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Trinity College Dublin
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Coventry University

SERVICE EVALUATION OF THE JACK & JILL CHILDREN'S FOUNDATION

FULL REPORT

COVENTRY UNIVERSITY | Faculty of Health and Life Sciences

no care like home care
THE JACK & JILL CHILDREN'S FOUNDATION
1997 2017
• 20 YEARS •

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MESSAGE FROM JONATHAN IRWIN

The best result for me in this service evaluation is the simplicity and effectiveness of the Jack & Jill home nursing care and respite model.

This is a unique service that really works.

This Jack & Jill model, based on my own son Jack's home care plan, has changed little over 20 years. However, it is a model that has changed lives, making difficult care journeys for over 2,200 families a little easier and less lonely. It is humbling and reassuring to hear the voice of parents coming through loud and clear in this report. Parents who know the Jack & Jill service well, parents who, all too often, have to fight for every little support for their child. My personal thanks to busy parents who have taken the time to help us evaluate the service which will benefit those families coming behind them.

We have a lot of stories to share and our nurses have built up a major bank of knowledge and know-how, to be very proud of. Reading through these pages you see a child and family-centred, wraparound, bespoke service, delivered by a dedicated team of highly qualified, hands-on nurses who are care champions. Never forgetting our colleague, Rhona Kett Sheridan, specialist children's nurse and friend, who passed away last year, leaving a legacy of love, laughter and care everlasting to the families and colleagues under her wing.

I want to salute each and every one of our nurses, these quiet champions, and to remind them of their importance and their impact in every community. As an organisation we never stand still. We constantly strive to listen and to learn and to improve our service, while also aspiring to make the lives of the children and families we support that bit easier. Maintaining those family fundamentals is a thread that runs deep throughout this report.

And the role of the Jack & Jill liaison nurse as carer, case manager, advocate, champion, challenger, counsellor and friend is a broad and challenging job and it is on these broad shoulders that we've built our service.

We've funded that service 80% through the continued loyalty and generosity of individual, family and corporate supporters and a paltry 20% through our Health Service Executive (HSE) grant. All fuelled by a dedicated fundraising team. We hope that this report rewards and encourages that generosity and encourages the HSE to invest more in a service that really works.

Jack & Jill is a service to be embraced, replicated and invested in throughout the Health Service. We show good governance in practice from the boardroom to the sitting room, and, while others talk about the money following the patient into the home, we make it happen.

To the families under our wing today, tomorrow and yesterday I say thank you from the bottom of my heart. What a privilege it is to be invited into your home and into your lives to accompany you on your journey.

Like you, we put the extra into the ordinary, and that starts with a gift of time from our family to yours.

I may be retired now from Jack & Jill but my commitment is full time and I am so proud of what we have achieved together in 20 short years.

Thank you.

Jonathan Irwin, FFPAED (Hon),
Founder, The Jack & Jill Children's Foundation

PREFACE

The blueprint for Jack & Jill's unique model of home nursing care was put together in 1997, under tremendous pressure, by two exhausted parents looking for solutions to help their family from falling asunder—and it has barely changed in 20 years. Why? Because it was parent-led from the very start; because it was lean financially, and nimble in terms of when and how often; because it cut through every obstacle or delay; because it worked.

Now, 20 years on, it felt appropriate for the Foundation to commission two great Centres of Learning—Coventry University and Trinity College Dublin—to evaluate that model of care, to ask its users to verbalise how they feel about it, and to let us know if it has maintained its relevance. Jack & Jill has, after all, played a very central role in changing paediatric homecare forever in this country. In 1997 State assistance simply did not exist, and today it does: The Health Service Executive are now firmly in this space. But, like any Healthcare system, there continue to be devastating shortfalls, and there probably always will be. Only last year, a senior HSE manager gave us the firm advice to "stay operating outside the system," where we can offer flexibility, where we can fill in the cracks as they appear, where a euro goes a lot further, and where we continue to offer a superior service – because we are giving families what they need, not what we need families to accept.

This is also a report which gives unequivocal credibility to Jack Irwin's parents, and the brilliant and ground-making decisions they made two decades ago, and the team of nurses and office staff that Jonathan Irwin has built.

We dedicate this report to the memory of Jack Irwin who was the inspiration for the setting up of the Jack & Jill Children's Foundation.

Hugo Jellett
CEO, Jack & Jill Children's Foundation

1.0 BACKGROUND OF JACK & JILL CHILDREN'S FOUNDATION

The Jack & Jill Children's Foundation is a registered charity established in 1997 following the extraordinary experiences of Jonathan Irwin and Mary Ann O'Brien. Their son Jack, born on 29th February 1996, sustained an invasive neurological trauma two days later, which resulted in severe brain damage leaving Jack disabled, deaf, blind and unable to swallow, thus, necessitating full-time care. Whilst the exact sequence of events is not certain, it is probable that he collapsed and was resuscitated in the maternity hospital. Certainly, from that moment the dreams of Jack's parents were shattered and the heart-breaking task of keeping Jack alive began. Their story recounts that the senior paediatrician in the hospital was brutal but honest when asked for a 'route map of care' for Jack, once he left the intensive care unit, it was made clear that there were simply no services in Ireland available in 1997 to care for a baby like Jack. The family were traumatised by these events which were further exacerbated by this lack of support and bureaucratic obstacles and suggestions by the medical team that they should abandon their child. This only served to strengthen their resolve and galvanised the Irwins to work tirelessly to make a difference with their mantra that"no family should have to go through the same dark valley ". Jack lived for 22 months, a short, desperate and painful life punctuated with a mix of drugs, physiotherapy, postural drainage, seizures, reflux operations, gastronomy and suctioning. The only saving grace was that he was loved and helped around the clock by a dedicated band of five nurses and carers from the neighbourhood. Jack's short but significant life revealed to his parents the ideal way in which infants and young children like Jack can be nursed.

The untimely death of Jack at 22 months of age was the catalyst that led Jonathan and Mary Ann to establish the 'Jack & Jill Foundation'. Through their own experience, they felt there was an unfilled gap in care and the need for a home-nursing service for children in the community in the Republic of Ireland. There are also gaps in service provision by the Health Service Executive (HSE), the national health service provider. The Jack & Jill Children's Foundation provides a home-based specialist nursing care service to families of children with severe neurological conditions and all palliative and end-of-life care for children up to 4 years of age. More details about Jack's story and how his family managed can be located on the Jack & Jill website at www.jackandjill.ie/about-jack-and-jill.

The ethos and philosophy of the Jack & Jill Children's Foundation is that it "cannot cure the children but it can help to alleviate some of the difficulties that exist" (www.jackandjill.ie). The Jack & Jill Children's Foundation strongly subscribe to the concept that '**There's no care like home care**' which is advocated throughout the professional literature (DH 2004, DH 2010, Law et al 2011, Bluebond-langner et al 2013).

THE JACK & JILL CHILDREN'S FOUNDATION ASSERT IN THEIR MISSION STATEMENT THAT THEY:

> "Endeavour to help improve families' lives by engaging with the child and family to empower them and give them the choice to care for their child at home, often in extraordinary circumstances with extraordinary responsibilities"

The Jack & Jill Children's Foundation is presently the only voluntary organization in the Republic of Ireland which provides nationwide specialist home-nursing (respite care) for children age 0 - 4 years, who have life-limiting, and/or severe neuro-developmental conditions. The Foundation also provides palliative and end-of-life home nursing care for all children age 0 - 4 years. Historically the impetus to fill this gap in care was galvanized through the establishment of two charities: **'Nurse for Daniel'** (1996 - 2012) and the '**Jack & Jill Children's Foundation**' (1997 - present), both of which were founded as a direct result of personal family tragedies. In 2001 the National Advisory Committee on Palliative Care acknowledged that the needs of children and young people were different from adults, which initiated a review of paediatric palliative care services in Ireland. The United Nations Conventions on the Rights of the Child (1989) affirms that children have the right to the highest attainable standards of health and the right to equitable access to healthcare services which meet their needs (Killkelly and Savage 2013: 3). The Jack & Jill Children's Foundation prides itself on having a commitment to children's rights to good health and healthcare.

During 2001 this was reinforced by the launch of the Laura Lynn Foundation and as a result the first children's hospice was opened in 2011 (Ling et al, 2012). These events were a watershed in the evolution and development of palliative care services for children and young people, and witnessed the publication of the 'Palliative Care Needs Assessment for Children' (DoHC, 2005) in association with the Irish Hospice Foundation (IHF, 2005). This provided further impetus for the 'National Policy on Palliative Care for Children with Life-Limiting Conditions in Ireland' (DoHC, 2010). The implementation of this policy formally acknowledged the special needs of this group of children and young people thus providing the impetus and future direction for children's palliative care in Ireland. In 2011 the first Specialist Consultant in Children's Palliative Care and eight Children's Outreach Nurses who now following a review have grown to ten Outreach Nurses known as 'Clinical Nurse Co-ordinators' for children with life limiting conditions were installed. Complimenting this, a small-dedicated team of Jack & Jill nurses provide care for children with life-limiting conditions across the twenty-six counties in Ireland, whose care and dedication is mirrored by their motivation and competence to continually improve the service and maintain a contemporary evidence-base to the care they deliver.

Now marking its 20th anniversary (2017), the Jack & Jill Children's Foundation has cared for and supported 2,300 children and their families, 365 days a year, employing 12 highly qualified and skilled Specialist paediatric Liaison Nurses. There can be no doubt that collectively the service provided by the Jack & Jill Children's Foundation makes an enormous difference to the lives of children and their families across the Republic of Ireland.

Introducing Specialist Liaison Nurse
MARIE BOWEN

Working in the community as a children's nurse gave me the passion to work for the charity. It allows me the autonomy to do my job providing respite, empowering parents and supporting them to care for their sick child. Every day is different and brings with it new challenges. On a daily basis, I am constantly learning from parents, which I can share with other families I work with. Families frequently inspire me, which drives me on to continue to do my job. Jack and Jill's mission statement is "to endeavour to help improve families lives by engaging with the child and family to empower them and give them the choice to care for their child at home often in extraordinary circumstances with extraordinary responsibilities".

1.1 INTRODUCTION

Significant advances in medical science, research and evidence-based care, technology and neonatal care have now enabled and supported infants and children to survive with complex life-threatening and rare conditions associated with preterm birth, congenital anomalies, genetic conditions, and conditions such as infectious diseases (Glendinning et al 2000, Balling and McCubbin 2001, Wang and Barnard 2003, Hill and Coyne 2012, Woodgate et al 2012, Caicedo 2014, Spratling 2015). This has resulted in the emergence of escalating numbers of children with complex disabilities with lengthened life expectancy, whose families are living with the reality and lived-in experience that the child and family will require assistive care, technical support and potentially ongoing respite and palliative care needs (Quinn and Bailey 2011). Concomitantly the transfer of care has accompanied these advances from acute settings to the home setting, supported by informal and formal care services with parents assuming a variety of roles, and O'Brien and Duffy (2010) assert that the time together as family at home is precious. Caring for children at home has been advocated for many decades. Platt (Ministry of Health 1959) who was at pains to encourage children to be cared for in the home environment stated:

> "…. Children, particularly very young children should only be admitted to hospital when the medical treatment they require cannot be given in other ways without real advantage" (Ministry of Health 1959: 17).

Most parents want the opportunity to care for their child at home to allow them to continue with family life and social inclusion (Noyes et al 2013, Hill 2016, Nightingale et al 2017). However, life takes on a 'new or different normal'. Brenner et al (2017) provide anecdotal evidence from an Irish perspective suggesting that the health service is struggling to meet demands of these families, and findings from an earlier Irish Needs Assessment (DoHC and IHF 2005) determined that the majority of families would prefer their child with a life-limiting condition to be cared for at home in a familiar environment. This is also the preferred place of death for that child. However, with adequate community support this has resulted in an increase in the numbers of children being cared for at home (Ling 2012). Furthermore, families with children with ongoing healthcare needs and disabilities require early intervention and ongoing support in order to minimise the wider impact upon the child and the family from the point of diagnosis onwards (Noyes et al 2013). Whilst caring for children at home is the most desirable option for the parents and siblings, the fragility of these exceptional circumstances has been described as 'living in a house of cards' as parents as caregivers experience frequent change, uncertainty and unpredictability and their lives as a result of caring for their child or indeed children with disabilities (O'Brien 2010). Moreover, caring for these infants and children potentially brings with it emotional, physical, financial and social challenges all of which impact upon family life, including family dynamics, siblings and the extended family, social isolation, depression, mental health and anxiety issues and employment problems (Millar 2002, DHC 2005, Himelstein 2006, O'Brien et al 2009, Thomas and Price 2012, Hill 2016, and Whiting 2014). The greatest unmet need identified by parents was the provision of respite care. O'Brien and Duffy (2010) warned that community support in Ireland was inadequate and the provision of respite care for children and their families was a significant challenge to be addressed. Moreover, the transition between curative and palliative care is less clear in children, and Price and McNeilly (2009) assert that the transition is difficult for families and professionals. This difficulty is further exacerbated by the unpredictable and often protracted trajectory of a child's illness and death which has further implications for service provision.

The Department of Health and Children (2010) define life-limiting conditions for children as:

> "Any illness in a child where there is no reasonable hope of cure and from which children or young people will die" (DHC, 2010: 11).

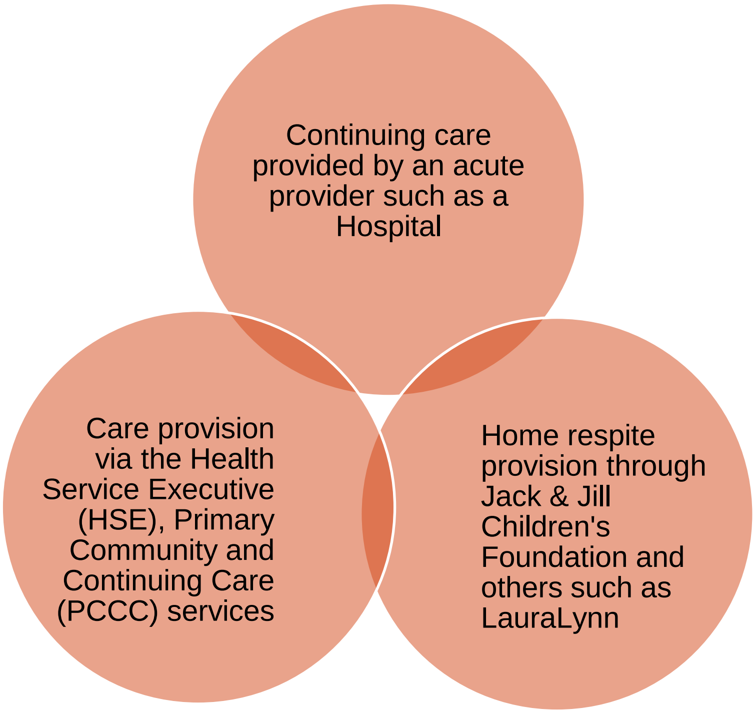
This is followed by the fact that premature death may not be immediate and these children can live with illness for many years (RCPI, 2015). However, the Department of Health, Social Services and Public Safety, Northern Ireland used a 'needs-led' definition to define children and young people with complex care needs as:

> "Children (and young people) with complex physical healthcare needs are those who require a range of additional support services beyond the type and amount required by children generally and those usually provided to children with impairments and long-term illnesses" ('Developing Services to Children and Young People with Complex Physical Healthcare Needs', 2009: 7).

Diagnoses common to children with special healthcare needs are numerous and include preterm birth, congenital genetic and metabolic disorders, and neurological disorders, sequelae of severe infections, or trauma and malignancies. These can include one or more chronic conditions some of which are extremely rare but cause functional limitations often necessitating technology assistance, and ongoing healthcare needs. There are periods of stability interspersed with acute/critical care needs, which may culminate in palliative and end-of-life care for the child. Technology dependency refers to the use of medical devices without which, if they were to fail or be discontinued, adverse health consequences and hospitalisation would be likely to follow. Examples include mechanical ventilators, intravenous catheters, tracheostomy tubes, enteral feeding devices, colostomy bags, and urinary catheters.

Expectations have risen substantially regarding the extent of care that can be provided in the home and the response from services in terms of planning, development and delivery models have not necessarily kept pace with these demands.

Within the Irish context, current models of care provision and delivery mostly include:



1.2 FOCUS OF THE SERVICE EVALUATION

The number of children who need support is rising rapidly and it is crucial to understand their needs from the time of diagnosis, throughout the child's life, end-of-life and beyond for grieving families. It is estimated that between 536-592 children die in Ireland each year prior to their eighteenth birthday and the numbers of children with life-limiting conditions remains unknown. It has been estimated at 3,840 but this figure may be underestimated (Ling et al, 2015).

This evaluation sets out to report upon the Jack & Jill Children's Foundation's, provision of care to infants and children 0-4 years in the Republic of Ireland today. The evaluation builds upon published work previously undertaken, including the cost and outcomes of alternative models of care for young children with severe disabilities in Ireland (Normand and Revill 2010, Nicol 2012, Revill et al 2013, Brenner et al 2015). The framework for this service evaluation is based upon a modified evaluation and outputs framework, which synthesises works from Donabdian (1988) and Reeve et al (2015).

Crucially, this service evaluation captures the voice of the families and their perceptions and experiences with the Jack & Jill Children's Foundation. Jonathan Irwin, as the former CEO of the Foundation, commissioned the evaluation of the service, which was conducted over a nine-month period from October 2016. This allowed time for parents to complete an online survey and attend regional focus groups, and for the nursing staff to respond to an online survey. Working in collaboration with the Jack & Jill Children's Foundation, the Coventry University team were keen to capture the views and voices of children through their families. Acknowledging the nature of complex and palliative care, the team were attentive and sensitive to the needs of the families and participants involved.

The major focus of this service evaluation centres upon exploring the referral process to the Jack & Jill Children's Foundation and outcomes of that process including timeliness, access and communication and the duration and quality of that care and support. The direction of this service evaluation has been focused around the provision of care to the child and family.

It builds upon work which has been previously undertaken in relation to the trajectory of the Jack & Jill Foundation (Normand and Revill 2010, Nicol 2012, Revill et al 2013, Brenner et al 2015).

Introducing Specialist Liaison Nurse
FIONA CALLAGHAN

It is a privilege to be part of the whole team that is Jack and Jill, the nursing staff, the office staff, the fund- raising team and the communities all over the country that raise much needed funds for the causes close to their hearts.

They are truly inspirational. As a Liaison Nurse, I see families sometimes at their darkest hour. I can arrange for them to get a little help that sometimes makes getting up each day easier when they know a nurse or carer is coming. I can be the ear to listen to their stories and worries and sometimes that is all they need. As an advocate for our families it is important to empower the parents as much as I can in caring for their child at home.

2.0 SERVICE EVALUATION

The project team comprised of three members of academic staff from Coventry University and two Specialist Liaison Nurses from the Jack & Jill Children's Foundation. Each member of the team had specific roles and responsibilities throughout the evaluation and compilation of the report.

2:1 AIMS AND OBJECTIVES

The overarching aim of this service evaluation has been to evaluate the impact of the Jack & Jill Children's Foundation service upon the holistic collaborative care of the children and their families in their care.

Specific aims of the service evaluation are:

- Review the impact of the care trajectory within life-limiting conditions and palliative care.
- Explore how the Nurses and Allied Health Professionals are involved with the children and their families.
- Consider the role of the Specialist Liaison Nurse within the Jack & Jill Children's Foundation.
- Analyse the captured data to inform the service evaluation.
- Provide recommendations for service improvements.

2.2 SERVICE EVALUATION DESIGN

The requirements of this service evaluation, and the nature and type of information required, were considered as key determinants in the design of the investigation whilst also taking account of practical issues such as the availability and accessibility of resources and service gate-keepers, and how best to engage the participants based upon sound ethical principles and protection of those individuals (Parahoo 2014). Moreover, it was important to make explicit the service evaluation design, this being integral to the internal and external logic and sequence of events, which connect the empirical data to the evaluation aims and questions, and ultimately to the conclusions and recommendations.

Healthcare evaluation is the rigorous process by which the provision of a service to a population is assessed, to understand whether that service delivery fulfils its objectives. Moreover, innovative methods to collect and analyse feedback are crucial to inform service delivery and at the local level to enhance and develop service delivery. Therefore, undertaking a deep dive into the Jack & Jill Children's Foundation service, aims to consider the following:

- Effectiveness - notably the benefits of Jack & Jill Children's Foundation service delivery for the infants, children and their families.
- Acceptability - the social, psychological and ethical acceptability regarding the way in which children and their families are treated in relation to healthcare.
- Equity - the fair distribution of healthcare.
- Sustainability - future-focused care delivery.

The major elements of this service evaluation were to capture feedback from parents/carers, nursing and liaison staff in order to provide tangible evidence which would inform the evaluation. The following table outlines the key approaches adopted for this service evaluation.

GOVERNANCE	Contemporary healthcare systems and all members of the nursing and allied professions are afforded the privilege of establishing and regulating their own standards for technical and ethical excellence. Therefore, developing an, 'ethical eye' refers to professionals who work in a 'research capacity' who work with agreed standards of professional conduct (Williamson 2001). Ethical principles were an integral element within this service evaluation and not purely reflected as a stand-alone component. Therefore, in order to comply with ethical principles, conjoint ethical approval was sought and granted by the Ethics Committee at Coventry University and from the Jack & Jill Children's Foundation Research and Development Group.
INFORMED CONSENT, ANONYMITY AND CONFIDENTIALITY	An opt-in/or opt-out approach was utilised as part of the process of consent. This was when the potential participants were informed of choices available to them and action taken only with their active assent (opt-in). Participant information was provided to all participants (Appendix 1). Furthermore, opt-in consent is viewed as a better form of consent because each individual is informed about the study in a formalised manner - in writing (Singleton and Wadsworth 2006). Consent information was presented to the prospective participants during the recruitment process and the prospective participants could evaluate the potential risks and benefits of participation (Polit and Beck 2008). Therefore, each potential participant was issued a consent form prior to embarking upon the data collection. Maintaining anonymity of the participants was addressed through a variety of measures including informed consent and the following procedures: - Transparency of consent procedures - The ongoing assessment of vulnerability - Sensitivity to any changes in the participants' decision - Emphasising the participant's right to withdraw Confidentiality was addressed through the following: - A statement, which clearly stated the purpose of participation, was for professional purposes only. - An assurance that as far as possible study participants' identity would not be apparent in the final report. - All material and data will be protected and stored and locked in a locked cabinet/drawer and material stored electronically will be password protected, and data will be destroyed within the accepted timeframe.
METHODS	Qualitative and quantitative methods were employed to satisfy the needs of the evaluation aims and by 'nesting' or mixing methods; this potentially offers richer and stronger evidence (Yin 2009).
PARTICIPANT RECRUITMENT	Parents were recruited through collaboration with the Specialist Liaison Nurses from the charity. Information sheets were provided so that they were clear on what the service evaluation was about and what their participation would involve. The parents were invited to respond to an introductory email as an expression of interest to be involved in the service evaluation and all participants completed an online disclaimer before being given access to the online survey. From this contact parents were then invited to join a bespoke focus group, which was arranged by one of the Specialist Liaison Nurses from the Jack & Jill Children's Foundation but conducted by two Senior Lecturers in Children and Young People's Nursing from Coventry University, the outline for which was structured and had pre-designed questions (Appendix 2). Inherently this technique is sought from a pre-specified group, which enabled the researchers to satisfy the needs of the evaluation whilst building a trusting relationship, and is a type of sampling commonly associated with flexible designs (Robson 2004), Gerrish and Lacey 2006).

SURVEY TOOL	A specialist online survey tool (Bristol Online Survey) was used to create a survey with a total of 20 questions consisting of a combination of simple Likert scales and semi-structured questions. Two different surveys were created for two audiences; firstly parents (Appendix 3) and secondly Nurses providing care for the Jack & Jill Children's Foundation (Appendix 4). Each survey was released via email to the two groups at different times with the instructions of how to access the survey from any device with Internet facilities. The survey tools were used for their functionality to upload results automatically back to the master database which is held confidentially.
PARENTS FOCUS GROUPS	In conjunction with the Specialist Liaison Nurses, key geographical locations across the Republic of Ireland were identified as the locations to host the parent focus groups. These were identified taking account of the current number of cases in each region. Remote areas were excluded due to the paucity of parents in the location and distance for travelling; however, parents were invited from remote locations to join the focus group and attended their nearest location. A pilot group convened in Naas to consider the questions to be used for the Focus group discussions that were held as follows; - Focus Group 1. Cork - Focus Group 2. Dublin - Focus Group 3. Limerick - Focus Group 4. Galway Consent forms (paper version) were completed prior to each focus group. Consent was obtained for the use of an audio recorder and permission to create a transcript. Following each focus group transcripts of the audio captured were created and stored securely for analysis.
TABLE TOP DISCUSSION	Health and social care professionals' roundtable discussions were held and a refined question set used to guide the discussion. Transcripts of the audio captured at the focus groups were created and stored securely for analysis.
DATA ANALYSIS	For the purpose of this service evaluation, key principles were adapted from two key pieces of work namely; Donabedian's (1988) quality of care paradigm linking structure, process and outcomes and evaluation theory, coupled with the work from Reeve et al (2015) assuring equity and access to quality healthcare. The Donabedian model has been identified as the most suitable model as it is a conceptual model that provides a framework for examining health services and evaluation quality of health care. The modified framework also provided a platform to review service performance and essential requirements for sustainability and improved performance indicators through the evaluation process. The data set was triangulated which led to the emergence of themes.
DATA CODING APPROACH	Coding: This refers to the processes of breaking down the data into discrete parts. Each audio recording was transcribed and then by listening to and reading the transcript of each focus group and the data from the BOS categories and themes emerged. For the purpose of the report quotations used have been coded from each source. A summary of responses from parents has been created (Appendix 5). BOS Parents survey has been identified with the letter P for Parent and the number to identify which parent but maintain anonymity. BOS Nurses survey direct quotations have been identified with the letter N for Nurse and the number to identify the response and maintain anonymity. A summary of responses from nurses has been created (Appendix 6). Roundtable discussion and focus groups are as follows: - Focus Group 1. Cork = CFG - Focus Group 2. Dublin = DFG - Focus Group 3. Limerick = LFG - Focus Group 4. Galway = GFG - Health and social care professionals = R (for respondent)

Additional considerations included analysis of risk and benefit, gatekeepers and the application of fidelity and justice.

Risk/Benefit Analysis

All types of investigations involve an element of risk and in many cases this risk is minimal. Minimal risk is defined as risks anticipated to be no greater than those ordinarily encountered in daily life, or during routine physical or psychological tests or procedures (Polit and Beck 2014). However, it was critical to assess carefully the risks and benefits that may be incurred in the conduct of this service evaluation due to the nature of the service provision (Polit and Hungler 2009). Therefore, the guiding principle was that the degree of risk should never exceed the humanitarian benefits of the knowledge gained, and the potential to improve the care to the children and their families.

Risk versus benefit analysis is not just about assessing risks against benefits, but the weighing of certain and uncertain negative effects (harms and risks) against certain and uncertain positive effects (benefits and chances). Furthermore, although the process of assessing risk is important, the decision-making processes must take account of clearly identifying the risks and their estimation and their magnitude and weighing the risks against the benefits. Therefore, risk-benefit analysis has been carefully undertaken, being particularly cognisant that participants may reveal personal details and recount traumatic issues, which may be deep routed. Therefore, it is critical to give credence to these issues, which have been addressed through risk-benefit assessment. Furthermore, due consideration was given to the evaluation team who were engaging with parents and carers who are currently in, or who have been through, very distressing experiences in extraordinary circumstances whilst caring for their child with life-limiting illness.

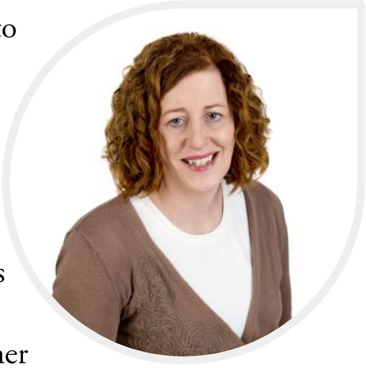
Gatekeepers

Conducting any type of investigation within any setting, organization or institution requires that the management or gatekeepers are aware and accepting of the activity taking place, and are as such the ‘gatekeepers’ therefore having the authority to grant or withhold access (Denscombe 2007). Access therefore was a crucial pre-requisite, which needed careful consideration and discussion at the planning stage of the service evaluation without which fieldwork could not commence. Once access had been granted through key gatekeepers from the Jack & Jill Children’s Foundation, it could not be disregarded and is described as a continual process whereby the gatekeepers can exercise influence over the research process in terms of access to participants, location and or events (Denscombe 2007:71). Therefore, communication between the evaluation team and the Jack & Jill Children’s Foundation was transparent and continuous.

Fidelity and Justice

Fidelity was associated with building trust between the evaluation team and participants. Therefore, we were obliged to safeguard the rights of participants, ensuring transparency and rights of the participants would take precedence over the needs of the evaluation outputs.

Introducing Specialist Liaison Nurse
SINEAD MORAN



Working for Jack & Jill allows me to make a difference in families' lives on a daily basis. We provide families with nurses and carers to support parents with what we call 'The Gift of Time', allowing them a night's sleep or time to themselves to go shopping, get their hair done or spend quality time with their other children, their partner or husband. The autonomy and flexibility of my position lets me do the best I can for each individual family I encounter.

I have the unique and rewarding experience of encouraging, supporting and empowering parents to care for their child at home. I consider it a privilege that families allow me to come into their home and help support them as best I can; as best we can as a Foundation. I can see the difference that the respite support from this charity makes to families, not only to the parents' lives but to the siblings lives as well. This drives me to do the best job I can do for families, day in day out.

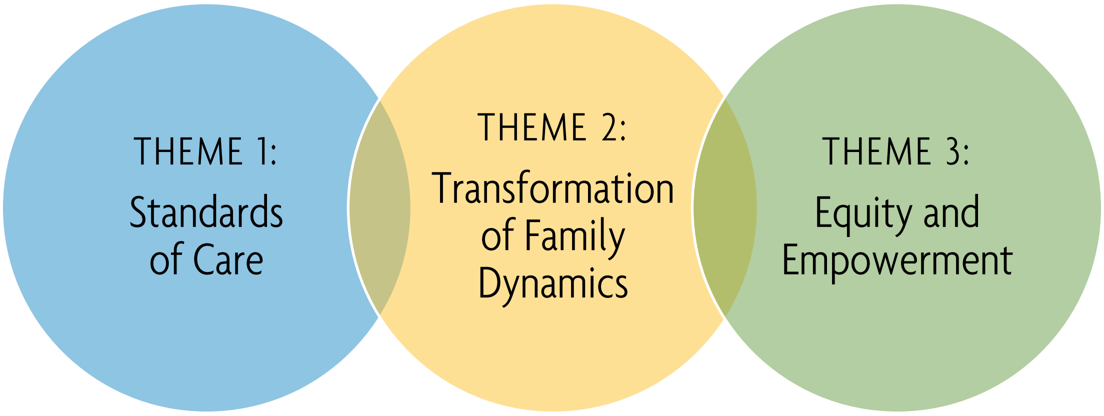
3.0 FINDINGS AND THEMES

Great care has been taken to ensure that the contents of this document are correct and representative of participants. The Foundation must be aware that this data set is not representative of all families using their services and therefore cannot be used as a complete record of activity of the service. The findings and information contained in this document are intended for general use only. Use of material in this report must be appropriately acknowledged. © Coventry University, 2017.

Key Themes

The purpose of data analysis regardless of method was to dive deep into the emerging evidence and elicit meaning, which was, an integral part of the overall design. Moreover, the process of data analysis occurred within and across each phase of the evaluation and, as the evaluation employed mixed methods, data analysis it therefore enjoined quantitative and qualitative analysis procedures.

Therefore, the ongoing process of data analysis at each phase of data collection, contributed to the continual systematic management and organisation of data, which were fundamental to accessing and retrieving data for triangulation and refinement, and development of the major themes. Moreover, meticulous attention to the organisation of raw data and record keeping contributed to the audit trail of evidence associated with this evaluation. The emerging findings revealed that the central thread throughout the data was that of 'child and family centred care', and three major overarching themes emerged as:



These themes will be discussed in more detail in the next section of this report and key findings will be included.

Introducing Specialist Liaison Nurse
JOANNE DOYLE

I am honoured to work with families at what is perceived to be the most difficult time in their lives. My role involves caring for the entire family, coping with the burden of care and the responsibility that it brings to that family. This often extends into the support of parents at the end of their child's life, into bereavement, and, I am with them to assist them with moving forward in their lives. I never imagined that I would be working with such varied healthcare professionals and agencies, working together in collaboration to help provide the best care possible for children and their families. People often ask, "How do you do your job?" and if I was to answer that question honestly, I would say "I don't actually know!", but I do know I've managed to achieve things I thought I never would and it is worthwhile, rewarding, challenging, always new and meaningful".

3.1 THEME 1: STANDARDS OF CARE

Caring for sick children demands a highly specialised body of knowledge and skills as children change dynamically during growth and development through to maturity. Evidence from the focus groups highlighted a disparity and concern relating to non-paediatric Specialist Liaison Nurses and other valued health professionals who have little experience of the effects of complex life-limiting neurological pathology upon the child. Fundamentally the Jack & Jill Specialist Liaison Nurses understood paediatric developmental physiology and anatomy, growth and development, coupled with policy. The Specialist Liaison Nurses hold a registered paediatric qualification(s) and essential experience of caring for children with life-limiting or complex care needs. Furthermore, as the Jack & Jill Children's Foundation continue to evolve several of the Specialist Liaison Nurses' are graduates with an MSc awarded in paediatric palliative care and other relevant qualifications (for example MSc award in bereavement). This in turn facilitates the Specialist Liaison Nurses' to utilise their knowledge and teaching skills to reinforce care interventions adopted by the carers in hospital or be taught new interventions as the child's condition demands. It is that practical and successful dissemination of these technical skills in combination with the home Nurses that provides effective care. One parent suggested:

> The liaison nurse is a counsellor, a 'trained' person, they do it automatically and with such ease. The whole thing, even talking to my other two boys when they are there, the role is immense, I don't know how they do it' (LFG).

Upholding professional standards is the cornerstone of quality care delivery to children and their families with qualified staff, registered with The Nursing and Midwifery Board of Ireland (NMBI). Qualified nurses have a duty to adhere to the principles outlined in the Code of Professional Conduct and Ethics for Nurses and Registered Midwives (NMBI 2014) www.nmbi.ie›Standards-Guidance).

The two main objectives enshrined in the Code are:

1. To protect the public.
2. Ensure the dignity of nursing and midwifery practice.

Furthermore, the Code is based upon five underpinning principles, which govern the following areas of care delivery:

1. Respect for the dignity of the person.
2. Professional responsibility and accountability.
3. Quality of practice.
4. Trust and confidentiality.
5. Collaboration with others.

The Jack & Jill Children's Foundation prides itself on its model of care and its ability to provide respite care at home. When asked if the Nurses found their model of care was effective 97% agreed that the model of care used was effective. The key successful ingredient to the Jack & Jill Children's Foundation's model of care is that it is truly centred on the child and family. There is a unique team of twelve Specialist Liaison Nursing Staff who co-ordinate an extensive range of nursing care at home to provide the families with the best quality of life while caring for their child at home. This often includes:

- Offering home visits.
- Providing practical advice on nursing issues and how to access the services the child will need.
- Sharing information and advice on entitlements and benefits.
- Lobbying the Government and the Health Service Executive on the family's behalf.
- Listening to what the parents want for their child and making representations on their behalf.
- Providing bereavement support following the death of their child.

Therefore, in delivering individualised holistic care to children and families within the service framework and their philosophy, the role of the Specialist Liaison Nurse and the fundamental role components can be captured.

Theme 1: Key Headlines STANDARDS OF CARE
The complexity of the unique needs of the children and families is difficult to capture. Children and their families must be retained at the epicentre of care.
The online surveys and round table discussions provided positive evidence that the service provided by the Jack & Jill Children's Foundation is of a high standard and quality.
Endure the challenges with commissioning for effective care and service delivery.
Facilitate a collaborative approach and support between the Jack & Jill Foundation and other agencies, ensuring seamless support is provided across the multi-agency services including effective co-ordination.
Regular meetings between the Specialist Liaison Nurses and Allied Health Professionals are required.
The Jack & Jill model of care should be used as an exemplar for other services.

Introducing Specialist Liaison Nurse
MARY JOE GUILFOYLE

When I was offered the job as the first liaison nurse at the Jack & Jill Foundation, I jumped at the opportunity and relished the challenge. Jonathan respected my professional judgement and gave me total freedom and permission to develop the nursing service to meet the needs of children and their families like never seen before in Ireland. I love every day that I spend out in family homes, listening to parents, meeting their beautiful children and offering what support and information I can and setting up some practical respite for them. Our model is simple and tries to support the child and family on an individual basis and reflects that every family is unique and the rhythm of every household different. This is what gives me such job satisfaction and what has fuelled me for the last 20 years.
I feel very privileged to be part of and to represent an organisation that can provide such support to children and their families.

3.2 THEME 2: TRANSFORMATION IN FAMILY DYNAMICS

The philosophical driver for care delivery focuses upon the ubiquitous relationship between the child and the family as a central functional unit, and is founded upon the principles of partnership, empowerment, advocacy and negotiation with healthcare providers. Currently coming under intense professional scrutiny (Shields 2017), child and family centred care as a philosophy still holds favour for parents whose child is cared for by the Jack & Jill Nurses, and anecdotally is endorsed as indicated by the following comment;

> “Only for Jack & Jill we would have been lost as a family” (CFG).

A key objective of the Jack & Jill Children’s Foundation is to preserve family life. As explored and stated previously, the child is at the centre of care with family members and carers being supported by the Jack & Jill Foundation Specialist Liaison Nurses and Nursing staff. The four focus groups produced a tangible correlation between recurrent and fundamental aspects of child and family-centred care, and the perceived success of the service delivered by Jack & Jill nurses. All four focus groups (FG), Cork (CFG), Dublin (DFG), Limerick (LFG) and Galway (GFG) provided emotive, informative and structured responses to the trigger questions. The specialist care, specialist knowledge in understanding dynamic paediatric anatomy and physiology, paediatric pathology and pathogenesis are heralded as critical issues in the success of care outcomes by family groups. For the purpose of this service evaluation the family unit consists of the child, parent/s, siblings and extended family members whether this is grandparents, aunts, uncles and other family attachments. Through focus group discussion, there is high value placed upon this acumen and specialist knowledge-base assigned to assessing and fulfilling the needs of the family group.

From the outset, the pilot group made it clear that the Specialist Liaison Nurses attempt to empower parents to gain control in their newfound circumstances. They encourage the parents and family to recognize their attributes and strengths and subsequently increase their confidence to manage this new extraordinary and at times unpredictable journey that they have embarked upon with their child. There is an acknowledgement that this care delivery is absent in many parts of Ireland, that the ‘home’ is central to a family’s security and well-being (Hannah and Gibson 2005). This specialist care is effective and economically viable (Normand and Revill 2010), although paradoxically the need to be at ‘home and normal’ is often undermined by the lack of specialist care and lack of specialist outreach services. Through the lens of the Jack & Jill Children’s Foundation and through the eyes of these parents, the Specialist Liaison Nurses co-ordinate and direct care ensuring that each individual family member is supported. This trust and relationship is highlighted by a parent from the Dublin focus group:

> “As long as we live we will be promoting Jack & Jill and doing everything, as we know what the service does for a family. We realize how much they do for families, relationships, your marriage and your own sanity. I can trust the nurse to know that she will look after my family” (DFG).

Understanding the needs of the family and responding to their needs is unique because every child is different; every family has varying needs and the level and type of support afforded to them. Regardless of the 'care provision package' and intervention by child welfare services and the HSE, it has to be acknowledged that caring for a child with life-limiting conditions and in some cases deteriorating health, places immeasurable and sustained strain upon the family unit. Our findings suggest that culture and society play an important part in determining the support families receive from their own family units and child welfare services. At times, the structure and lack of support from child welfare services can be detrimental and contributes to what may have become 'fragile' family circumstance and therefore is at risk of undermining family life rather than working in collaboration with the family to preserve some order to family life. One parent from the Cork focus group captured this by saying,

> "It has changed everything, it's nothing like you can imagine" (CFG).

Analysis of the data shared from all of the focus groups revealed that caring for a child with life limiting conditions has had an impact upon the relationships between each parent, relationship and dynamics with the sibling groups, and that there has been a changing landscape in the wider family dynamics.

> "To me the Jack and Jill Foundation, is not just caring for children, it is caring for families, caring for adults" (DFG).

So many stories were shared and one underlying concern is the impact upon not only the psychosocial challenges for the family, but also the effect upon the physical and mental health of the parents as the main carers.

> "Jack & Jill do so much more than just end of life care – they are there throughout their life not just at the end" (DFG).

During the focus groups, the respondents were encouraged to reflect in detail on how caring for their child has had an impact upon themselves and family life. The respondents shared their emotions and experiences, and a constant emerging issue throughout the data analysis was that **"it has changed my life completely"**(DFG). In the majority of cases at least one parent has had to give up work to become a full time carer. This in turn has placed financial strain upon the family and has a twofold effect; the mother has become isolated by being housebound and the father must bear the full responsibility of being the wage-earner. One mother shared the practicality of her situation when she said,

> "I have a husband working away up country and at any time I might have to ring him to say that our child is going into hospital and he will have to come home" (DCG).

Other parents praised Jack & Jill when they said,

> "It was the caring for us as a family and how it affects us and our extended family. Jack & Jill are like a second family to us" (DFG).

This was reflected across all of the focus groups and praise was given by parents about the reassurance that they were not undertaking this journey alone,

> "You're not on your own with Jack and Jill" (LFG).
>
> "It's about the little things, just like, checking in with you" (DFG).
>
> "Jack and Jill are passionate and show compassion, they know that time is of the essence" (DFG).

The Jack & Jill Children's Foundation provide direct funding to families of children with severe neurological developmental problems enabling them to purchase home respite care. The Foundation prides itself on being able to offer these children and their families 'the gift of time'.

The term 'time' can be interpreted in a variety of ways as it is not only the 'time' to spend at home with their child but also 'time' to undertake activities that we so often take for granted like shopping, looking after their other children, self-care and a well-needed break from the responsibilities associated with caring for their sick child or children. It was perceived by many of the parents that the hours **'gifted'** from the Jack & Jill Children's Foundation enabled them to engage with activities in and outside of the home environment.

It was articulated by several of the respondents that there is a misunderstanding and misconception of 'how they should be using the hours granted to them' (see overleaf).

Embedded within the parental responses is an evaluation of the way in which the service adheres to the emotional and psychological needs of the family and child. The family unit and extended members are faced with a myriad of adjustments and role confusion. Life progresses with uncertainty and incremental demands. The Home Nurse and Specialist Liaison Nurse are an intrinsic part of assisting and supporting the family through initial diagnosis, continuing care, transition to other services and through possible bereavement.

> "The Jack & Jill nurses' are passionate about their job. They carry us all emotionally and all the kids, our families and us." (P5).

THE FOLLOWING STATEMENTS DETAIL HOW SOME PARENTS ARE USING THEIR HOURS.

“Sometimes I just sit in my car and rest – it’s the only time I get to catch up on some much-needed sleep” (DFG)

“My hours give me the time to do all the paperwork that has to be completed for my child and the phone calls that have to be made to agencies for help” (CFG)

‘I use my hours to do all the jobs around the house’ (CFG)

“A round trip to collect equipment, medications and I might be able to grab a cup of coffee before driving home with all the resources” (GFG)

“I get to go down to the chemist, the shopping centre to do the grocery shopping; that is part of my fun time” (DFG)

“I can take my other son & help him with his homework, take him football training & swimming. It is so important when they grow older they will be able to say we could do what our friends could do” (GFG)

The recognition of individual members within the family and their coping strategies and emotional strengths and weaknesses are evaluated by certain parental responses,

> "The success for us has been around the social aspects of family living. They are aware of how the family functions, how you function as a mother, how you function as a father and how you function as a family unit" (LFG).

The experience of providing emotional support to many families and being able to guide and support others was seen as a strength of the Specialist Liaison Nurse, Home Nurse and wider service,

> "The Jack and Jill nurse used to meet us in hospital; the nurse was fantastic for advice. They gave us time to be a family, their knowledge from other families, other kids, other facilities that were available to you that you would not have thought of-and I thought that was worth its weight in gold" (DFG).

It is valid to surmise that from practical actions that facilitate seamless care delivery to direct emotional support for parents and carers the service provides an informal vital intervention. The Specialist Liaison Nurses are sometimes referred to as 'their counsellor' by some of the parents in the focus groups.

> "Sometimes doctors and nurses would give different opinions, and then the Jack & Jill nurse would come and she was a sounding board, someone you trusted, someone that you knew was on your side" (P11).

Throughout the data set families highlighted how through the model of care adopted by the charity, the Specialist Liaison Nurses go the extra mile to provide support for them. It was evident from the data that part of the reason for this was that they met not only the clinical care required for the child, but also the wide range of social, psychological and emotional needs of both the child and their family. In essence, they provide a true holistic model of care. This is highlighted in one parent's comments,

> "I constantly say that the Jack & Jill model is pretty perfect and simple" (P45).

This level of compassion and care does not go unnoticed by other health and care professionals. The care and compassion demonstrated is intrinsic in all of the nurses and Specialist Liaison Nurses working for the Jack & Jill Children's Foundation.

> "If you have your child in hospital, you can use your Jack and Jill hours for the nurse to come into the hospital so that you can go home to see her other children. It's amazing, the recognition that it is an important part of family life; that mum can go home, be there when the other children come home from school, cook their dinner and maybe come back to the hospital later that same night" (R5).

Maintaining family life is fundamental to the work of the charity. It is appreciated and clearly understood by the Jack & Jill Children's Foundation that when a child has a complex care need, time may also be limited and you have to be flexible and act and respond in a timely manner so that children and families are enabled to have quality time together and respect family life. One of the health and social care professionals captured this when they stated:

> "Jack and Jill have walked the walk and understand the needs of these children and families. Jack and Jill respectfully and safely, flex the rules and mould them in a way that is just where the families are at – I think that it is amazing" (R7).

Theme 2- Key Headlines
TRANSFORMATION IN FAMILY DYNAMICS

Jack & Jill Children's Foundation recognize the importance of parental wellbeing and the effect this can have on both the parents' holistic health and the child's emotional health and wellbeing.

Jack & Jill Children's Foundation continue to recognize the importance of good relationships with family, friends, nursing staff and others (as this is paramount in building resilience) and share this with other agencies involved with families.

Effects of direct and indirect costs falling on families with severely disabled children in the Republic of Ireland – whether their child is in hospital or not is recognised and where possible the Jack & Jill Children's Foundation assist the families.

Introducing Specialist Liaison Nurse
SHEILA HAYES

I enjoy working with the Jack & Jill team; each day is different and brings new challenges, with huge diversity. Although I am working with the foundation for a short period of time I find it fulfilling to witness the benefits of respite and the support afforded to the families by the Jack & Jill Children's Foundation.

I feel very privileged to be in a position to visit the children and families in their own home and to gain insight into their world of chronic illness plus or minus their disability. Alongside this, I love the relationship that develops with the families, especially getting to know the siblings as well as the child who has additional care needs. A deep trust develops over time with the families, which is unique, though, at the same time the relationship remains professional whilst maintaining boundaries.

I feel fortunate to be one of the team and it is humbling to be part of the journey with the children and families that I meet daily.

3.3 THEME 3: EQUITY AND EMPOWERMENT

Smith et al (2014) suggest that within the context of limited resources and population predictions costing the effectiveness of an alternative method of health care delivery is becoming more important as the demands upon services continue to grow. The economic evaluation of care delivery services to children, including palliative care, have been slow to develop and there remains paucity in the evidence base with a call to establish a national database. In 2010 the Department of Health and Children (DoHC) in Ireland established that there was no national data base therefore the numbers of children requiring care are unidentifiable (Hill and Coyne 2012). This was echoed within an International perspective as no country has a national database due to practical, ethical and financial challenges and it is suggested that the prevalence and numbers of children living with life-limiting conditions in Ireland is higher than estimated (Vousden 2017). Currently, non-acute services to the value of approximately €15million annually are provided by the Health Service Executive (HSE). This provision is made directly or through partnership working with voluntary and/or private services. This may be arranged by families/carers with funding provided by the HSE and/or not-for-profit organisations.

As indicated by the HSE (2014) there is the need for:

- The development and implementation of national policy and standard service development and service delivery frameworks for this client group.
- The provision of clarification regarding general and clinical governance in respect of the responsibilities and accountabilities of all service providers to this client group.
- Strengthening the discharge/transition processes between acute and community settings.
- Provision of a standard needs assessment tool that incorporates risk assessment.
- Standard approach to care planning and the development of the individualised care plan.
- Provision of training and continuous development of staff.
- Inclusion of a performance management process including clinical audit.

The Jack & Jill Children's Foundation as a registered charity strive towards achieving these indicators in their structure of services and care provision.

It has emerged from the data captured, that the role of a Specialist Liaison Nurse encompasses problem solving and liaising with hospitals, Physicians, Pharmacists, HSE, Public Health Nurses, disability services, charities and suppliers (amongst many others). Their role incorporates assessing the home environment and establishing what resources are required and ensuring that the logistics are in place to support the child and family. They are seen as enablers and every caseload requires assessment and careful planning. The children within the service often require specialist resources and specialist prescriptions. There is a huge responsibility placed upon families to collect equipment and supplies. The Specialist Liaison Nurse is able to give specialist and practical advice, liaising with pharmacies and providing equipment. One parent shared their experience,

> "My little girl was too big for her age and her cot, so she was entitled to a profile bed, but the HSE said you have to be a certain age. She is tall for her age. So, I had to intervene with the Jack &Jill Liaison Nurse and two days later the bed arrived" (GFG).

A disparity between rural and urban locations also emerged but parents are assured that agencies will always determine the availability and specialist knowledge of health services around the child. The Specialist Liaison Nurse seeks to overcome the logistical and resource issues that are evident. Several parents commented through the focus groups and online survey, the stark differences across the country, with one parent stating,

> "There is a difference from county to county and different suppliers. Across one area you might be able to order a month or 3 months at a time, but others will only allow you to order one week or one month at a time and that is it" (CFG).

Throughout the focus groups there was strong sense that the Specialist Liaison Nurse advocated for the child and families especially when navigating relationships with other health and Social Care professionals, and this was an emotive issue. Choice is a key underlining and fundamental right that the service protects and advocates for. The service seems reactive especially when action is time-critical as expressed by a parent,

> "Jack and Jill came to us in the 10 days before he died, the HSE would not let us discharge him from hospital as they said it was an unsafe discharge, other agencies couldn't help because they couldn't move quickly enough. Jack & Jill nurse came to the hospital and said we will get him home. We are grateful obviously that we got to bring him home" (DFG).

Introducing Specialist Liaison Nurse
CATHY KEIGHERY

I love working for Jack and Jill because I have autonomy with my case load and my working hours, which allows me to keep the families and their needs at the centre of my working day. It also gives me the flexibility to spend time with the family, as they need it and to work around their schedules and appointments to the best of my ability. The days can be very varied and this type of job keeps you on your toes and alert at all times to the ever-changing needs of families.

Jack and Jill has been both the absolute most satisfying and challenging job of my career to date. I feel it is a privilege to work with these families at what can be the worst and best moments of their life.

The awareness of a family's journey up to the point of referral or first point of contact seems to allow the Specialist Liaison Nurses to co-ordinate and engage services effectively. Although there seemed to be some disparity in relation to the awareness of the service by some healthcare staff,

> "We got home and the Jack & Jill liaison nurse arrived at our house. That was it; she was the first person to talk some sense to us. The hospital staff, whilst being lovely were completely disconnected, a simple phone call would have pulled the services together. The Consultant Neonatologist did not know about Jack & Jill. There is a huge knowledge gap, from Consultants right down to any level of medical staff, about Jack and Jill" (LFG).

The frustration and upset highlighted by many parents in relation to the administration of medical cards and the word **'fighting'** for services is seen as strong within all focus groups. The Specialist Liaison Nurses provide advocacy, direction, negotiation and co-ordination of services. As one parent highlighted that they had fought for a medical card and "**they couldn't understand how they were surviving on so little money**." (CFG). Other parents shared similar statements,

> "They would (the Liaison Nurse) make phone calls for us when we have issues. If you are stuck the first person that pops into your head is the Liaison Nurse, you don't necessarily want them to do it for you, but they will give advice on how to do it and who to contact" (LFG).

> "Eventually we got a medical card for my child, thanks to the Specialist Liaison Nurses and Jack and Jill team" (GFG).
>
> "The rights of the child are very specific; the rights of the disabled and sick child are not so clear" (DFG).

There is a perceived need for the Specialist Liaison Nurse to continue to advocate and join up services as there is an apparent lack of understanding.

> 'You realise what kind of gaps that are in the whole system and how it is disconnected. Why isn't everyone interlinking? Because it seems to me that the whole pathway could be so much smoother for everyone" (DFG).

The Jack & Jill Children's Foundation have had a long-standing battle with the Health Service Executive (HSE) regarding the sanction of medical cards for children with life-limiting conditions requiring care at home. They have, through the voice of Jonathan Irwin and others, been instrumental in the changing landscape in relation to the entitlement of medical cards for children receiving domiciliary care allowance in the Republic of Ireland. Medical cards are now automatically sanctioned to children requiring domiciliary care.

Theme 3: Key Headlines EQUITY AND EMPOWERMENT
Continued care with a focus upon building resilience and confidence to care for self and child.
Confusion and lack of knowledge over referral and role of the Jack & Jill Children's Foundation.
Financial threats: Ring-fence a National Paediatric Home Nursing Care Budget, to relieve the pressure on HSE.
Extra funding to be provided to the Jack & Jill Children's Foundation, particularly in relation to end-of-life care. Use Jack & Jill Children's Foundation as the Pilot for "money following the patient" model.

Introducing Specialist Liaison Nurse
EILÍN NÍ MHURCHÚ

I love my work in Jack & Jill because I can make a difference to the lives of the families we support. Every day is different and I am learning all the time. It can be very challenging as every house you enter has such sadness, grieving for a healthy child and often-anticipatory grief for the limited life a child may have. Advocating for services can be soul destroying at times, as it can be such a bureaucratic nightmare. While my caseload has been very challenging cross covering a large geographical area in the past few years; I work with an amazing group of women who have supported me and kept me going, through much laughter and tears!
I feel very privileged to work for Jack & Jill.

3.4 ROUNDTABLE DISCUSSIONS

Findings from the Nurses

As part of the service evaluation, the team recognized that the Specialist Liaison Nursing team networked with a range of nursing staff that were employed to deliver the care at home to the child. It was therefore important to explore the configuration of the 'nursing team' and how they engaged with the Jack & Jill Children's Foundation. The nurses employed by the parents' through the Jack & Jill Children's Foundation are invaluable not only to the Foundation but to the children and their families. Working collaboratively with an identified Specialist Liaison Nurse from the charity, questions were formulated for the nurses and packaged into a secure online application (Bristol Online Survey, BOS). An invitation, which was linked, to the online survey was distributed to 102 nurses known to be engaged with providing nursing care through the arrangements proffered by the Jack & Jill Children's Foundation. The link to the questionnaire was shared in a two-part email system for security, and at regular intervals an electronic reminder was forwarded to the nurse whilst the short survey was open.

In total 31 (30%) of the nurses responded to the survey. The results of the online survey provided an insight into the geographical location of the nurses with the largest distribution of respondents being from County Dublin (33.3%). The mean distribution of the respondents represented County Cork (6.7%) and County Kildare (6.7%), County Tipperary (6.7%), County Waterford (6.7%) and County Wicklow (6.7%). It is not clear why the other geographical areas have not engaged with the survey.

Of the 31 respondents 33.3% indicated that they had been working with families linked with the respite services facilitated by the charity from between six months to fifteen years plus with the average length of employment being around 6-10 years.

The team were interested in how nurses became aware of the Jack & Jill Foundation and their employment opportunities. The responses revealed that 66.6% of the nurses became aware of the charity through their own work place, usually the tertiary care centres/hospitals. A further 16.7% of nurses indicated that it was 'word of mouth' and the remaining learnt about the Jack & Jill Children's Foundation through using social media such as Facebook.

Nursing children with complex care needs can be both challenging and rewarding. In order to support nursing staff with managing the challenges, the psychological and emotional wellbeing of the nurses should not be ignored. Various professional groups with the United Kingdom (UK) participate in a clinical supervision process, which can be a formal means of professional support to empower the clinician and ensure clinical governance (Pearce et al, 2013). The data from the nurses' survey reflected that 78% of the nurses felt supported by the Jack & Jill Liaison Nurses/team. From their responses, 84% felt able to raise any concerns with the Specialist Liaison Nurses/teams and only 13% received any clinical supervision from the Jack & Jill liaison nurse/team. The negative results may indicate that the nurses did not find it necessary to raise concerns to the Specialist Liaison Nurse/team or that clinical supervision was the role of the Jack & Jill liaison team. The employment status of the Jack & Jill nurse is one of 'self-employment' so therefore the role of clinical supervision may not be mandatory as a formal process through the Jack & Jill Children's Foundation. Clinical supervision provides an opportunity to reflect upon personal emotional wellbeing, identify personal needs and ensure effective working partnerships with an employee. It is also known to be effective when reviewing personal development goals, discussing case reviews, management plans and treatment plans (Gardner, McCutcheon and Fedrouk, 2010). From the nurses' responses, it is evident that clinical supervision is a process that they would like to be considered as one respondent voiced,

> "I would like to touch base with a Liaison Nurse" (N3).

Another nurse suggested that

> "…with each individual case, the Liaison Officer should seek a monthly / 6 monthly review with the nurse to ensure that both the client and nurse are happy" (N22).

The Jack & Jill Children's Foundation pride themselves on their model of care and their ability to provide respite care at home. When asked if the nurses found their model of care was effective 97% agreed that the model of care used was effective. However, suggestions were given as to how the current Jack & Jill model could be improved. The responses represent improvements for the child and their family, and the nurse delivering the care and service.

A vast amount of material reiterated the same messages from both the Bristol Online Surveys (BOS) responses received from nurses and parents. Both were satisfied that the Jack & Jill Children's Foundation provide:

- Immediate nursing care in the home with no cost to the family.
- The parents have the opportunity to remain at home with the support of nurses with experience and competence in caring for a child with complex and/or palliative care needs.
- Opportunity to support and build the parents' confidence to care for their child and receive invaluable emotional support for the family.
- The provision of flexible, family-centred care with the child as the main focus.
- Nurses caring for the child at home to witness how they are all coping and managing with the situation and immediately access further support needed on an individual basis for appropriate care.
- Opportunity to build up a rapport and good professional relationship with the family and one that develops into a trusting relationship resulting in effective management of the needs for both the child and their family.
- Continuity of care and consistency of care from a nurse that is known to the child and family, someone who is not a stranger to them.

Whilst the commentary is encouraging, several of the nurses indicated that they would like to meet on a six-monthly basis with the Specialist Liaison Nurse or more frequently to review their caseload. Generally, the majority of nurses felt that the flexible working hours were a positive and that they received good, ongoing support from the Specialist Liaison Nurse when contacted. The overall sentiment from the nurses' survey is captured by one statement, “I feel privileged in the work that I carry out for families in need of the support of the Jack and Jill Foundation” (N28).

It is evident from triangulating the data captured that the children and their families appreciate the hard work and dedication of the nursing teams across the Jack & Jill Children’s Foundation. This is summarized by one mother’s comment,

“I thought my nurse was a fairy godmother, each time that we were in hospital she appeared, she knew what to say, what to explain, hold your hand and kind of just tell you things are going to be OK. They visit your home, they are part of your life, part of your family” (DFG).

Conversations with Health and Social Care professionals

Children who require palliative care or possess complex health needs can be cared for in a variety of settings: at home, in hospital, in a children’s hospice and across day services and other settings during their age and disease trajectory. The Jack & Jill Children’s Foundation pride themselves on working in collaboration not only with parents and families but also with all health and social care professionals involved in the care around the child and family.

Conversations with the health and social care professionals intimated that they valued the professional approach from the Jack & Jill Specialist Liaison Nurses and the collaborative working practice that has been adopted.

From these conversations praise was given for how the Jack & Jill Children’s Foundation were respectful to each family they encountered, provide exceptional support and empower them and renew confidence in parents’ ability to care. What was resonant with the respondents from the roundtable discussion was their perception of how the Specialist Liaison Nurses from the charity provided seamless care, stood by the families, walked the same journey beside the families and when required carried them through the challenges they faced. Several respondents agreed that the Jack & Jill nurses;

“...walk alongside the parent and help them through the process” (R4).

All parties involved those delivering the services of the Jack & Jill Children's Foundation, and those working in collaboration with them found each other to have a positive working attitude, competence, knowledge, flexibility and were accessible to meet the needs of the child and family.

It was important to have a named Specialist Liaison Nurse from the Jack & Jill Children's Foundation to ensure continuity and consistency with both the Health and Social Care professionals and knowledge of the family as this forged strong links, familiarity, support and trust.

> "I have regular interdisciplinary meetings throughout the year and we often plan to meet up to discuss certain cases outside of these scheduled meetings" (R3).

All of the health care professionals praised the Jack & Jill Children's Foundation teams for meeting the family and child in the hospital, one respondent states,

> "one of the great assets of Jack and Jill is that they will come into the hospital" (R3).

This personal touch prior to transfer home is welcomed by all parties to initiate the relationship-building, and plan for individualized care. One message that has been repeated is that,

> "they always make the transition from a difficult, stressful crisis in the hospital to a more settled situation at home and are key to reconstructing the family at home" (R5).

Introducing Specialist Liaison Nurse
RHONA KETT SHERIDAN

Rhona was a member of the nursing team in Jack and Jill since 2002. She took on her role with passion and determination to get the best for the families she supported. Rhona was a wonderful advocate and had a feisty energy about her, she left no stone unturned in her resolve to gain services and support for families. Rhona was an inspiration to all and has been described by those she cared for as “a bridge between falling apart and coping”, a light in a darkened room”, and a “most remarkable person”. Rhona always showed great courage and determination, especially with her battle against cancer. She was a beautiful lady, full of life and fun and will always be remembered in our hearts.

Several elements of good practice were raised, reinforced and reiterated during the round table discussion. These can be captured as follows:

- The Specialist Liaison Nurses and home Nursing team are very accessible, responsive and flexible.

- The Specialist Liaison Nurses always advocate for the family, understand and are aware of the family dynamics, health status of the child and what they need.

- The Jack & Jill Children's Foundation strives to be pragmatic and set realistic expectations with families.

- Continuity of a Jack & Jill Specialist Liaison Nurse is positive for both the families and professionals and enhances the synergy between all parties.

It is evident that there is a high level of respect for the Jack & Jill Children's Foundation and the work that they do with the health and social care teams that they encounter. However, several frustrations were voiced in relation to certain challenges and less highly rated elements of care provision. These included:

- The HSE are slow at processing the funding for care at home and this many take several months. When the child meets the criteria for the Jack & Jill services and a referral can be made, then, regardless of the funding arrangements, the Specialist Liaison Nurses are drafted in and are onboard, and funding is dealt with at a later stage.

- A package of care from the HSE appears to be quite a different experience as they are reliant upon using agency nurses and this impacts upon quality and continuity of carer for the child.

- Discourse arises when the child has to graduate from the Jack & Jill Foundation at the age of 4 years. It would appear from the discussion that children surviving past this age would benefit from measures to ease their transition to school and reduce the burden. There was a consensus that 6 years of age would be a more suitable age to graduate.

Introducing Specialist Liaison Nurse
MARGARET NAUGHTON

When I was approached by my colleague who had been involved in setting up the Jack and Jill Foundation I was excited by the concept of a home-based nursing service as this was something new to Ireland at that time. I like the "can do" attitude that permeates the workplace. The work ethic is exemplary with both the office and nursing staff. I like the immediacy of decision making, the lack of bureaucracy and the autonomy I am given to carry out my case load. I am fortunate to be surrounded by a team of highly motivated and supportive people who are passionate for what they do, and am confident that the families we deal with are treated efficiently and with respect and courtesy. The awareness of our Foundation in the community and the high regard for the work we do is wonderful, and I feel very proud to be part of something that works well.

3.5 MOVING FORWARD: RAISING THE PROFILE OF THE JACK & JILL CHILDREN'S FOUNDATION

Three overriding themes emerged from all the data gathered with a reiteration that the Jack & Jill Children's Foundation need to raise their profile and have a stronger presence in social media and marketing.

Within the facilitation of the parental focus groups, it was apparent that the parents had a desire and wish to become more involved with the publicising of the service. In many responses, parents offered views, as they wanted to see the success and evolution of the service that had offered them so much. The various focus groups, through distinct commentary, highlighted that the service must amplify the important care and therapeutic interventions they facilitate and the way in which this benefits the lives of the children and families they support. One parent commented,

> "I don't think that any of us had heard about Jack and Jill. You would hear about them on the radio requesting second hand mobile phones, but not what they actually did" (GFG).

Within the focus groups, parents referred to and accessed the Jack & Jill Children's Foundation website and associated resources. Parents commented upon the terminology and language used. One parent remarked that 'brain injury or damage' is language that does not interpret well. They highlighted that most children 'were born with a brain that would not develop or function, so I think it is strange to use that language'. The addition of 'and neurological illness or disorders' would capture the breadth of the neurological pathology that the service encounters.

The focus groups determined that 'the enabling of children and families', 'the financial support provided in purchasing highly skilled nurses' and the 'emotional assistance and intervention delivered' is not transmitted and communicated effectively. The Jack & Jill Children's Foundation have previously commissioned 'A Cost and Outcomes Analysis of Alternative Models of Care for Young Children with Severe Disabilities in Ireland' (Normand, Revill 2010). This provides seminal analysis and must compliment a further study of the services' success in maintaining economically independent family groups, and the resultant economic output and locality impact of family groups. The service continues to provide an informal emotional and psychological intervention service for parents, other care providers' and siblings. Undoubtedly, without the service, the economic burden upon the State would be much greater in relation to mental health and loss of family function. The purpose and impact of the service therefore, has to be measured comprehensively and eclectically.

There are other more tangible and measurable outcomes for the service that could be incorporated into the purpose of the service as they certainly do exist; admission prevention (AP) and early discharge (ED). There is of course an emotional and functional benefice to these measurements, but there is also a financial saving from professional endorsement. This is reflected in parents' commentary,

> ‘The medics would allow you to go home earlier, like in my case, even though we wouldn’t be so close to the hospital; we would have returned home every time, because we have a Jack and Jill Nurse at home.’

> ‘I’ve been sent home from A&E in the middle of the night because I have a Jack & Jill Nurse at home’.

> ‘There are a lot of times that if it wasn’t for knowing that the nurse was coming, we would have ended up in A&E when we didn’t necessarily have to be in there, because the nurse would be in the house and she’d be watching (the child’s condition) closely and giving reassurance’.

There is difficulty in capturing the qualitative impact upon families’ lives succinctly and how the purpose of the service is translated and measured by the families. Parents do this concisely:

> ‘I wanted people to understand what Jack and Jill is and what they do and how families like ours can’t live without them. I think that message needs to be brought out to the public a bit more’.

> ‘Laura Lynn are brilliant, they are great but they are a hospice and it’s around death unfortunately. Jack & Jill is about life and living and the quality of life’ (DFG).

The focus groups consisted of parents of ‘active children’, those that had graduated through the service (due to age) and some parents whose children had died. For all of these parents who have had individual experiences of service delivery, the passion for the Jack & Jill Children’s Foundation to enhance its media profile was evident. From referral pathways and professionals’ awareness of the service to public understanding and the communication of its function; this provided much discussion. One parent remarked:

> 'Generally, in Ireland I think everyone knows about an organization Jack and Jill. They have a brand, but that brand needs to be explored and exploited, people do not know who they are and what they are' (CFG).

It was important to remind the respondents that the services' overriding concern was not only to support children and families, but also to offer some protection from public exposure as a duty of care. This was almost entirely negated by the parents, with many parents expressing an overwhelming desire for exposure, and child and family involvement with marketing. These findings actually mirror a '25-year service evaluation' of the charity 'Dreams Come True' by Galinsky (2014). Within the evaluation, nominal group technique was employed, parents overwhelmingly highlighted marketing and profile considerations. The evaluation sought the views of 10 parents and 18 health professionals, the health professionals stated that there was 'more money and time needed for marketing and communications'. This was substantiated by parents who stated there needed to be a 'bigger public profile', 'adapted marketing materials to reflect family and key informant views', and 'better fundraising practices' with 'enhanced fundraising with existing parents'.

The focus groups echoed these earlier findings and used words such as exploit and explore:

> 'The Jack and Jill service is exceptional and they need to have more personal stories to exploit, personal stories: like, you have helped this baby come home this Christmas. You have helped this family go to a family wedding.'

Parents discussed the need to utilise television as a medium to facilitate a commissioned documentary to detail the lives of children and families and highlight the impact of the service. The parents asserted that they actively wished to share and disseminate their stories as real lived-in experiences and what this meant to families living on a day-to-day basis. They discussed the communication strategies when utilising a variety of methods including television and radio. They suggested the use of an alternative on-line newsletter and the need for the current newsletter to reach people outside of those using the Jack & Jill Children's Foundation as they commented,

> 'A paper newsletter is coming to people that already know about them, rather than those who don't.... a newsletter online should be enough and more user friendly' (CFG).

Introducing Specialist Liaison Nurse
SAUNDRA NOLAN

Working for the Jack & Jill Children's Foundation is hugely rewarding. It is a great privilege to work for the amazing families I have met over the years. Each one has taught me something and I continue to learn from them. Needless to say, there are some very sad, difficult days when families lose a precious child. Being there after a loss is just as important as before. I remain inspired by families when they speak so highly of how the nurses make a difference to their lives. The work that we do enables parent's time to breathe and time to do 'normal things'. The ethos of the Charity, thankfully, has not changed in 20 years. We work for and on behalf of families, providing home respite and advocating for them when needed. They are the very core of what we do. Families with sick children face so many challenges, especially in the early years and our service offers a support system that helps them navigate their way.

The parents overriding desire was for the amplification of the impact of the services offered by the Jack & Jill Children's Foundation. This impact needed a multi-media approach that was enhanced, and the families wanted to have an explicit role in developing this strategy. One parent enthusiastically stated how social media could be used to raise the profile of the Jack & Jill Children's Foundation,

> 'They could be all over Facebook, Snapchat, and Instagram. Look long term rather than short term' (GFG).

The focus groups wanted Ireland to understand how Jack & Jill enabled the family, responded to, cared for and supported all of them. Initially this may be best addressed with the creation of a parent forum (Galinsky 2014) in conjunction with the Specialist Liaison Nurses to identify and facilitate participants in such strategies.

Building upon the ethos of the Jack & Jill Children's Foundation the team have developed a unique framework of care. When you take the time to listen to the Specialist Liaison Nurses explain the holistic care they provide to children and families they reflect the fundamental values of care, compassion, competence, communication, courage and commitment as seen in the 6 C's (NHS, 2012). This is the corporate strategy of the Foundation and although challenges and at times conflicts can compromise or threaten their intentions the standards and quality of care are always their priority. They appear to make every contact with the children and families count, as each member of the team shares responsibility and accountability for the quality of care delivered. Emerging from the discussions with a group of Specialist Liaison Nurses, a new nursing framework 'Rainbow of Care' has been developed.

(Adapted by Doyle, J and Clay C, 2017)

Within this RAINBOW OF CARE the core aspects of what the Jack & Jill Children's Foundation provide to children and their families has been captured:

- RESPITE care at home is provided to families with children up to the age of 4, with complex and/or palliative care needs. Direct funding is given to families to enable them to purchase home respite care.

- ADVOCACY for entitlements, advice and information on how to access all the services the child may require. Listening to what parents and families want for their child and making representation on their behalf. When necessary the Specialist Liaison Nurses will lobby Government, HSE and other agencies on the behalf of children and their families.

- INTERDISCIPLINARY WORK with a range of health and social care professionals to ensure that children and their families receive the best care and quality of life.

- NURSING CARE at home coordinated by a Specialist Liaison Nurse located across all of the Republic of Ireland. Individualized nursing care and advice on how to care for a child at home is fundamental.

- BEREAVEMENT support and follow-up from the team.

- FAMILY CENTRED CARE is at the core of our care for children and their families.

- WORKING TOGETHER with families as a team through the trajectory of the child's illness and challenges encountered. Walk alongside the parents and help them navigate through the process and procedures. The key points related to moving forward are captured below.

MOVING FORWARD Raising the profile of The Jack & Jill Children's Foundation
Develop a Parent Forum - parents welcome opportunities to communicate and/or meet with other families in similar circumstances.
As the majority indicated that they were 'housebound' they said that they would like to network through internet based social media.
Raise the profile of specialist care, palliation and end-of-life care for children through social media (and other contemporary social media methods).
Embed the 'Rainbow of Care' framework to ensure that a high standard and quality of care is always achieved for children and their families.

Introducing Specialist Liaison Nurse
ANN REILLY

One of the best parts of my job is meeting parents, and offering them in-home respite, that we both know will make such a huge difference to their family life, and offering it with no conditions or paybacks. I undertake my duties with compassion and am mindful that every child deserves to be cared for, not just nursed. I always consider what I would want for my own child, and this is what I try to give to my special little Jack and Jill children.

I feel extremely lucky and privileged to be part of this fantastic Foundation. I will always be proud to say I am a Specialist Children's Liaison Nurse with Jack and Jill. Not many people get to say that they love their job and are proud of what they do. I am one of those few, who can.

4.0 RECOMMENDATIONS

The overarching aim of this service evaluation has been to evaluate the impact of the service provided by the Jack & Jill Children's Foundation upon the children and their families. In addition to this, recommendations for future practice have been included. The findings, which support this review, are important to inform ongoing developments, strategic direction and sustainability of the Jack & Jill Foundation and as such the following recommendations have been identified:

That the Jack & Jill Specialist Liaison Nurses should:

1. Continue to develop strategic relationships with other partnerships through which services are delivered.

2. Ensure that they maintain their clinical skills and maintain competency relevant to the needs of the children in their care and extend this to the nurses caring for the children at home.

3. Continue to work with all relevant stakeholders in order to ensure that the commissioning of services and fiscal arrangements have a clear focus upon the child and their family.

4. Assure them that nursing professionals providing care to their children and families at home are able to access support in the form of supervision or in a manner that is responsive to the needs of both the nurse and their clients.

And further recommendations are:

5. Consider new ways of supporting parents through social media, support groups and encourage the emergence of 'parent or family champions' within each geographical location across the Republic of Ireland.

6. For the Foundation to develop and embed their ethos and framework of care to include the 'Rainbow of Care' that reflects children and family centred care.

In addition, two further important recommendations have been drawn from the data. These are Governmental considerations when reviewing the support for children with life-limiting conditions:

7. Funding to be provided to ensure 24-hour nursing care in the home for children who require palliative and end-of-life care.

8. Services should be funded to enable the upper age of the child, currently 0-4 years of age to be extended and increased up to 6 years of age, in line with the Republic of Ireland's early year's strategy, and previous recommendations.

Introducing Specialist Liaison Nurse
CAROLINE THOMAS

I thoroughly enjoy being part of the Jack & Jill nursing team; a unique and special team, they are all colleagues and friends. I wholeheartedly believe in our service, one that permits respite and quality time for families to care for their child at home. No two days are the same working with Jack & Jill families. My diary is never dull or boring and my schedule is constantly changing to meet and respond to the needs of the families. There is a saying that it is in giving we receive. I know when I meet a family for the first time I have something to offer them, show them kindness and compassion. I am honoured to be a part of their journey in caring for their child during their life trajectory. I realise at this stage in my life I probably won't become a millionaire but have I can affirm that I have developed a wealth of experience and knowledge that no money can buy.

5.0 CONCLUSION

The Jack & Jill Children's Foundation Home Nursing service has made a significant difference to the lives of many families across all of the twenty-six counties in the Republic of Ireland. Their tag line 'no care like home care' is apt as it is evident through this service evaluation that they endeavour to help improve the lives of families caring for children with complex and palliative care needs by engaging with the child and family to empower them and give them the choice of care at home.

The service evaluation revealed a series of recurring and related themes within the data set. The main focus of this service evaluation was to capture the voice of the families and their perceptions and experiences with the Jack & Jill Children's Foundation. This element was considered from the view point of both the parents and the Jack & Jill nurses and provides a platform for the Foundation to move forward with any future developments. Analysis of the data, indicate that the Jack & Jill Children's Foundation work relentlessly to ensure that the children are cared for at home enabling the continuation of family life and inclusion within their communities.

It is evident from the data captured that the Specialist Liaison Nurses and the team around the child and family at home have taken on significant roles as child and family advocates. Each team works in close partnership with parents, empowering them to take control of their situations and circumstances. The data captured from parents in this service evaluation shines a light on the challenges and barriers faced by parents but it does not fully demonstrate how many of the parents, supported by the Jack & Jill nurses, have become experts in their child's care. It has, however, provided a rich insight into the fragility of their world and experiences. It has to be remembered that these parents are caring for their children throughout the 24-hour day, every day, from the onset of diagnosis, and have ongoing healthcare needs that require nursing intervention and support.

Returning to the key themes it is admirable how the Jack & Jill Children's Foundation impacts upon and transfigures family life. This normalisation of the family and approach to care delivery is a continuous thread within the focus groups, surveys and roundtable discussions. The Specialist Liaison Nurses' provide an important first point of contact and the nurse-family relationship becomes essential as specialist care continues to be delivered. Some parents see this relationship as a functional transaction, but the majority of parents see this relationship as dynamic and punctuated with care, consideration and understanding. The services' relationship with the parents, sibling(s) and extended family members becomes an essential care component.

From listening to the voice of the families, health and social care professionals a resounding message for the charity is that they need to continue their work with the aim to improve the support for families and ensure that services are centred on the child and their family and not on processes and funding streams.

This unique relationship and insight into the family at such a vulnerable juncture affords the team an opportunity to address the needs not only of the child but the family. This facilitative, informal psychosocial support appears to be another unique and highly valued (by nurses and families) service attribute. It demonstrates that the humanistic requirements satisfied through care, confidence and trust that are mediated through specialist skills and knowledge. The services amalgamate the scientific demands and nature of nursing with the art and skill of nursing.

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7.0 APPENDICES

Appendix 1 – Participant Information

Jack & Jill Foundation Service Evaluation

1. Title of Project

Evaluating the delivery of care to children with complex health needs and their families: A Service Evaluation.

2. Purpose of the project

The overall aim of the project is to evaluate the effectiveness and efficiency of current practice and services delivered by Jack & Jill Foundation

3. Why have you been chosen?

You have been chosen as you have either have had use or still use the nursing services of the Jack & Jill Foundation.

4. Do I have to take part in the service evaluation?

It is up to you to decide whether or not you would like to take part in the service evaluation. If you do decide to take part you will be given this information sheet to retain and be asked to sign a consent form. Even if you decide to take part you are free to withdraw at any time without providing a reason. The decision to withdraw at any time, or not to take part in the service evaluation will not affect your current use and care package from the Jack & Jill Foundation.

5. What do I have to do?

Participants will be invited to join a bespoke focus group, which will be facilitated, by one of the Jack & Jill Liaison nurses and researches from Coventry University. The focus group is expected to last up to two hours. The purpose of this is for the researcher to capture in your words your experience of using the Jack & Jill Foundation. Permission will be sought to have the discussion recorded for data capture only.

During the focus group permission will be sought to have the discussion recorded. The audio recording will be of you talking about your experiences with learning and using mobile technologies. The purpose of this is for the researcher to be able to capture word for word the discussion and for recall of the information shared. These photos and/or audio recordings will become part of the data that will inform my project investigating how learners make use of mobile technology and with what consequences?

Only those persons you have agreed to will view or hear the recordings for the purpose of data analysis. The audio recordings will be stored securely within the researcher's place of work and be used for the period to which you have agreed.

After the agreed period of use, the recordings will be destroyed. You may withdraw your consent before, during and after the recording or ask for it to be edited if necessary. If you decide you are not happy for the recording to be used it will be destroyed. If you have consented to the use of the data recorded then once it has been retrieved, transcribed and analysed it will be destroyed appropriately.

6. Will my taking part in this service evaluation be kept confidential?

All information received from this service evaluation will be treated as confidential. Your name will not appear on the evaluation tool; instead a code number will identify your responses. Evaluation data will be input onto a datasheet that will only be accessed via the project team with a password.

7. What will happen to the results of the service evaluation?

The results of the service evaluation will be used to inform future planning decisions related to service provision and service improvement within the Jack & Jill Foundation. The data collected will be presented in a report to Coventry University and University of Dublin/Trinity College Dublin. If an opportunity arises the compiled report will be forwarded for publication in a relevant journal and disseminated at relevant conferences.

If you have any questions about this service evaluation please contact the designated members of the project team (contact details below).

Thank you for taking the time to read the information about the service evaluation and I hope that you consider joining the team for a focus group and/or completing a short survey/questionnaire.

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Appendix 2 - Guidance for Focus Group

Launch: You are invited to this focus group to share your views and experiences on using the nursing team and resources from Jack & Jill Foundation.
Thank participants for coming, tell them what to expect and how long they will be there (approximately 2 hours).

Housekeeping:

- **Ground rules**: confidentiality and respect, relaxed environment
- **Consent** forms for participation and recording will be available for the session.
- **Photos**: If willing and with consent the group will be encouraged to have a photo working as a group or to capture the ambiance in the room.
- **Recording**: Session will be recorded (with consent), as it will be later transcribed for recall purpose and in order to extrapolate the questions for the formal Focus groups and survey questionnaire.
- **Room setting**
  Arrangement of tables
  Equipment required: flip chart paper, flip chart marker pens, recording device

Activity 1 (10 minutes)
Icebreaker: each member of the evaluation team and participants should introduce themselves.
This will be led by one of the members of the evaluation team

Activity 2 (30-40 minutes)
Each group (if enough attendees) to share one piece of flip chart paper
Guide the parents to nominate a scribe
Give the trigger questions to the group and ask for thoughts, experiences, feelings, and statements to be captured on the flip charts.
Trigger questions for group:

From your experience can you explain:

1. What was good about the service?
2. What was not so good about the service?
3. How did you see the role of the Jack & Jill liaison nurse?
4. How did you see the role of the Jack & Jill nursing staff delivering care?
5. Was using Jack & Jill beneficial to your child and family?
6. What was the waiting time from referral to start of service?

7. Relationship with nursing team, was there effective communication?
8. How regular were the visits from the Jack & Jill team? Did you consider that you had enough visits?
9. What other agencies were involved in the care of your child and how well do you think they worked with the Jack & Jill team?
10. How did you store equipment (if needed)?
11. Did you find the funding arrangements for the Jack & Jill nursing team easy, straightforward or stressful?
12. Did you access respite hours from Jack & Jill and if so how long, how often etc?
13. Did you need any input from acute services and if so was this easily accessible for you?
14. Did you find the liaison nurse approachable if you needed to raise a complaint?
15. How much were the extended family supported and involved in the care of your child?
16. What other questions do you think are important to ask parents and users of the Jack & Jill team?

Refreshments (20-30 minutes)

Activity 3 (10 minutes)

The evaluation team will present the findings of activity 2 to the group. Prime questions to see if they agree with the emerging themes that have been identified as this will ensure that the information has been interpreted correctly.

Record with permission the discussion from this activity.

Refine the themes emerging, which will forge the questions for the formal focus group sessions and guide the survey questionnaires.

Feedback and Close (5 minutes)
Thank participants for coming and their contribution. Reinforce the importance of their input and how it will shape the service evaluation.

Appendix 3 – Survey for families

Jack & Jill Foundation: Service Evaluation Survey

Working in collaboration with the Jack & Jill Foundation, Coventry University are seeking to evaluate the services provided by the Foundation. We are keen to have the views and voice of children and their families so that we can evaluate if palliative and nursing care is being delivered in a way that meets the needs of the children and their families. The information that you provide will be treated in the strictest confidence and held on a secure Online Survey Database at Coventry University for the duration of the evaluation (approximately 12 months) and accessed only by the evaluation team. After this time, the information will be destroyed appropriately. The information is not shared with any other organization and will only be used to inform the evaluation and work of the Jack & Jill Foundation.

The number of children who need support is growing and we must ensure that their needs are understood from the time of diagnosis, throughout the child's life, death and beyond. We invite you to complete the following survey and take this opportunity to contribute to this important evaluation.

Gender: *choose an item*
Nationality: *choose an item*
Ethnic origin: *choose an item*
If selected other ethnic background please specify:
click here to enter text
Religion or belief: *choose an item*
Ethnicity/country of origin
click here to enter text
Relationship status: *choose an item*
Geographical location: *click here to enter text*

1. How were you referred to the Jack & Jill Foundation?
   Enter text……………………

2. Who is the main career for your child?
   Enter text……………………

3. Did you find the funding arrangements for the Jack & Jill services easy to access and manage?
   Enter text……………………

4. Did you feel that the number of hours allocated from the Jack & Jill service met your child's needs?
   Enter text……………………

5. How many hours were covered from the funding you received?
   Enter text………………………

6. How long have you used the Jack & Jill service?

7. How long following referral to Jack & Jill did you have to wait to be seen by a liaison nurse?

8. What other agencies were involved in the care of your child?

9. If you needed to would you know what to do if you were unhappy with the standard of support being provided?

10. Did the Jack & Jill team listen to the wishes of the family?

11. If you required equipment how did you source, collect and store the equipment?

12. Up to what age do you think Jack & Jill liaison nurses should be involved in providing care for your child?

13. Where would you prefer to have your child's care? At home, hospital or hospice.

14. What was good about the Jack & Jill service?

15. How could the Jack & Jill service be improved?

16. Did Jack & Jill provide a flexible family-centered service?

Thank you for taking the time to complete this survey. Your feedback is essential to our evaluation of the service.

Appendix 4 – Survey for nurses

Jack & Jill Foundation: Service Evaluation Survey (Nursing staff)

Working in collaboration with the Jack & Jill Foundation, Coventry University are seeking to evaluate the services provided by the Foundation. We are keen to have the views and voice of the nurses caring for the children and families using the service so that we can evaluate if palliative and nursing care is being delivered in a way that meets the needs of the children and their families.

The information that you provide will be treated in the strictest confidence and held on a secure Online Survey Database at Coventry University for the duration of the evaluation (approximately 12 months) and accessed only by the evaluation team. After this time, the information will be destroyed appropriately. The information is not shared with any other organization and will only be used to inform the evaluation and work of the Jack & Jill Foundation.

The number of children who need support is growing and we must ensure that their needs are understood from the time of diagnosis, throughout the child's life, death and beyond. We invite you to complete the following survey and take this opportunity to contribute to this important evaluation.

Gender: *Choose an item* Nationality: *choose an item*

Geographical location: *click here to enter text*

1. How long have you held your contract with the Jack & Jill Foundation?
   Enter text………………
2. How did you know about the Jack & Jill Foundation?
   Enter text………………
3. Did you find the employment arrangements for the Jack & Jill services easy to access and manage?
   Enter text………………
4. Did you feel supported by the Jack & Jill liaison nurses/team?
   Enter text………………
5. Do you feel able to raise any concerns with the Jack & Jill team?
   Enter text………………

6. Is the current Jack & Jill Foundation model of care effective?
   Enter text………………

7. Are you proud to represent the Jack & Jill Foundation?
   Enter text………………

8. Do you receive any clinical supervision from the Jack & Jill liaison nurse/team?
   Enter text………………

9. How could the Jack & Jill Foundation service be improved?
   Enter text………………

10. Did Jack & Jill provide a flexible family-centered service?
    Enter text………………

Thank you for taking the time to complete this survey.
Your feedback is essential to our evaluation of the service.

Appendix 5 – Responses from families

Service Evaluation Jack & Jill (users) responses

Summary of responses made to the BOS from parents

QUESTION	RESPONSE SUMMARY
How were you referred to the Jack & Jill Children's Foundation	The following responses (n=205) demonstrate most ways in which families were referred; - Hospital referral (133 responses) - Referral from social worker (17 responses) - Early intervention team (19 responses) - Self-referral (15 responses) - GP/Doctor (7 responses) - Public Health Nurse (9 responses) - Other (6 responses) Additional statements leading to a self-referral included: - Our daughters nurse suggested Jack & Jill to us and organised for us to meet the liaison nurse - Met another parent in hospital and she gave me the number for Jack & Jill - When my daughter was being transferred to hospital the ambulance driver told me about Jack & Jill
How long following referral did you have to wait to be contacted by a Specialist Liaison Nurse?	The average length of time that parents had to wait before being contacted by a specialist liaison nurse ranged between 1 day to 3 months. From 207 responses 102 parents indicated that contact was made within the first 2 days. - Before discharge home (6 responses) - A few days (102 responses) - 1-2 weeks (77 responses) - 3-4 weeks (20 responses) - 3 months (2 responses)
How long following referral did you have to wait before respite started?	The average length of time following referral that parents waited for respite care to commence varied; - Immediately as part of the discharge plan from hospital (20 responses) - Within 48 hours (47 responses) - 1 week (40 responses) - 2-4 weeks (65 responses) - 4-8 weeks (33 responses)
How many hours were covered from the funding (gift) you received from the Jack & Jill Children's Foundation	The gift of time in hours varied following assessment of the child's needs. The responses indicated these hours to be between 5-20 hours a week with some cases receiving more where and where required. - 5-10 hours per week (64 responses)

	- 11-15 hours per week (55 responses) - 16-20 hours per week (60 responses) - 21 hours + per week (26 responses)
Did you find the funding arrangements for the Jack & Jill Children's Foundation services easy to access and manage?	All respondents indicated that the funding arrangements were easy to access and manage. Additional comments have been captured as follows; The Jack & Jill office administrator is extremely prompt in replying to queries/questions It is easy but could do without the extra paperwork
Did you feel that the number of hours allocated were sufficient to provide care and respite to your child?	Parents are extremely grateful for the gift of time and hours allocated for them and the majority (160 respondents) felt that they had a sufficient amount of allocated hours
How long have you used or did you use the Jack & Jill Children's Foundation service?	In total 205 responses were received. The mean length of time that families use the services is 2-3 years with the service being used from between 2 days, a few weeks to four years; Less than 4 weeks = 12 responses 1 month – 5 months = 32 responses 6 months – 1 year = 24 responses 1-2 years = 49 responses 2-3 years = 45 responses 3-4 years = 43 responses
What other agencies are/were involved in the care of your child?	In addition to using the Foundation parents, identified the following as the main agencies involved in the care of their child. Out of 198 responses 35 parents indicated that they only used Jack & Jill Children's Foundation. Enable Ireland – 30 responses Early Intervention – 33 responses HSE – 39 responses Laura Lynn – 19 responses Other - 42
Did the Jack & Jill Specialist Liaison Nurse listen to the wishes of the family?	Yes – 204 responses No – 0 responses Other – 1 response
If you were unhappy with the standard of support being provided would you know how to raise a complaint?	Yes – 143 responses No – 42 responses Other – 13 responses Additional comments include, - We never had any reason to complain

	- I was never unhappy with the service to warrant a complaint - Never needed to complain as the service is fabulous
Where would you prefer to have your child's care?	At home – 199 responses (97.1%) Hospital – 0 responses Hospice – 2 responses Other – 4 responses
Did the Jack & Jill Nurses provide a flexible child and family-centred service	Yes – 191 responses (95%) No – 0 responses Other – 9 responses
Up to what age do you think Jack & Jill liaison Nurses should be involved in providing care for your child?	0-4 years = 19 responses (9.3%) 0-6 years -= 51 response (25%) 0-16 years = 103 responses (50.5%) Other = 31 responses (15.2%) It depends on my child's needs as she grows and develops as right now it's very difficult to predict what the future hold for her condition. I know this purely inspirational but the service is excellent & more often as the child gets older the greater the needs of the child especially physical needs. It is very difficult to put an age limit on their services. I understand it would be impossible to care for each sick child indefinitely but to avail of such a brilliant service and then loose it because your child reaches a certain age would be a major blow to a family. I think until the families are comfortable to continue without Jack & Jill they should be able to avail of the service. We are so thankful to Jack & Jill for the hours we do have it's hard to demand how long they should care for my child. Ideally as long as required. As long as possible. It's an invaluable service and we will be lost without it. Nurses and liaison nurses really work with the family and are so flexible and supportive. Repetitive theme "For as long as the child requires it".

When asked what was good about the Jack & Jill Children's Foundation the majority of respondents offered an opinion. Here is a snapshot of what has been shared;

- Jack & Jill were amazing to my family. A Specialist Liaison Nurse arrived into my life when it was upside down. She provided endless support and was always just a phone call away.
- Our referral to Jack & Jill for respite was completely seamless & stress free.
- Without their organisation, I would never had been able to bring my daughter home where she was loved and cared for in her own home surrounded by her family.
- Every Jack & Jill Nurse we met has been highly trained, professional, helpful and extremely friendly. They are always happy and proud to work for the Foundation.
- The Nurse was really friendly and easy to talk to. She was experienced, professional and it was a pleasure to welcome her into our home.
- Having a qualified Nurse to take care of our child provided a much-needed break for us as parents without the feeling of guilt.
- Friendly, compassionate Nurses that gave us peace of mind, great home care.
- Gave us a chance to have good a night sleep and time to spend with our other children.
- Jack & Jill are an amazing service, the respite hours are often the glue that helps keep the family going, and we have excellent support for our Jack & Jill Specialist Liaison Nurse, especially at the start when things were so tough.
- Care, support and reassurance that my child is in good hands.
- The respite offered to me is invaluable - from an emotional & mental perspective, in particular. It also gives me guaranteed invaluable and uninterrupted time with my other young children.
- It was a great weight lifted off my mind.
- Friendly, compassionate nurses that gave us peace of mind, great home care.
- I started to live when they became involved. They changed everything; I would not have survived without them.
- It has changed my life, once a week for a few hours a weight is lifted off my shoulders and I can give my other children my undivided attention.
- My liaison nurse is always at the end of the phone when I need her.
- They have been there for us all the way and are of the backbone of support for the family.
- My Nurse is my guardian angel on earth. She provides me with so much help and support.
- Meeting Jonathan Irwin was the 'icing on the cake'.
- As parents and a family, we were drowning before Jack & Jill got involved, the practical advice is always welcomed from our Specialist Liaison Nurse.
- The level of care and service received from nurses and all the staff at Jack & Jill has been truly amazing. Everything they do is of a high standard.
- Knowing that I could contact a liaison nurse at any time day or night gave me peace of mind.
- Fantastic Nurses that support the family gives great advice and often just listen to your concerns making you feel that you are not on your own.
- Family friendly, family centred, kind and compassionate.
- Without Jack & Jill, we cannot function as a family.
- They are a lifeline when you are thrown into a world that you know nothing about!
- They offered respite care during the most stressful even in our lives. Without their support, there would have been a detrimental impact to our family unit. We are forever indebted to them.
- They are a constant companion to us.
- The service is flexible. When you have a sick child, you have to juggle when you need help as it could be more one week than another and this can be done with the Jack & Jill team.
- We feel privileged to have had this service.

How could the Jack & Jill Children's Foundation be improved?

Responses to this question were varied and not always directed toward the Foundation but the whole process from hospital to homecare. Key comments include;

- When the Specialist Liaison Nurse meet the family for the first contact that they explain their role rather than asking the family what they expect from the service.
- Increase the number of Nurses in rural locations.
- Increase the rate of pay for the Nurses.
- Increase the number of hours for nursing care.
- Extend the age criteria from 4 years to 6 years or even up to 12 years of age.
- Involve the parents/users more in promoting the services offered by the Jack & Jill Foundation.
- It would be great if they had a holiday house with nurses where you could experience a family holiday.
- Create a 'live database' for parents to access and see a list or make a request for available nurses at a time and day that suited the family.

"We have never expected anything and greatly appreciate being linked with the Jack & Jill Foundation and the support that they have given to us".

Appendix 6 – Responses from nurses

Summary of responses made to the BOS from nurses

QUESTION	RESPONSES
How long have you been working with families that are receiving respite services from Jack & Jill Children's Foundation?	In total, there were 31 responses. The following indicates the length of time working with the service: 0-2 years = 6 nurses 2-5 years = 4 nurses 6-10 years = 8 nurses 10+ years = 6 nurses
How did you find out about the Jack & Jill Children's Foundation?	The majority of Nurses were introduced to the Jack & Jill Children's Foundation through their workplace either as a paediatric nurse in an acute hospital setting or from a nursing agency. Others had been through media, social networking (Face book) or word of mouth from families using the Foundation.
Do you find the model of care that the Jack & Jill Children's Foundation use effective? Why?	The majority of the Nurses (97%) agreed that the model of care adopted by the Jack & Jill Children's Foundation is effective because: - The Nurses provide expert nursing care to children and their families in their home environment. - It is children centred. - It is rewarding and they build up a trusting relationship with families. - When working with families within their home you can establish the different dynamics and how identify how best you can provide the care the child and family need. - It offers a lifeline of support to families
Do you feel supported by the Jack & Jill Specialist Liaison Nurse/team? Do you feel able to raise a concern?	Of the Nurses asked 22 respondents (90.7%) felt supported by the specialist liaison nurse/team and able to raise any concerns whilst 3 respondents (9.4%) felt unsupported and unable to raise any concerns.
Do you receive any clinical supervision from the Jack & Jill Specialist Liaison Nurse/team?	Various mechanisms are available for Nurses registered with the professional body to receive supervision from their workplace. However, the majority of Nurses working as a representative and nurse for the Jack & Jill Children's Foundation do not receive supervision from the Specialist Liaison Nurses (27 respondents = 87.1%).
Do you think that Jack & Jill provide a flexible family-centred service?	The majority of Nurses (25 respondents = 78.1%) felt that the Foundation provided a flexible family-centred service. The remaining 7 respondents indicated that this was offered sometimes but were unable to add why this was the case.

<table>
<tr><td>How could the Jack & Jill service be improved?</td><td>When asked how the service could be improved the following suggestions were made:
- Support and ability to keep connected with the Specialist Liaison Nurse for each family.
- A monthly review with the Specialist Liaison Nurse and family to ensure that all parties are satisfied with support and care provision.
- More equity in the hours allocated to each family.
- Review the support and training for both the Nurses and parents in specialist skills.
- An annual meeting with the Specialist Liaison Nurses outlining the care packages, support and current entitlements for parents and families receiving domiciliary home care would be beneficial to keep up to date.
- Professional forums and meetings with the multi-disciplinary teams involved in the care of children with life limiting and palliative care needs to ensure that nursing staff are up to date with knowledge and planning for each case.
- Workshops and meet and greet with other Jack & Jill nurses to build the community of Nurses.
- De-briefing following the provision of end-of-life care at home with a family.
- Meetings with the specialist liaison nurse to discuss self-care and well-being of individual Nurses.
- Opportunity to meet as this role is often undertaken in isolation. Conversations about concerns and triumphs, sharing experiences with each other as a group.</td></tr>
<tr><td colspan="2">All nurses responding to the online survey indicated that they were proud to represent the Jack & Jill Children's Foundation.</td></tr>
</table>

No Care Like Home Care

Trinity College Dublin
The University of Dublin

no care like home care
THE JACK & JILL CHILDREN'S FOUNDATION
1997 2017
20 YEARS

Coventry University

NOVEMBER 2017