of the research process through a personal reflection.

Conclusion:

The chapter introduced the reader to the study. It outlined the aims, objectives and research questions that will be examined throughout the study. The study design and theoretical methods were also discussed. The chapter concluded by providing the reader with a brief outline of what's included in each chapter throughout the research study.

Chapter 2

Background Literature Review

Introduction:

This chapter considers relevant Irish, British and international legislation protecting the rights of children and parents. It is important to consider this, because the Gard case was a UK legal case, whereas Mito Families Ireland is an Irish based organisation. Following this, medical case law is analysed to establish just how cases like the Gard case might be treated in Ireland. The next section discusses Charlie Gard and the Gard legal case. The final section examines cases like the Gard case, and compares the decisions made in those cases with the Gard case.

European Convention on Human Rights:

It is important to discuss The European Convention on Human Rights (ECHR) because Charlie Gard's parents and legal team persistently referred to it when they appealed court decisions in the Gard case. ECHR is an international treaty that protects human rights and the fundamental freedoms of people in countries that belong to the Council of Europe (European Convention on Human Rights~~)~~

Charlie's parents initially argued that Great Ormond Street Hospital had deprived Charlie of "his liberty in contravention of Articles 2 and 5 of the European Convention on Human Rights" by not allowing him access to life-sustaining treatment (Hammond-Browning, 2017, p.464). Article 2 of the ECHR states that "everyone's right to life shall be protected by law. No one shall be deprived of life intentionally". Article 5 states that "everyone has the right to liberty and security. No one shall be deprived of their liberty". Charlie's parents, in the court of appeal, relied on Article 8 of the ECHR to assert that the best interest test was wrongly applied (Cave et al, 2017). Charlie's parents claimed under Article 8 that they "suffered disproportionate interference in their parental rights". As the High Court's decision was

based on the best interests of the child, the court failed to consider whether there was a likelihood that the child "is suffering, or likely to suffer, significant harm" (Hammond-Browning, 2017, p.464). Article 8.1 states that "everyone has the right to respect for his private and family life, and there shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law" and for what is necessary in the protection of health, or the rights and freedoms of others. Cave et al (2017, p.504) maintain that:

> "Disputes between parents and doctors that cannot be resolved through mediation must be determined by the court with respect to the welfare principal while the parental view is important and relevant the court is not obliged to act in accordance with the wishes of the parent".

United Kingdom Legislation Concerning Children's Rights:

The primary legalisation that protects children in the UK is the Children Act 1989. It is important to consider the UK legalisation because Charlie Gard was a citizen of the UK, therefore the Gard case was a UK based legal case.

The Children Act 1989 "introduced legislative provisions for children in the UK who were involved in private law disputes and public law provisions for children experiencing difficulties in their own families and provisions to protect children from maltreatment and other forms of developmental impairment" (Timms et al, 2006, p.154). Section 1 of the Children Act 1989 "ensures the child's welfare shall be the court's paramount consideration". Section 1 of the Act was referred to in the court throughout the Gard case. In the UK, the Children Act 1989 gives parents the primary responsibility for their child:

“Parental responsibility means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and the child's property” Children Act, (1989, s.3).

Therefore, under UK legislation, the legal relationship between parents and children is defined by responsibility, not rights, while parents require rights to undertake their responsibilities if the welfare of the child is at risk, and if parents do not protect their children's best interests. Only then can the court act on the child’s behalf. This rule was considered throughout the Charlie Gard case, as the medical professionals believed lifesaving treatment could cause significant harm to Charlie.

Irish Legislation Concerning Children’s Rights:

The primary legislation relating to childcare policy in Ireland is the Child Care Act 1991. This act is a wide-ranging piece of legislation which sets out to promote the welfare and protection of children. Section 24 of the Child Care Act 1991 “considers the child’s welfare as the first and paramount consideration having regard for the child’s age, understanding and wishes”. It is important to note that this is similar to the UK legislation, as outlined above. In Ireland, parental responsibly is referred to as guardianship. Guardianship refers to the rights and duties a parent has while rearing a child (Courts Service Ireland, 2017). A guardian has the rights and responsibilities to make decisions and choices that affect a child, e.g. choice of medical treatment, religion, education and health requirements.

United Nations Convention on the Rights of the Child:

Both the UK and Ireland are signatories to the United Nations Convention on the Rights of the Child (UNCRC). Four of the general principals of the UNCRC are as follows:

- That all the rights as outlined by the Convention must be available to all children without discrimination of any kind (Article 2);
- That the best interests of the child must be a primary consideration in all actions concerning children (Article 3);
- That each child is entitled to life, survival and development. (Article 6);
- That the child's views must be recognised and considered in all matters that affect them (Article 12).

(Children's Rights Alliance, 2010)

According to the UNCRC, a child is defined as a person under the age of eighteen. The UNRC recognises the primary role of parents and their families in caring for and protecting children as well as the state's obligation to assist parents to carry out these duties. The UNCRC was referred to throughout the Gard case. Article 3(1) states that "in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration" (Children's Rights Alliance, 2010, p.10).

Medical Law in Ireland:

It is important to consider medical law decisions when determining how a case like the Gard case would be treated in an Irish context. Disagreements about the rights and best interests of children versus parent's rights concerning medical decisions made, create complex legal questions for the courts to deliberate on. This is because healthcare decisions made on behalf of children can have significant impact on a child's wellbeing, future health or in some instances a child's life (Madden, 2009). The UK courts have in recent years been involved in making several important decisions about medical interventions for children. These decisions concerned child welfare, respect for parental authority and child autonomy.

In contrast, similar cases in Ireland are rare. However, Madden (2009), suggests it is important to consider how the Irish courts would reconcile the rights of those involved, because medical decisions, as we saw in the Gard case, can often be quite difficult, emotional and complicated. Madden (2009, p.458) suggests that "decisions made by courts, therefore, involve balancing of risks and possible benefits and weighing up potential quality of life with dignity and pain free existence". It is however notable that Madden (2009) emphasises that Irish legal cases, dealing with parental authority in the treatment of children are scarce, consequently case law in other jurisdictions is relied on if similar cases arise in Ireland. Madden (2009) also emphasises that in Ireland, medical teams and parents need to act in collaboration in the best interests of the child when treating children who have substantial disabilities. However, disagreements arise concerning what parents consider are the best interests of the child, compared to what medical teams decide, as what happened in the Gard case.

The principal duty of paediatricians, like all medics, is to maintain life, however this may not always be the case as they sometimes find themselves involved in exceptional cases, where further treatment of a child would be ineffective or even harmful. In cases where uncertainty arises, the law is asked to intervene. Quite often, when parents are required to make decisions about their child. They are usually in shock, vulnerable and inexperienced in medical language and in decision-making (Hammond- Browning, 2017). Therefore, in most cases parents tend to agree with medical professionals, however Charlie Gard's parents disagreed, so Great Ormond Street Hospital applied to the court to ensure Charlie didn't receive medical treatment that they believed would not be in his best interests and potentially harmful to him (Hammond- Browning, 2017). The medical team believed that further treatment was pointless, and palliative care was recommended. The parents wanted Charlie to receive nucleoside therapy in the United States, a therapy that had not yet been properly tested.

Usually in cases where children lack capacity to give consent parents make decisions on their behalf but in cases where conflicts exist, decisions are referred to the court (Hammond-Browning, 2017). This is what happened in the Gard case as the medical team believed that treatment was not in Charlie's best interests, and sought court intervention when Charlie's parents disagreed.

Who is Charlie Gard?:

"Charlie Gard was born in England in August 2016, with mitochondrial DNA depletion syndrome" (Lagercrantz, 2018, p.409). The type of mitochondrial disease Charlie had caused muscle weakness and brain damage and is typically fatal in infancy or early childhood. He was at the centre of a high profile legal case in the UK that gained worldwide attention in the summer of 2017. Charlie's parents wanted him to receive nucleoside therapy in the United States, however, the doctors taking care of Charlie at the Great Ormond Street Hospital felt that the new therapy was not suitable for Charlie (Lagercrantz, 2018). The case was heard in "The High Courts of Justice, in both England and Wales, and the European Court of Human Rights" (Lagercrantz, 2018, p.409). All courts agreed with Great Ormond Street Hospital and ruled that the proposed treatment in the United States was not in Charlie's best interests. Charlie died a short time later.

Other Child Medical Cases:

In this section, I will compare and contrast other medical legal cases, similar to the Gard case, to illustrate how the court decisions in these cases were inconsistent.

Alfie Evans was a 23-month-old English child, who suffered from a medical illness known as severe neurodegenerative disorder, meaning Alfie was kept alive in hospital using a medical ventilator. Alfie's parents wanted the life support machine to continue but Alfie's doctors felt this was futile for him (Wilkinson et al, 2018). The hospital believed that continued ventilator

support was "unkind and inhumane", and not in Alfie's best interests, so they applied to the court to have the ventilator turned off. Alfie's parents contested the application (Wilkinson et al, 2018). Following a series of unsuccessful appeals by Alfie's parents, the ventilator support was removed in April 2018 and Alfie died five days later. The Court ruling in the Evans case was similar to the Gard case, with the courts again ruling in this case that the best interests of the child outweighed the rights and wishes of the parents.

The Ashya King case was also UK based. This case concerned the treatment options that were best for a 5-year-old boy. Ashya suffered from medulloblastoma, a form of brain tumour which was successfully removed by surgery. However, Ashya's parents wanted their son to be treated with proton therapy following the removal of the medulloblastoma, as they felt this therapy was less harmful than conventional radiotherapy (O' Brien et al, 2014). The issues regarding his treatment were referred to the High Court for resolution. The court ruled that Ashya could receive the proton therapy. When Judge Baker gave, Ashya's parents the permission to go to Prague for the proton therapy, he put considerable emphasis on the parental viewpoint (Cave et al, 2017). In his ruling, he stated that "it is a fundamental principle of family law in the UK that responsibility for making decisions about a child rest with the parents" (Cave et al, 2017, p.5).

According to Cave et al (2017, p.504), in most cases "the parents are the best people to make decisions about a child and the State whether it be the court, or any public authority has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm". When you compare the King case with the Gard and Evans cases, the decisions arrived at were not equal, as the parents' rights and wishes were not considered in those cases. It is important to have considered these cases because it shows

how court decisions concerning children with life-limiting illnesses are not consistent, and each case needs to be viewed in isolation.

Conclusion:

It is evident from the legislation outlined in my research, and from the review of the Gard, Evans and King cases, that current legislation fails to adequately support parental rights and wishes concerning the medical care of children with life-limiting illnesses. This is because each medical case presents with an entirely different set of medical circumstances, making this a difficult area to regulate using legislation alone. Nevertheless, the examination of the legislation has identified deficits and conflicts in the law concerning medical decisions regarding the best interests of the child, versus the rights and wishes of the parents about their treatment. The research also identified a lack of support for parents in terms of their rights, with help in making decisions, and consideration of their rights and wishes when decisions are being made concerning their child's life-limiting illness. It was important to have discussed the legislation, the Gard and the other medical legal cases, here, before exploring the topic further.

Chapter 3

Rights and Best Interests

Introduction:

This chapter examines the terms "life-limiting illness" and "mitochondrial disease", as well as the effect that such illnesses can have on families in order to gain a greater understanding of the topic. Following this, the rights and responsibilities of parents with children who have life-limiting illness, as well as the decisions made in the Gard case, are analysed. Finally, the 'best interest' principle and the relevant arguments used in the Gard case are discussed and compared with a 'best interest' case of an older child in order to understand the nuances of the Gard case.

Life-limiting Illness:

The Irish Hospice Foundation (2005, p.18) defines a life-limiting condition in children as "a condition in a child where there is no reasonable hope of cure and from which the child will die". Popejoy et al (2017, p.628) offer a similar definition, describing life-limiting conditions as those "for which there is no reasonable hope of cure and from which ultimately the child will die". The symptoms experienced by children with mitochondrial disease can indeed be life-limiting. These can include seizures, cardiac defects and respiratory complications. All of which can come with social prejudices and physical implications, with which both the child and families have to cope with. The Laura Lynn Foundation estimated that in 2018, approximately 4,000 children in Ireland were living with life-limiting conditions. Some children are born with life-limiting conditions, while others acquire them through brain injury or other illnesses. In most cases, their illness is incurable, and they require on-going specialist medical and palliative care.

Mitochondrial Disease:

The United Mitochondrial Disease Foundation (2016) describes mitochondrial disease as an illness that "results from failures of the mitochondria, which are specialised compartments present in every cell of the body except the red blood cells". Mitochondria are responsible for creating the energy needed to support organ function and sustain life. When the mitochondria fail, less energy is produced in cells, which results in cell injury or cell death. When this process is repeated all over the body, the bodily organs fail, resulting in organ failure. Mitochondria is classified as a rare disease, which the National Rare Disease Action Plan for Ireland defines as a disorder affecting fewer than 5 in every 10,000 of the European population (Minister for Health, 2014). Mitochondrial disease is a progressive disease that mainly affects children. Charlie Gard was born with infantile-onset mitochondrial DNA depletion syndrome, a genetic disease "where abnormal mitochondrial DNA causes cells to malfunction" (Birchley, 2018, p.448). This meant Charlie's cells were unable to transfer energy to his brain, kidneys or even his muscles including cardiac and other life supporting muscles.

Parental Rights/ Responsibilities:

This section considers the decision-making rights and responsibilities of parents, concerning children with life-limiting illness, and explains why these rights and responsibilities were not applied in the Gard case.

In Chapter 2, we discussed the 1989 UK Children Act, and the fact that section 3 of the Act gave parents the parental responsibility and authority for their child, i.e. parents by law are responsible for making all decisions regarding their child's health care and upbringing. Their position as primary caregivers are therefore enshrined in law internationally.

As Charlie Gard was an infant who lacked the capacity to make decisions about his own medical treatment, his parents made such decisions for him, including the decision that Charlie should receive experimental medical treatment that may prolong his life. However, Bridgeman (2012) felt that while parents rightly make decisions about their child's health care, in situations where children are too young or unable to express their views, the inherent needs of the child must also be considered by the parents. Due to Charlie's age and condition, he clearly lacked the ability to consent to medical treatment, and therefore his parents were his decision makers. Nevertheless, in Charlie's case, Great Ormond Street Hospital refused to allow him to travel to the United States to receive the experimental treatment his parents wanted for him, because they felt it was not in Charlie's best interests. Charlie's parents appealed the decision to the courts and asked that their wishes be upheld, so Charlie could receive the treatment. Normally in these circumstances, the parents have the power to make medical decisions, but Great Ormond Street Hospital believed that the treatment was not in Charlie's best interests (Hammond Browning, 2017). Because of the hospital's intervention in Charlie's case, the question as to whether parental authority was absolute and unlimited requires further exploration (Caplan et al, 2017). Most of the media attention in the Gard case concentrated on the decision-making rights of parents on behalf of their children, and queried if the court intervention in the Gard case meant that medical decisions generally overruled parental rights (Wilkinson et al, 2017). Furthermore, Wilkinson et al (2017, p.438) felt that "if Charlie had been a young adult who had made clear his wishes to be kept alive on a ventilator, and to receive experimental treatment even if there was a low chance of it benefiting him, then it should certainly have been provided". This finding it based on precedence being set by other cases such as the Hannah Jones case.

It is interesting to compare the Gard case with a similar case that occurred in Florida. The case involved a 2-year-old boy who suffered from irreversible brain damage. His father

wanted his son to receive an experimental therapy known as *hyperbaric oxygen therapy* (Paris et al, 2017). The medical professionals treating the boy declined to provide the experimental therapy because they believed the therapy could have a negative impact on the child's brain. So, the boy's father highlighted the case in the media and brought the case to court (Paris et al, 2017). As Paris et al (2017, p.1269) outlines: "The circuit judge in the case issued an order directing the hospital to install a hyperbaric oxygen chamber within its facility", provided the parents were willing to pay for the treatment and waive any liability. It appears from this judgement that if the Gard case had occurred in the United States, the wishes of the parents would have been considered to a greater extent.

On the other hand, Gillion (2018), in the paper "Why Charlie Gard's parents should have been the decision makers about their son's best interest", argued that the ethically preferable judgement in the case would have been not only to rule as the courts did, that Great Ormond Street doctors were not legally obliged to provide treatment they believed was against the child's best interest. Gillion (2018) stated that they also should have ruled that other doctors, who supported the parents' wishes for experimental treatment, were not legally prohibited from providing the treatment that his parents thought was in his best interests. This would have removed the restrictions surrounding Charlie's treatment, meaning the parents could seek this treatment elsewhere. The judgement restricted their choices.

Parental rights are mainly concerned with promoting the welfare and wellbeing of the child. Even though the 1989 UK Children Act gives parents responsibilities and rights in terms of their children, it seems those rights are limited for parents when making decisions about their children with life-limiting illness, especially if those decisions disagree with medical opinions regarding the best interests of the child. There is an obvious conflict here, between specialists and parents.

Living with Mitochondrial Disease:

According to the United Mitochondrial Disease Foundation (2016), the quality of life of a child with mitochondrial disease is restricted based upon the degree of mitochondrial malfunction that they suffer from, and some children can function better than others. There is currently no cure for mitochondrial disease and very few medical professionals specialise in mitochondrial disease research worldwide. "A multidisciplinary approach by health professionals is needed to address the complex care required to manage children with mitochondrial illness" (Senger, et al 2016, p.34).

The unpredictability of the disease can create many difficult challenges for parents affected. Parents are continually responsible for managing their child's care, while often being fearful about their health (Senger, et al 2016). As the majority of caregivers are not trained medical professionals, they may often feel uncertain regarding the management and care of their child at home (Hionjosa, et al 2012). Parents need healthcare professionals to help and support them in managing the daily demands of caring for a child with a rare disease. According to Senger et al (2016, p.34) "parents require specialised knowledge, skills, and organisation to raise a child with mitochondrial disease". This need for external help can lead to feelings of loss or self-doubt.

In a study that explored the parental experiences of caring for a child with mitochondrial disease, conducted by Senger et al (2016, p.32), parents "experienced a burden of responsibility that exceeded the typical caregiver role". Parents consider their child to be fragile, and naturally worry about the future for their child. Recognising and identifying these parental concerns can assist professionals, such as social workers, to better support parents and families. Structures such as support groups can be put in place by social workers, to allow parents to come together and share experiences, so they can learn how to support each

other. Social workers can assist families by listening to parents, and helping them access services to better support their needs as caregivers. Similarly, Collins et al (2016) conducted a study to explore the lived experience of parents providing care to children with a life-limiting illness. The results showed that these parents experienced physical and social isolation, as well as diminished supports from professionals, at a time when the support provided should be increasing. The results highlight a demand for more physical and emotional support, greater than the support currently offered by professionals. The research makes clear that parents play a central role in caring for their child with a life-limiting illness, and because of this care burden, they need to be supported both emotionally and physically, by the multidisciplinary team involved in their child's care.

What is 'Best Interests'?:

Mc Partland (2010, p.10) argues that the "best interest of the child is widely used and is a fundamental concept in the treatment of children within the Irish legal system and under the UNCRC, to have true effect, must be given meaning in practise". The child must be at the centre of decisions made about his/her best interests, in order to ensure that the best possible outcome for the child is achieved. The "best interests of the child" principle is defined in The UNCRC, as described earlier, in Chapter 2. In the Gard case, the best interests of the child principle was regularly used throughout the case. Shah et al (2017, p.937) felt that in the Gard case, "medical professionals and courts relied on a form of the best interest standard in overriding the parents' decision to seek experimental nucleoside treatment". Shah et al (2017) also state that the best interest's standard has been used internationally, in cases involving medical decisions in the best interests of children, for over 200 years. At times, it is difficult to decide what constitutes the best interests of a child many factors need to be weighed up. While Charlie's parents wanted him to receive nucleoside treatment to help prolong his life,

the medical professionals argued that the treatment was not suitable for Charlie and they were also concerned about the trauma the continuing life support was causing to Charlie.

Shah et al (2017) believed that despite its faults as a basis for state intervention, some value has been found in the best interest's standard, and that medical teams should use it when deciding which treatment option best supports the medical needs of a child. This is despite the fact that parents may disagree with the options using in the best interest standard, as this restricts their choices and it's often the only system or fall back there is for solving such conflicts between parents and medical professionals.

It is worth considering if an alternative standard, such as the harm standard, was used in the Gard case, would the outcome have been different. The harm standard is used to identify "the threshold for state action in cases where a parent refuses medical intervention on behalf of a child" (Shah et al, 2017, p.937). In comparison to the best interest's standard, the harm standard allows parental opinions to be considered, because it is the parents who are most affected by the verdict.

Best Interest Arguments in the Gard Case:

Cave et al (2017, p.500) carried out a study offering "a critical analysis of the legal principles surrounding unproven treatment and application of the best interests test" in the different contexts of hospital and court, and in the Gard case, found that the court's decisions were in Charlie's best interests. Cave et al (2017, p.510) recommended that "in decisions about life-sustaining treatment of a young child, best interests are determined neither by parents nor clinicians, but either through a hospital-based process of compromise and mediation, or a court-based judicial decision". Cave et al (2017) also proposed that clinicians must be convinced that any harm associated with contravening the wishes of the parents is less impactful than the harm associated with accommodating the parents' view point.

Close et al (2018, p.479) in their paper "Charlie Gard in defence of the law" argue that "the law on withholding and withdrawing life sustaining treatment from children like Charlie Gard is sound". They contend that the best interests test is an appropriate test despite the need for more clarity on its application, and an equal need for an independent judicial or quasi-judicial process to resolve intractable disputes, given the gravity of the issues involved. However, Close et al (2018, p.479) also claim that "although the current legal approach is adequate it could be improved by removing doctors' present ability to unilaterally withhold or withdraw treatment that they regard is futile".

Best Interests of Older Children:

This section considers the best interest test, whereby older children have the right to make decisions about their own medical treatment. Article 12 of The UNCRC states that "the child who is capable of forming his/ her views should be accorded the right to express those views freely in all matters affecting them given due weight to their age and level of maturity" (Children's Rights Alliance, 2010, p.15). According to Madden (2009), arguments exist concerning children taking part in decisions about their own health treatment, because of their immaturity and the increased risk of conflict. However, there are opposing arguments which advocate that children should be treated with dignity and have their own personal decisions respected. It is also worth mentioning that in Ireland, the Non-Fatal Offences Act, states that "children over sixteen do not have to seek parental consent for surgical, medical and dental treatment" (Non-Fatal Offences Act, 1997, s.23). In the UK, a child who is under 16 can be given permission to be involved in the decision-making process in relation to their medical needs and treatment if deemed adequately mature by an assessment conducted by the medical team.

As there are no known Irish cases where older children made decisions about their health treatment, I chose an example from the UK. Hannah Jones was a 13-year-old girl who decided she did not want a heart transplant, and her parents agreed with her wishes. Despite this family agreement, the child protection team within the hospital were concerned about the decision and initially considered making an application to the courts to reverse it (Cornock, 2010). However, when they heard Hannah's reasons for not wanting to have the transplant, they decided to withdraw the application. In this instance, Hannah's wishes were considered and taken into account. The following year Hannah changed her mind and decided to have the transplant and again Hannah's wishes were taken into account. According to Cornock (2010), in order for legal consent of a minor to be valid, three principles should be considered. These include the competence of the child, the voluntary nature of the decision and the information on which the decision is based.

It was important to have considered how the legislation protects older children's decisions regarding their medical treatment, for, if Charlie Gard had been older, and had the capacity to make decisions for himself, the best interest principle may not have applied. Therefore, doubts exist about the reliability of using the best interest principle when making important decisions about children and their welfare.

Conclusion:

Throughout this chapter, I focused on parental rights and responsibilities, concluding that parental rights are limited, by external forces especially if parents do not agree with the medical team on the best course of treatment for their child. I also examined the best interest principal, and concluded that uncertainties still exist regarding its reliability, as it is difficult at times to determine what decisions are in the best interests of the child. In order to correctly balance these difficulties, parental opinions should also be considered. A fine balance must

be maintained so that all parties in the decision-making process feel empowered, listened to and respected, at such a sensitive time.

Chapter 4

Social Work & Recommended Legislative Changes

Introduction:

Throughout this chapter, I will examine the role of social work and social workers from a palliative care perspective, as part of a multi-disciplinary team. I will investigate studies undertaken on the implementation of palliative care, and consider parents' opinions on how palliative care can be improved to better support them while ensuring their voices are heard when making decisions in relation to their child's life-limiting illnesses. I will then discuss the findings of previous research into legislative change, and recommendations have been proffered to support parental rights when difficult decisions need to be made. Finally, I will consider proposed changes to legislation in the UK, following the Charlie Gard case, and conclude by offering my own opinion on how I feel parental rights can be supported in these difficult contexts.

Palliative Care and Social Work:

Payne (2009, p.514) recognises palliative care as 'a multi professional practice'. Social workers in palliative care settings have an important role as part of a multi-disciplinary team providing advice, support and a link between parents and other medical professionals. Existing research does not mention if social workers were involved in the care of Charlie Gard or Alfie Evans. However, I feel social workers should always be involved, as they can assist the medical professionals as part of a multi-disciplinary team, while supporting the families as they make very important decisions about their child's life-limiting illness. According to Bosma et al (2009, p.79) social work practitioners will encounter "adults, children, and families who are facing progressive life-limiting illness, dying, death, or bereavement" within their social work careers. Social workers working within palliative care settings are specifically trained to work with people experiencing bereavement. The World

Health Organisation (WHO) in the *Palliative Care for Children with Life-limiting Illness National Policy Document* defines palliative care for children as "a total care of the child's body, mind and spirit that also includes supporting the child's family" (Department of Health and Children, 2009, p.2). Palliative care commences when a child is first diagnosed with a life-limiting condition and continues regardless of whether the child receives treatment or not. Palliative care sets out to maintain a quality of life for the child suffering from a life-limiting illness. A large multi-disciplinary team approach is required to carry out palliative care effectively. Both palliative care and social work show caring values that distinguish individuals in all aspects of their lives. Small (2001) claims that social workers make three important additions to palliative care:

- Social workers in all fields of work are tasked with responding to loss.
- Social workers view the child and the family as systems, putting individual experience into a wider context.
- Social workers are concerned with helping and supporting families.

"Social work draws on an ecological approach to problem-solving that considers the multidimensional impact of individual, family, and sociocultural influences" (Bosma et al, 2009, p.79). This natural, holistic approach works well for palliative care, by helping to reduce suffering and improve the quality of life for the living and dying by focusing on "physical, psychological, social, spiritual, and practical concerns of the individual and their families" (Bosma et al 2009, p.79). Social workers in paediatric palliative care settings work as part of a multi-disciplinary team. They work to reduce many of the difficulties and complexities that children with life-limiting illnesses and their families are confronted with, by listening to their needs and linking them with support services. Social work interventions can prove effective for families in the home, hospital or community setting. By working directly with the patients, their families and communities, and with other members of the

multi-disciplinary team, social workers can help children with a life-limiting illness while providing advice to the families as they navigate their way through the many challenges they encounter. Social work, as part of a multi-disciplinary team palliative care service, can be very effective, however in Ireland this does not seem to be standard procedure or policy. There is scant research available regarding Irish social worker involvement with children suffering from life-limiting conditions. One research study, which examined the issues parents experienced when their child suffered from mitochondrial disease, found that social workers appeared almost non-existent in the paediatric health system in Ireland. Each of the participants in the study stated that they "never had social worker involvement, and if they did, it appeared minimal and not a positive experience for the participants". (O'Sullivan 2018, p.45).

Parental Experience of Palliative Care:

I will now consider some studies that focus on parental experiences of interacting with palliative care teams. It is important to understand and learn from these experiences, in order to fully understand how social workers within multi-disciplinary teams can better support and help parents.

Gilmer et al (2012, p.53) examined parental perceptions of the care that hospitalised children with life-limiting illness receive, from a "clinical management, interdisciplinary support and pain management perspective". The study found that parental satisfaction with their child's care, during this end of life period, revealed the need for improved pain management and parental involvement in decision-making. This study also showed us that parents can feel excluded when it comes to decisions made by professionals in relation to their child. It raised questions in relation to how involved parents, such as Charlie Gard's, were in decisions about their child's care before the case reached the courts. Popejoy (2015, p.20), in a study which

set out to understand "the lived experience of parents through the process of making and revising end of life decisions for their child", identified two main issues. Parents felt that they lacked power when it came to decision-making in relation to their child, and required more support when revising and implementing end of life care plans. They recognised the importance of planning for their child but found talking about the plans difficult during acute life-threatening episodes: "Clinicians should be aware of this and take steps to assist parents in making these decisions" (Popejoy, 2015, p.24).

Cadell et al (2012) presented results from a research study of posttraumatic growth in parents caring for a child with a life-limiting illness. Posttraumatic growth occurs when individuals experience positive effects following highly stressful, traumatic events in their lives. The results showed that parents experienced a financial burden associated with caregiving while also experiencing posttraumatic growth. This information is critical, because it can inform social workers and palliative care teams how to best support parents. The Irish Hospice Foundation (2005, p.28) conducted a palliative care needs assessment for children and the research identifies the challenges parents encounter when caring for a child with a life-limiting condition. These challenges are as follows:

- Feeling their concerns are not being met and listened to.
- Social, mental, physical health burden on the entire family.
- Insufficient time with medical professionals.
- Poor communication between professionals and parents.

This research suggests that palliative care teams fail to support parents in all aspects of caring for a child with life-limiting illness. It is clear from the research that parents require increased support regarding decisions about their child's illness. They also require help and assistance in coping with the stress and worry that a child's terminal illness causes to a family. Charlie

Gard's parents had to deal with this stress as well as the stress of litigation in the courts, and so we need to consider how overwhelmed and unsupported both of his parents must have felt. A practical way to reduce some of the obvious concerns would be to design and implement a paediatric palliative care program. Koch et al (2018, p.1) "describes a paediatric palliative care program as a way of helping children and families with communication, decision-making, psychosocial support and pain management, as well as bereavement care". Care giving, according to the authors, should be divided into five basic types of support:

- Instrumental (e.g. community engagement)
- Personal (e.g. support with personal care)
- Informational (e.g. provide information)
- Medical (e.g. medical care)
- Emotional (e.g. address emotional needs)

If these key areas of support are targeted in the plan, and multidisciplinary teams work together to provide them, then parents will feel more supported in the care of their child.

Legislative Changes to Support Parental Rights:

Throughout this section I will discuss what fellow researchers have said in relation to legislative change, and what has been recommended in order to support parental rights when making decisions about a child's life-limiting illness. There were many criticisms and concerns raised following the verdicts in both the Charlie Gard and Alfie Evans cases in the UK. Wilkinson et al (2018) question whether courts should reach verdicts based on the "best interests" test. Currently, the courts apply this standard when making decisions in relation to medical treatment. The authors argue that decisions overruling parental wishes should be based on a second, more stringent question, as this would ensure that legal decisions regarding medical treatment are consistent with the standard applied to other types of

decisions. They highlight the changes they believe are necessary to the law regarding parental authority and suggest the following options:

- "Respecting parental autonomy and allowing parents to be the final decision makers about medical treatment" (Wilkinson et al, 2018, p.1). This would avoid legal arguments. However, it would also consume and limit medical resources.
- Resolving disputes without court involvement, by applying a treatment tribunal model, similar to that used in Texas. In cases of potentially inappropriate treatment, the Texas model applies an explicit process for assessment and arbitration. This model allows timely decision-making and avoids costly legal appeals. However, according to Wilkinson et al (2018), this model also has its critics, who argue that it compromises the legal rights of the patient and family because they can't access the court.
- Independent mediation: this involves a neutral external facilitator. Following a pilot training programme in a paediatric hospital in the UK, staff felt they were better able to recognise potential conflict and managed to reduce actual conflict situations.

The authors conclude that there is a need for professionals and families to come together and explore constructive solutions to avoid disagreements and ensure the best interests of all children are met (Wilkinson et al, 2018). In addition, Dauber (2018) examined whether the courts should have had the power to decide to withdraw life sustaining treatment over and above the parents' rights as decision makers, in both the Charlie Gard and Alfie Evans cases. Dauber (2018) concluded that courts should not have the power to make such decisions and that going forward, such decisions should be resolved by facilitating open, honest and transparent communication between all the parties involved.

The Charlie Gard case identified a gap in UK and European Law regarding the widespread absence of parental rights. Since Charlie's death, his parents have been working with legal experts as well as medical professionals to draft legislation and policies aiming to prevent such cases in the future (Charlie Gard Foundation, 2018). The proposed bill puts forward three methods of improving current legislation, to ensure that parents have more of a say about their child's treatment. The improvements proposed are as follows:

- Preventing cases from reaching court, by providing families with more support and advice.
- Improving access to ethical and legal advice, independent second opinions and legal assistance to ensure families do not have to pay expensive legal fees.
- Restricting court involvement in cases where there is a risk of significant harm to the child

(Charlie Gard Foundation, 2018)

It is important to also examine the situation regarding life-limiting conditions from an Irish perspective. It is noteworthy that the Health Service Executive (HSE) made an application to the Irish courts, in 2014, to allow a hospital treating a baby boy with mitochondrial disease not to resuscitate him if his condition deteriorated. The HSE argued that cardiopulmonary resuscitation (CPR) would be invasive and further, that babies with his condition do not survive beyond a year. A judgement was never arrived at, as the case was resolved through mediation between the parents and the health care professionals (Ryan, 2017).

It is interesting to contrast the Irish case with the Gard case, in order to highlight the nuances involved. In the Irish case, the boy's parents knew there was no treatment available to prolong their child's life, they just wanted their child to live as long as possible, and the case

was also resolved through mediation. In contrast, in the Gard case, the parents wanted Charlie to receive experimental treatment abroad in the hope it would prolong his life. The medical team disagreed, so the matter was referred to the courts for a resolution. It is important to mention the Irish case, as it demonstrates how some cases can be resolved through mediation, when mediation is suitably used and implemented between parents and medical professionals. There is no simple answer to all such cases, as each case and individual circumstance will be unique, however analysis of the research presented indicates that legislative changes are not required at this stage in order for parental rights to be supported. Instead, I would advocate that a formal mediation process be established that supports parents and their rights as decision makers, whilst providing clarity and transparency on all decisions made in the best interests of the child.

Conclusion:

This chapter discussed the important work that social workers perform as part of a multi-disciplinary team, providing help, advice and support to families. The chapter also highlighted the fact that parents need better support when making decisions regarding their child's illness. Even more concerning was that one research study found that social workers are almost non-existent in paediatric health in Ireland. The analysis of previous research studies, regarding the legislative changes required to support parental rights, indicated that such changes were currently unnecessary, and that a mediation process would be more suitable.

Chapter 5:

Findings, Recommendations & Conclusion

Introduction:

This chapter summarises the key findings from the research study, concentrating on the central research questions and aims, as outlined in chapter one. The limitations and recommendations of the research study are also identified and discussed. The chapter concludes with a personal reflection on my experiences encountered while completing the research study.

Summary of key findings:

What rights do parents have in making decisions about their child's right to life, when their child is suffering from a life-limiting illness?

Parents' rights are derived from "parental responsibility", a term used in the legislation outlined in Chapter 2. While the term appears to be clearly defined in law, both in the UK and Ireland, the term "parental responsibility" is less clear in relation to its application in everyday life, without a distinct explanation of the term being universally agreed upon (Bain, 2009). Therefore, when using the term in medically based legal disputes, uncertainty arises. Bain (2009, p.1) suggests that "in order to understand the concept of parental responsibility fully, it is necessary to establish a country-specific meaning through legislation and policy documents".

The research shows that in medical case law, the courts consider the best interests of the child as paramount when parental rights and decisions conflict with the best interest of the child. While parents have rights to make decisions about a child's medical treatment even when the child is suffering from a life-limiting illness, those rights can be limited if the treatment options are not in the best interests of the child. As each medical case presents with an

entirely different set of circumstances, it can be difficult to regulate and ensure parental rights are protected in legislation and policy, because their rights would need to be balanced with the child's rights, as revealed in the examination of the Charlie Gard case, and other child medical cases.

Does legalisation protect a child's best interests when it comes to making decisions about children with life-limiting illnesses?

This is a challenging question to answer, because it is difficult to determine what the best interests of a child are, as demonstrated in the Gard case. Legislation in Ireland and the UK protects a child's best interests when decisions are made about the medical treatment of said child with a life-limiting illness. However, difficulties arise when trying to determine what a child's best interests are. Is it always in their interest to prolong a child's life through medical treatment, or to allow the child die with dignity and without pain? This research has demonstrated how each child's best interests can differ, depending on the circumstances of each child. The research also showed that when the best interest standard is used on its own as a standard, it is narrowly focused, and fails to take other considerations into account. If the harm standard was used in conjunction with the best interest's standard in the Gard case, as suggested by Shah et al (2017), the parent's views would have been considered. While the legislation protects the best interests of the child, the difficulty lies in determining what the best interest of the child actually is.

How can social workers best support families who have to make important decisions when their children are terminally ill?

My research examined several different research studies, in order to identify parental experiences of palliative care service delivery. The research study concentrated on the social aspects, in order to highlight how social workers can better support families when working as

part of a multi-disciplinary team. O'Sullivan (2018) highlighted, in his research on mitochondrial disease, that social work involvement with families was minimal and non-existent in some cases. Taylor el al (2018, p.329) suggests that "social workers aim to support the needs of patients and their families during and after traumatic experiences including diagnosis, or during the final stages of life".

The research found gaps in the provision of palliative care services to families and children such as: poor communication between medical professionals and parents, insufficient support for families when making decisions in relation to their child and lack of social support. Therefore a new approach is needed to ensure children and families are better supported in palliative care settings. Koch et al (2018) suggested five supports to reduce the concerns of families to ensure they are better supported. Koch et al (2018) proposes a paediatric palliative care program based on the five types of support: instrumental, personal, informational, medical and emotional. Social workers working as part of a multi-disciplinary palliative care team must ensure a comprehensive support program is implemented, based on these five supports. This will ensure that families are better supported, and will help to reduce the stress and burden of care experienced by the families and children with complex medical conditions such as mitochondrial disease.

Should legislative changes support parental rights?

"Parental responsibilities", along with rights, are already included in the legislation, but because legislation is complicated and can be interpreted in many different ways, it is difficult to envisage how changing the legislation can improve or support parental rights. As we have seen in the Gard case, where there is disagreement in interpreting the legislation, or if it conflicts with existing legislation, the result may not be supportive of parental rights.

One of the main reasons why legislative change can be complex is that when cases are referred to courts, the circumstances of each case can be quite different. However, the case studies suggest some similarities exist between the cases, the parents in all cases are affected by grief and loss and in some cases, were dissatisfied with the court decisions.

This study aimed to investigate if the rights of both parents and children could be protected and balanced. As discussed earlier, I would not personally recommend legislative changes because of the legal complexities involved. However, I would recommend that a formal mediation process be introduced - one that supports parents and considers their rights, while balancing those rights with rights of the child. This should help resolve disagreements between parents and medical professionals, and reduce the risk of cases like the Gard case reaching the courts. This will ensure that parental rights are better supported, even though it is not through legislative changes.

Recommendations:

Policy

- A parental responsibility interpretative document should be created, offering a comprehensive explanation and interpretation of the term "parental responsibility" as specified in the Child Care Act 1991, that can be referred to in medical and legal disputes.
- A formal mediation service should be established that offers supports to parents and considers their rights as decision makers, whilst providing clarity and transparency on all decisions made in the best interests of the child.

Practice

- Social workers need to be an integral part of the multi-disciplinary team in palliative care settings, so that they can provide care and support to children with life-limiting illness and their families, acting as a link with other medical professionals.
- Educational modules on the subject of palliative care support should be included in social work and other medical-orientated university programmes.

Research

- Further research and continued collaboration with CARL would benefit Mito Families Ireland in their efforts to raise awareness of mitochondrial disease. Combining this research with Meehan (2017) and O' Sullivan (2018) will provide a useful base for further studies on the topic.

Limitations:

- There is a lack of information, from an Irish context, in relation to parental experiences of palliative care-based social work.
- Medical case law in relation to children with life-limiting illnesses in Ireland is limited, therefore it is difficult to consider how a case, like the Gard case, would be treated in the Irish courts.
- Information on the implications that mitochondrial disease has on families in Ireland and the UK is scarce. Therefore, much of the literature utilised throughout this research refers to life-limiting illness.
- The study is limited to 10,000 words.

Conclusion:

The research found a need for more specific supports for parents of children with life-limiting illnesses, in order to avoid difficult legal proceedings being triggered. It is essential these

supports are made available to families to help them make informed decisions about their children. A formal mediation service should be used to resolve disputes between families and medical professionals. A fine balance should be maintained so that all parties in the decision-making process feel empowered, listened to and respected, when important decisions are made about children with life-limiting illness.

Personal reflection:

Now that I have completed this research dissertation, I feel it has been a significant learning experience for me. It has helped me increase and develop my research skills, and allowed me to complete a research dissertation that I was interested in carrying out, as it was newsworthy, relevant and of significant benefit to others. This really appealed to me, because for my previous dissertation I was not sure if anyone would be interested in the research topic I had chosen.

I enjoyed being involved in the CARL process, and working with the CARL liaison person. This was a useful and valuable experience for me as it meant I had to discuss and agree the content of the dissertation, and any changes made, with that person. This meant I had to consider others when I wanted to make changes, which was a very important learning experience.

I found the process of learning and understanding my research methodology difficult, and spent a lot of my time trying to comprehend it, so that I could show how it applied in my research. If studying methodology again, I would definitely try harder to understand what is being taught, be more engaged, and ask questions at lectures.

The information that I learnt from completing the research will benefit me as a social work practitioner, as the research has helped me to increase my knowledge surrounding the experiences of families who have children with life-limiting illness and about the supports and assistance they need. It has also helped me to learn new and improved ways of supporting families, both in palliative care and disability settings. The research has also

widened my knowledge and understanding of legislation concerning children's and parental rights, knowledge that I can apply in social work practice.

I hope that this research study will provide useful, valuable information for Mito Families Ireland, so that they can continue to raise awareness of mitochondrial disease and the effects the illness can have on the children affected, as well as their families.

Bibliography

Bain, K. (2009). Parental Responsibility. Social Work and Society International Online Journal, 7(1), p.1.

Birchley, G. (2018). Charlie Gard and the weight of parental rights to seek experimental treatment. *Journal of Medical Ethics*, 44(7), pp.448-452.

Bosma, H., Johnston, M., Cadell, S., Wainwright, W., Abernethy, N., Feron, A., Kelley, M. and Nelson, F. (2009). Creating social work competencies for practice in hospice palliative care.*Palliative Medicine*, 24(1), pp.79-87.

Bridgeman, J. (2012). *Parental responsibility, young children and healthcare law*. Cambridge: Cambridge University Press.

Cadell, S., Kennedy, K. and Hemsworth, D. (2012). Informing Social Work Practice Through Research With Parent Caregivers of a Child With a Life-Limiting Illness. *Journal of Social Work in End-Of-Life & Palliative Care*, 8(4), pp.356-381.

Caplan, A. and Folkers, K. (2017). Charlie Gard and the Limits of Parental Authority. *Hastings Center Report*, 47(5), pp.15-16.

Carey, M. (2013) *The Social Work Dissertation.* Using Small-Scale Qualitative Methodology. McGraw Hill: Open University Press, pp.43,61,58,109.

Cave, E. and Nottingham, E. (2017). Who Knows Best (Interests)? The Case of Charlie Gard. *Medical Law Review*, 26(3), pp.500-513.

Charlie Gard Foundation, (2018). Available at: https://www.thecharliegardfoundation.org/

Children's Rights Alliance (2010) United Nations Convention on the Rights of the Child: Dublin, United Nations, pp.10,15 Available at: https://www.childrensrights.ie/sites/default/files/submissions_reports/files/UNCRCEnglish_0.pdf

Close, E., Willmott, L. and White, B. (2018). Charlie Gard: in defence of the law. *Journal of Medical Ethics*, 44(7), pp.476-480.

Collins, A., Hennessy-Anderson, N., Hosking, S., Hynson, J., Remedios, C. and Thomas, K. (2016). Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study. *Palliative Medicine*, 30(10), pp.950-959.

Corby, B. (2006) *Applying Research in Social Work Practice.* Maidenhead: Open University Press.

Cornock, M. (2010). Hannah Jones, consent and the child in action: a legal commentary. *Paediatric Care*, 22(2), pp.14-20.

Costantino, M. (2010). Parenting Children With Disabilities: Navigating Through the Storms. Journal of Creativity in Mental Health, 5(1), pp.87-92.

Court Service Ireland, 2017, Available at: http://courts.ie/Courts.ie/Library3.nsf/PageCurrent/56F2259BE71F74E180257FB00055003D?opendocument&l=en

Crotty, M. (1998).*The Foundations of Social Research*. 1st ed. Sage Publications, p.3.

Dauber, M. (2018). Bioethics and the law: Should courts be allowed to make end of life decisions? Reflections on the Charlie Gard and Alfie Evans controversies. *Ethics, Medicine and Public Health*, 6, pp.94-104.

Denzin, N. and Lincoln, Y. (2005). *The SAGE handbook of qualitative research*. Thousand Oaks: Sage Publications, p.102.

Department of Health and Children (2009). Palliative care for children with life-limiting conditions in Ireland, p.2.

European Convention on Human Rights, s.2,5,8 available at: https://www.echr.coe.int/Documents/Convention_ENG.pdf

Gillon, R. (2018). Why Charlie Gard's parents should have been the decision-makers about their son's best interests. *Journal of Medical Ethics*, 44(7), pp.462-465.

Gilmer, M., Foster, T., Bell, C., Mulder, J. and Carter, B. (2012). Parental Perceptions of Care of Children at End of Life. *American Journal of Hospice and Palliative Medicine®*, 30(1), pp.53-58.

Goldsworthy, K. (2005). Grief and loss theory in social work practice: All changes involve loss, just as all losses require change. Australian Social Work, 58(2), pp.167-178.

Guba, E. and Lincoln, Y. (1994). *Competing paradigms in qualitative research*. [S.l.]: [s.n.], p.110.

Gwyther, L., Altilio, T., Blacker, S., Christ, G., Csikai, E., Hooyman, N., Kramer, B., Linton, J., Raymer, M. and Howe, J. (2008). Social Work Competencies in Palliative and End-of-Life Care. *Journal of Social Work in End-Of-Life & Palliative Care*, 1(1), pp.87-120.

Hammond-Browning, N. (2017). When Doctors and Parents Don't Agree: The story of Charlie Gard. *Journal of Bioethical Inquiry*, 14(4), pp.461-468.

Hinojosa, M., Knapp, C., Madden, V., Huang, I., Sloyer, P. and Shenkman, E. (2012). Caring for Children With Life-Threatening Illnesses: Impact on White, African American, and Latino Families .*Journal of Pediatric Nursing*, 27(5), pp.500-507.

Ireland Child Care Act 1991, s.24, Dublin, Available at: http://www.irishstatutebook.ie/eli/1991/act/17/enacted/en/html

Irish Hospice Foundation (2005). A Palliative Care Needs Assessment for Children, p.18,28.

Koch, K. and Jones, B. (2018). Supporting Parent Caregivers of Children with Life-Limiting Illness.*Children*, 5(7), p.85.

Langercrantz, H. (2018). Observations on the case of Charlie Gard. *Arch Dis Child May*, 103(5), p.409.

Laura Lynn Foundation. (2019), Available at: https://lauralynn.ie/

Madden, D. (2009). *Medicine, ethics and the law*. 4th ed. Sussex: Tottel Publishing, p.458.

Mc Partland, E. (2010).The best interests of the child, p.10.

Meehan, T. (2017). *An Exploration of Anticipatory Grief in Families of Children with Mitochondrial Disease and the Role of Social Work*. Masters. University College Cork.

Minister of Health (2014) *National Rare Disease Plan for Ireland 2014-2018,* Dublin, Stationary Office, p.5.

Non-Fatal Offences Act 1997, c. 23, Available at: http://www.irishstatutebook.ie/eli/1997/act/26/enacted/en/html

O Sullivan, P. (2018). *Dress to Impress: Parents' Fears of Allegations of Fabricated Induced Illness in Cases when their Child has Mitochondrial Disease - Exploring the Voices of MITO Families Ireland.*. Postgraduate. University College Cork, p.45.

O'Brien, A. and Sokol, D. (2014). Lessons from the Ashya King case, pp. 5563-5563.

Onwuegbuzie, A. & Frels, R. (2016) *7 steps to a Comprehensive Literature Review: A Multimodal and Cultural Approach*, 1st eds, London: Sage Publications Ltd. p.18.

Paris, J., Ahluwalia, J., Cummings, B., Moreland, M. and Wilkinson, D. (2017). The Charlie Gard case: British and American approaches to court resolution of disputes over medical decisions. *Journal of Perinatology*, 37(12), pp.1268-1271.

Payne, M. (2009). Developments in end-of-life and palliative care social work. *International Social Work*, 52(4), pp.513-524.

Popejoy, E. (2015). Parents' experiences of care decisions about children with life-limiting illnesses. *Nursing Children and Young People*, 27(8), pp.20-24.

Popejoy, E., Pollock, K., Almack, K., Manning, J. and Johnston, B. (2017). Decision-making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis. *Child: Care, Health and Development*, 43(5), pp.627-644.

Ritchie, J. and Lewis, J. (2003). QUALITATIVE RESEARCH PRACTICE. 1st ed. Sage Publications, pp.38,76.

Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. (2014). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. 2nd ed. London: Sage, pp.6,16.

Ryan, O. (2017). In 2014, A case similar to Charlie Gard's came before the Irish High Court. *The Journal*, Available at: https://www.thejournal.ie/charlie-gard-irish-case-3490904-Jul2017/

Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching*, 5(9), p.9.

Senger, B., Ward, L., Barbosa-Leiker, C. and Bindler, R. (2016). The Parent Experience of Caring for a Child with Mitochondrial Disease. *Journal of Pediatric Nursing*, 31(1), pp.32-41.

Shah, S., Rosenberg, A. and Diekema, D. (2017). Charlie Gard and the Limits of Best Interests. *JAMA Pediatrics*, 171(10), p.937.

Small, N. (2001). Social Work and Palliative Care. *The British Journal of Social Work*, 31(6), pp.961-971.

Taylor, K., Drost, L., Wan, B., Yee, C. and Chow, E. (2018). The valuable role of social workers in palliative care. *Journal of Pain Management*, 11(4), pp.329-330.

Teater, B. (2010). *An introduction to applying social work theories and methods*. 2nd ed. McGraw-Hill Education.

Timms, J. and Thoburn, J. (2006). Your Shout! Looked After Children's Perspectives,p.154.

UK Children Act 1989, s.1,3, Available at:

https://www.legislation.gov.uk/ukpga/1989/41/contents

United Mitochondrial Disease Foundation (2016) 'Defining Mitochondrial Disease' [Online] Available at: http://www.umdf.org/what-is-mitochondrial-disease.

Wilkinson, D. and Savulescu, J. (2017). Hard lessons: learning from the Charlie Gard case. *Journal of Medical Ethics*, 44(7), pp.438-442.

Wilkinson, D. and Savulescu, J. (2018). Alfie Evans and Charlie Gard—should the law change? *BMJ*, p.1.