

# Respite Services for Children with Life-Limiting Conditions and their Families in Ireland

➤ A National Needs Assessment





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# Foreword

It is always a tragic event when a child dies. In many senses, children are not supposed to die – but they do. In Ireland approximately 450 children die each year, 350 of them from a life-limiting condition. The journey towards death is a difficult and emotive one and families need all the support and help they can get. Respite care is aimed at supporting families along that journey, helping them to sustain their energy, commitment and mental health. The goal of respite care for children with life-limiting conditions is to provide time out for caregivers who are providing the bulk of care to their child – to get some rest, tend to other children or simply do the weekly shopping. Frequently, parents are exhausted but desperately want to keep going – respite care gives them strength and is an essential element of children’s palliative care.

In 2010 the Department of Health and Children formally launched *Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy*. The report noted that, “*in order to provide support to children with life-limiting conditions and their families primary care services need to be developed, including the provision of a Consultant Paediatrician with a Special Interest in Palliative Care and Outreach Nursing posts, therapy posts, Hospice-in-the-Home and respite care (both in home and away from the home) in each of the HSE regions.*” The policy went on to make two specific recommendations regarding respite care:

- A range of respite services should be developed for children with life-limiting conditions and palliative care needs.
- Each HSE area should develop a plan for respite facilities for children with life-limiting conditions and their families.

In 2010 a respite needs assessment was undertaken in the Dublin North-East and Dublin Mid-Leinster regions of the Health Service Executive (IHF/CSH, 2011. Jointly commissioned by the Irish Hospice Foundation and the Children’s Sunshine Home, it set out to assess the respite needs of families caring for a child with a life-limiting condition and requiring palliative care in these regions. Since the publication of this report, it has become clear that a national respite needs assessment is required if services are to be planned and developed equitably across the country.

The intention of this new report is to provide a national overview of the current provision of and future need for respite care for children with life-limiting conditions. Once again commissioned by what is now LauraLynn, Ireland’s Children’s Hospice (formerly the Children’s Sunshine Home) and the Irish Hospice Foundation, in partnership with the HSE, it seeks to provide a clear overview of national requirements for respite as part of a palliative care service for children in Ireland.

Building on the work of the 2011 Dublin North-East and Dublin Mid-Leinster report, this needs assessment provides some new and updated information on the services currently provided in all areas of the HSE, including HSE West and South. The data used for all areas refers to the same time period to provide uniformity and allow for comparison. The literature review has been updated, and where possible, all figures have been updated and verified.

In presenting this report, we acknowledge that for a number of reasons, the data are not complete. Where figures are estimated, all information available has been used to ensure that they are as accurate as possible. It was difficult to capture the data regarding current service provision. In many cases this was due to the ambiguity surrounding definitions and terminology currently in use, which meant that in some cases service providers were uncertain as to whether they provided respite to children with life-limiting conditions or not, and whether their services should be included.

The findings of this report indicate that service deficits exist and that accessing respite services can be challenging for families. In order to provide children with life-limiting conditions and their families with appropriate and timely respite care, it is necessary first to build our understanding of what constitutes good respite care and subsequently to expand the provision of quality services. This is something the National Development Committee for Children's Palliative Care is currently addressing.

In presenting this report we acknowledge the work of the authors/project team led by Julie Ling, the steering committee who guided it, the contribution of Prospectus Consulting in preparing the 2011 report, and the project advisory group for that report, who provided some of the definitions and costings that formed the basis for this needs assessment.

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# ↘ Executive Summary

The diagnosis of a life-limiting condition in a child is an immense challenge for a family. Although caring for a child with a life-limiting condition can be physically and emotionally demanding, most parents wish to care for their child at home. Regular respite provides valuable support to families on their care journey, and the availability of the appropriate range of respite services can assist families in making the best decision regarding the location of care for their child.

In 2010 the Department of Health and Children published *Palliative Care for Children with Life-limiting Conditions in Ireland – a National Policy* (DoHC, 2010). This policy provides the foundation for the development of paediatric palliative care services in Ireland. The significance of respite care as a component of children's palliative care is reflected in the policy document, which recommended that:

- a range of respite services should be developed for children with life-limiting conditions and palliative care needs
- inpatient hospice beds specifically for respite should be developed as part of the children's palliative care service.
- each administrative area of the Health Service Executive (HSE) should plan and develop respite facilities for children with life-limiting conditions and their families.

One of the priorities identified in the national policy was an audit of the need for respite services for children with life-limiting conditions and their families. In response, and to assist with the implementation of the policy, the Irish Hospice Foundation and LauraLynn, Ireland's Children's Hospice, in partnership with the HSE, undertook a national needs assessment in late 2012 to identify existing services and to assess current and future need. The findings are presented in this report.

This project has built on a similar exercise already undertaken in 2010. The original study was confined to just two HSE regions, Dublin North-East and Dublin Mid-Leinster. The present needs assessment replicated this study in HSE South and HSE West, while also endeavouring to update the data from the two regions previously surveyed. It has therefore sought to provide a national picture across all four HSE regions.

Obtaining accurate data on respite services for children with palliative care needs is challenging, not least because of a lack of consistency in the use of terms and definitions – for example in relation to what constitutes a 'life-limiting condition'.

The need for respite services for children with life-limiting conditions is projected to steadily grow over the period analysed, 2011-2021. Families' respite care needs are dynamic, changing over time. Service plans and delivery must therefore be flexible and responsive, and respite care should be made available both within the family home and outside of it, for example in a children's hospice or respite unit.

This needs assessment has found that while respite services for children with life-limiting conditions are currently provided in all four HSE regions, access is often dependent on the nature of the child's diagnosis and the part of the country in which the family lives rather than on need.

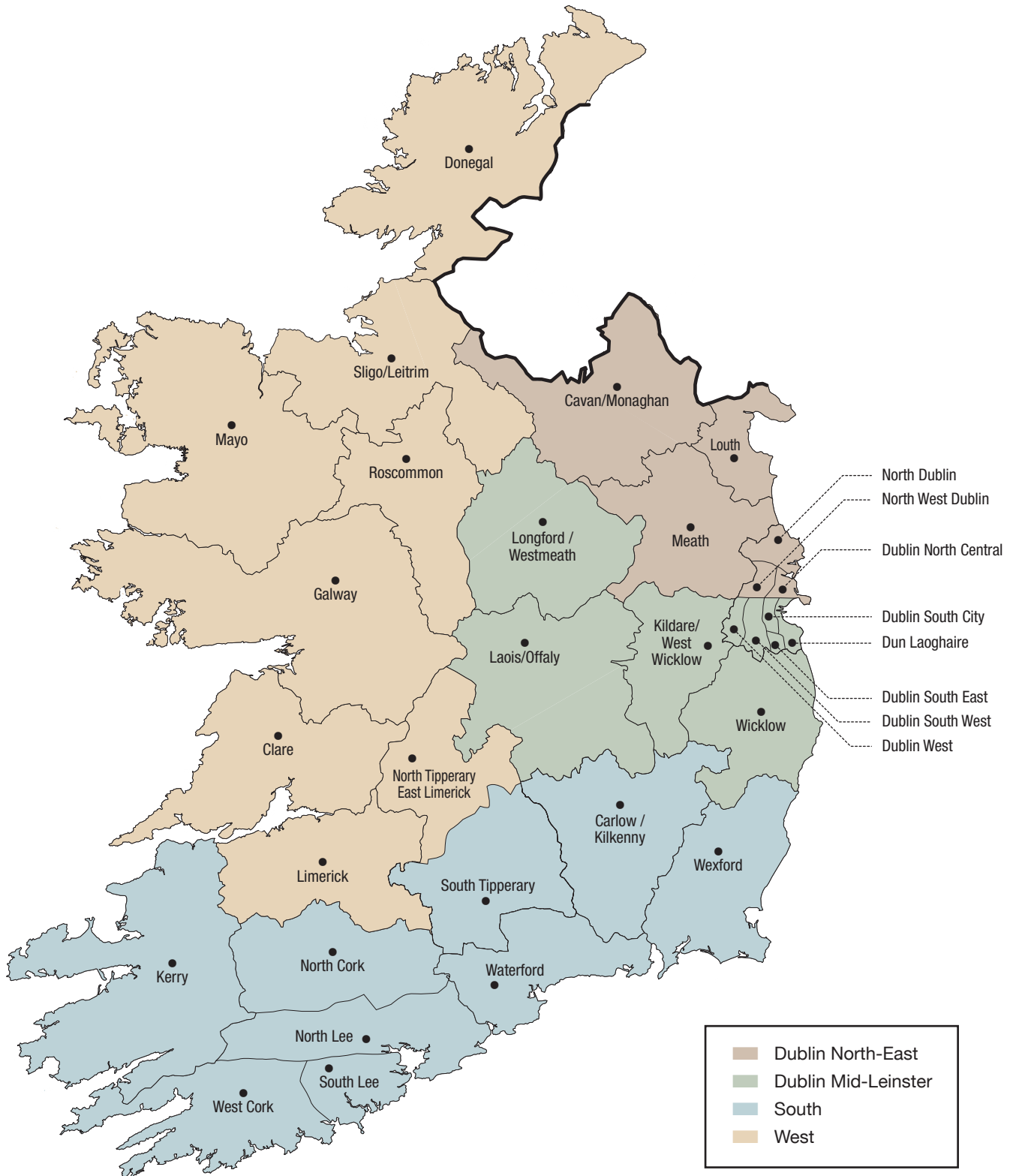
A range of respite care programmes, developed in a structured and coordinated way, will be required to meet the needs of at least 816 children currently, and up to 925 children by 2021. It is estimated that the development and operation of the six forms of respite care outlined in this needs assessment will require a budget in excess of €7.6 million per annum currently, rising to €8.6 million by 2021. These costs are based on a 70:30 split between in-the-home and out-of-home respite care.

If appropriate respite services are to be provided, a number of key actions need to be undertaken. Among the recommendations made are the following:

- Through the National Development Committee for Children's Palliative Care, national standards should be developed for respite care, and the feasibility of developing an assessment tool for respite services should be explored.
- Regional groups should be established to progress the findings of this report, with representation from paediatrics, disability services, acute and community services, children's outreach nurses and specialist palliative care services. These groups should be facilitated to map the full range of existing respite services for children with life-limiting conditions, identify where services need to be developed/provided and ensure that national standards, when developed, are implemented.
- As regards respite care outside the home, the health services should work with regional service providers, both voluntary and statutory, to ascertain, among other things, whether facilities already available may be further developed to meet the needs of children with life-limiting conditions, and to identify where additional facilities are required.
- The education and ongoing support needs of organisations providing respite care should be considered both nationally and regionally.

Finally, it is recommended that this needs assessment should be repeated in four years time, by which point it is hoped that tangible improvements will be seen in the provision of respite services for children with life-limiting conditions and their families.

Figure 1 Administrative areas of the Health Service Executive





# ➤ SECTION 1

## Introduction to respite services for children with life-limiting conditions

### 1.1 Introduction

Planning respite as part of palliative care services for children is challenging. In Ireland there is a dearth of accurate data on the location and number of children living with life-limiting conditions who require respite services. This lack of information is in part due to a lack of clarity surrounding the definitions used in children's palliative care, for example, defining what constitutes a life-limiting or life-threatening condition. While diagnosis can be helpful in identifying children in need of respite services, it must be considered in conjunction with other factors, such as the individual needs of the family, the severity of the condition and any other relevant complications. In this document the term 'life-limiting condition' will encompass 'life-threatening conditions', as described in Section 1.2.

In some cases there is an overlap between children's palliative care services and disability services, and it is therefore at times unclear whether the respite care that children are receiving is 'palliative' or part of a regular disability respite service. This poses challenges not only for service users but for the planners and providers of respite care for children with life-limiting conditions.

This report sets out to present a needs assessment for respite services for children with life-limiting conditions in the Health Service Executive's (HSE) South and West administrative regions. In addition, the project team undertook to update the data presented in a similar needs assessment undertaken in 2010 for the HSE's Dublin North-East and Dublin Mid-Leinster regions (IHF/CSH, 2011). This involved analysis of existing reports and available data, as well as examining international benchmarks such as the work of the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) in the UK.

The present project replicated the Dublin North-East/Dublin Mid-Leinster needs assessment. The structure and format of the previous report have been largely maintained in order to provide the HSE with a consistent framework for establishing a national requirement for respite services for children with life-limiting conditions. Many aspects of the original study were relevant to the needs assessment for HSE South and West also.

Both the South and the West regions have their own unique services which currently provide support for children with life-limiting conditions and their families. In cooperation with the HSE, and in order to ensure engagement with all the relevant national and regional experts in paediatric and palliative care, the project team established regional support groups for the needs assessment in both regions (Appendix 2).

The objectives of the study were to:

- Estimate the number of children in the HSE South and West administrative regions who are living with a life-limiting condition and whose families need or have access to respite services.
- Where possible, update the information provided in the previous report on HSE Dublin Mid-Leinster and Dublin North-East.
- Establish as accurately as possible current service levels and location of care.
- Where possible, identify the gap between the projected need for respite services for children with life-limiting conditions (based on age, location, condition) and the current levels of respite care provided.
- Estimate the cost of providing appropriate services to children based on population estimates.

In Section 1, palliative care and respite care for children with life-limiting conditions are defined and described. The international experience is outlined and relevant Irish policy reviewed. Categories of respite care are presented, along with a brief overview of national and regional service provision, and some examples are given. The issues to be considered in responding to the respite needs of children with life-limiting conditions are discussed. This section concludes with recommendations for a clinical governance framework for respite services.

## **1.2 Background to respite care for children with life-limiting conditions**

### **Life-limiting conditions in children**

A life-limiting condition in a child is defined as “*any condition from which there is no reasonable hope of cure and from which the child or young adult will die* (ACT, 2009). While the majority of children with such a condition are unlikely to live beyond 18 years, some of those diagnosed in childhood can survive unexpectedly into early adulthood.

Life-limiting conditions in children can be diagnosed either prior to birth or during childhood, with the expectation that the condition will lead to premature death. ACT also provides a categorisation of life-limiting and life-threatening conditions that affect children (Table 1).

**TABLE 1 ACT categories of life-limiting conditions (ACT, 2009)**

1. Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included. **Examples:** *Cancer, irreversible organ failures of heart, liver, kidney.*
2. Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. **Example:** *Cystic fibrosis.*
3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. **Examples:** *Batten Disease, muscular dystrophy, mucopolysaccharodosis.*
4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. **Examples:** *Severe cerebral palsy; multiple disabilities, such as follow brain or spinal cord injury.*

In Ireland, there is an average of 423 deaths each year in children under 18 years of age. (Table 2). Of these, 322 die from one of the life-limiting conditions identified in the ACT categories shown in Table 1.

**TABLE 2  
Mortality data for children under 18 years in Ireland, 2005-2010 (CSO, 2012)**

Year	Number of deaths	Number of deaths from life-limiting conditions
2005	417	292
2006	421	321
2007	413	306
2008	462	347
2009	403	316
2010	423	348
<b>TOTAL</b>	<b>2,539</b>	<b>1,930</b>
<b>Average annual no. of childhood deaths</b>	<b>423</b>	<b>322</b>

## **Children's palliative care**

Children's palliative care is a unique and highly specialised field of healthcare which focuses on improving the quality of life of children who are living with, or dying from, a life-limiting condition. The needs of children with life-limiting conditions differ significantly from those of adults, and professionals and care-givers supporting children therefore require specific training and expertise to deal with their unique needs. Ideally, support for those with palliative care needs starts at the time of diagnosis, and for many children with life-limiting conditions this can be birth. There is a notable overlap between the needs of children requiring palliative care and those with disabilities and other complex care needs.

Life-limiting conditions in children are often marked by an unpredictable disease trajectory. Some children require palliative care for a few days or months while others may live into adulthood and may require care, including respite care, over many years.

Palliative care for children embraces the whole family. Despite struggling to cope with a diagnosis of a life-limiting condition in their child, home remains the care location of choice for parents and families who, with support, often take on the child's personal and nursing care. Respite is a necessary component of this care.

## **Respite care in children's palliative care**

In the context of children's palliative care, respite care has been defined as: "*the provision by appropriately trained individual(s) of care for children with life-limiting conditions for a specified period of time, thus providing temporary relief to the usual caregiver.*" (Horsburgh et al., 2002). Respite is an essential element of a comprehensive palliative care service for children with life-limiting conditions and their families, providing a break for both child and family.

The respite needs of the families of children with life-limiting conditions tend to vary considerably and can be determined by a number of factors, including:

- the child's condition
- the child's age
- the home and family situation of the child
- the child's diagnosis and prognosis
- the capacity of parents and other family members to meet the child's needs.

Caring for a child at home with complex care needs can be challenging and affects all members of the family (Emond and Eaton, 2004), with many parents finding it to be both physically and emotionally stressful (Llewellyn et al., 1999). Often, despite initial reluctance to use respite services, parents find respite beneficial (Eaton, 2008). Respite enables families to have a break from the routine of caring and to spend more time carrying out some of the normal daily tasks, such as shopping or spending time with their other children.

For children with life-limiting conditions, respite needs are dynamic and likely to change over time. This poses challenges for providers of respite care when trying to be flexible and responsive to the needs of a child and family. Where respite is provided, parents unsurprisingly prefer services to be available locally (DoHC, 2010). Respite care must be provided in a manner and location acceptable to the family; where possible it should be flexible and tailored to meet the individual needs of each family (Ling, 2012).

ACT (2009) gives seven examples of the type of short (respite) breaks families may require to enable them to care for their life-limited child (Table 3.). In Ireland not all of these types of short break is currently available.

**TABLE 3 Short break provision**

**Hospice/hospice at home** – helps families to have a break together or time to themselves in a home-from-home environment, or in a family’s own home.

**Statutory funded short breaks in the home** – community children’s nurses and competent carers delivering short breaks in the home to children with medically complex needs, sometimes funded through continuing care.

**Sitting services** – people who regularly visit the child in his or her home, enabling parents to spend time with their other children, have an evening out or just do routine things such as shopping.

**Befrienders/activity services** – people who take the child out in the community, for example to the cinema, swimming, to the park, shopping or a wide variety of other activities.

**Short break fostering** – people who look after the child in the carer’s own home, perhaps for one night, a weekend or longer, depending on the child’s needs.

**Community houses** – where children and young people can have the opportunity to be creative with arts, crafts, and take part in other activities within the community.

**Domiciliary care** – care provided at home which gives help with the child’s personal care/domestic tasks.

An independent economic review of palliative care services for children in the UK confirmed that due to a general lack of community-based support, children and young people were being unnecessarily admitted to acute care, with an unexpectedly high proportion attending outpatient clinics on a regular basis for a range of tests and procedures (Craft and Killen, 2007). The authors concluded that this inflation of hospital-based activity puts significant strain on the healthcare system in general, decreases opportunities to achieve value for money and is not in the best interests of children and families.

They suggested that a well-structured respite service can reduce hospital admissions, both because it provides the additional community supports that may prevent a child's condition from deteriorating to a point where hospitalisation becomes necessary, and because many therapeutic procedures may be completed as part of a respite programme.

### **International context**

Assessments of the need for palliative care for children have been undertaken in many countries, including Ireland, and have consistently found the following:

- For children and their families, the location of choice through illness and ultimately death is home.
- Community resources as currently provided are inadequate to support children at home.
- There are insufficient essential respite services.
- The availability of services is often dependent on the location of the child's home and/or the nature of the diagnosis, with the better developed services often available only to children with cancer.
- Communication between professionals is poor and needs improvement.
- There is a need for better education for all professionals and volunteers involved in the care of children with life-limiting conditions.
- There is a dearth of evidence on the provision of respite care for children with life-limiting conditions.

Regardless of country of origin, respite needs assessments confirm that while respite care is viewed as being an essential component of palliative care services for children with life-limiting conditions, there are simply not enough respite services available to meet the needs of families. Healthcare professionals also recognise the importance of providing respite care. A study to establish the incidence and prevalence of children with palliative care needs in Wales (Hain, 2005) found that respite care was one of the key needs reported by paediatricians. In the UK, a study on respite for children with life-limiting conditions concluded that where respite care is offered on a regular basis, parents cope better with the demands of caring for their sick child (Eaton, 2008). Respite provides benefits, especially if services are designed with flexibility in mind to meet the changing needs of individual families and their children. A recent report from England states that 90% of the 46 children's hospices in England provide short breaks to children with life-limiting conditions (National End of Life Care Intelligence Network, 2012).

A paediatric palliative care sub-group of the European Association for Palliative Care (EAPC) produced standards for the development of children's palliative care (Craig et al., 2008). These standards suggest that:

- Respite services for family and child are essential, whether for a few hours or a few days at a time.
- It should be possible to provide respite both in the family home and away from home, for example, in an inpatient children's hospice.

The EAPC standards also recommend that all families should have access to flexible respite care in their own home and in a home-from-home setting, with appropriate paediatric multidisciplinary care.

## Children's palliative care policy in Ireland

The essential role of respite in the provision of palliative care for children with life-limiting conditions and their families has been acknowledged in two key documents from the Department of Health and Children.

### ***A Palliative Care Needs Assessment for Children*** (DoHC/IHF, 2005)

An assessment of the palliative care needs of children in Ireland was published in 2005 by the Department of Health & Children and the Irish Hospice Foundation. The assessment attempted to identify the number of children living with and dying from life-limiting conditions. Challenges with definitions and data resulted in estimated numbers, based on a combination of:

- Central Statistics Office (CSO) data
- International Classification of Disease (ICD) coding – see Appendix 3
- ACT categories of life-limiting conditions (Table 1)
- UK data on the prevalence of children with life-limiting conditions.

Based on CSO data over the six-year period 1996-2001, it was estimated that 370 children on average die in Ireland each year from a life-limiting condition, the majority (57%) in the first year of life.

Using Irish population data for 2002, combined with estimated figures for the prevalence of life-limiting conditions in children in the UK (12 per 10,000), it was also estimated that the number of children *living* with a life-limiting condition in Ireland, and thus requiring ongoing support, was 1,369, with an estimated rise to 1,610 by the year 2021. A caveat accompanying these figures warned that they were likely to be underestimates.

The children's palliative care needs assessment also included a number of key findings that have had an impact on the present respite needs assessment:

- accurate and comprehensive data on children with life-limiting conditions is needed
- the preferred location of care for a child with a life-limiting condition is the family home, with parents receiving adequate support
- the provision of readily available, locally-based respite care is essential
- palliative care services provided to children with life-limiting conditions in Ireland are inequitable, varying significantly according to diagnosis (the nature of the child's illness) and geographic location (the region of residence of child and family).

Research completed as part of this needs assessment also found that healthcare professionals often wished to refer to respite services. Over 80% of clinical nurse managers, 31% of clinical nurse specialists, 79% of medical social workers, 23% of GPs and 45% of public health nurses confirmed that they "*wished to refer to respite services but that appropriate respite care was not currently available*". The needs assessment concluded that: "*locally based, child-friendly and readily accessible respite facilities must be a priority in the development of a 'seamless' system of care.*"

### ***Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy*** (DoHC, 2010)

Building on the findings of the 2005 needs assessment, the Department of Health and Children went on to develop a policy, *Palliative Care for Children with Life-Limiting Conditions - A National Policy*, which was published in 2010. This policy provides the foundation for the development of palliative care services for children in Ireland.

Recognising the essential role that respite plays for children with life-limiting conditions and their families, the policy includes four respite-specific recommendations for implementation:

- A range of respite services should be developed for children with life-limiting conditions who have palliative care needs.
- Each HSE administrative area should plan and develop respite facilities for children with life-limiting conditions and their families.
- Hospice-at-home teams should be developed by the HSE.
- Inpatient hospice beds specifically for respite should be developed as part of the children's palliative care service.

### **Types of respite in children's palliative care**

The national policy also provides further detail in relation to the development of respite services, and makes recommendations for both in-the-home and out-of-home respite care.

#### **In-the-home respite**

- Respite programmes should be agreed on the basis of the assessed needs of each child and family.
- The service should be delivered by specially trained personnel, including registered nurses, carers.

For the purposes of the present respite needs assessment, **in-the-home respite** has been further broken down into the categories established for the Dublin Mid-Leinster/Dublin North-East respite needs assessment (IHF/CSH, 2011), as follows:

- **Category 1:** The provision of in-the-home care for a child with a life-limiting condition in order to enable parents and/or other regular carers to tend to other requirements/ activities. This type of respite is typically provided by a trained/ accredited healthcare assistant or a family member/ friend.
- **Category 2:** The provision of care by an appropriately qualified and experienced registered nurse with the requisite skills to care for a child with a life-limiting condition in the child's own home.



- **Category 3:** The provision of an extended range of respite services to a child with a life-limiting condition. Care is delivered by an appropriately qualified and experienced registered nurse with specific expertise/qualifications in palliative care and paediatrics.

In relation to out-of-home respite care, the national policy recommends:

### Out-of-home respite

- Out-of-home respite (or ‘centre-based respite’) should take account of the medical needs of the child, including the management of symptoms.
- The development of non-specialist hospice units dedicated to the provision of respite care for children with life-limiting conditions will be required.

For the purpose of this respite needs assessment, **out-of-home respite** is further broken down as follows:

- **Category 1:** The provision of support to a child with a life-limiting condition at a non-specialist unit by appropriately trained healthcare staff.
- **Category 2:** The provision of respite care to a child within a specialist unit. This involves the provision of care/support to children by appropriately trained healthcare staff, with access to specialist care as necessary.
- **Category 3:** The provision of an extended range of respite services to children with life-limiting conditions. Care is delivered by a registered nurse with specific expertise/qualifications in palliative care and paediatrics within a specialist unit.

Finally, the national policy introduces the concept of specialist respite care and defines it as follows:

### Specialist respite care

Specialist respite care refers to a setting of care, a programme of care or a service that provides additional services. It may take place in the child’s home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist respite care provides the support required to meet the child’s holistic care needs and enables children and families to access short break services. Specialist respite care will often address some aspects of symptom management.

### 1.3 Meeting the respite needs of children with life-limiting conditions

If respite services are to be developed to meet the needs of children with life-limiting conditions and their families, the following need to be considered (IHF/CSH, 2011):

- All families should have the necessary information they require to make an informed choice regarding respite options.
- All families should be provided with a standardised approach to the initiation of respite care.
- A standardised and consistent approach should be utilised to determine the suitability of a child and family regarding the receipt of respite care.
- An agreed approach should be in place regarding the notification of respite providers.
- All respite providers should have agreed acceptance criteria in place regarding their respite programme(s), and these criteria should be widely available and understood by referral agents.
- All respite providers should have agreed operational procedures in place regarding the review of respite placements and programmes.
- Care plans should contain specific information requirements and consideration regarding respite care.
- Care plans should be updated on a continuous and structured basis.
- Communications channels should be in place between respite providers and all other associated service providers where appropriate and necessary.
- Clear assignment and documentation of responsibility within and between clinical teams should be in place.

Children with life-limiting conditions who require respite should ideally have both in-the-home and out-of-home respite, or a combination of both, available to them. Respite care needs are dynamic and change over time; the planning and delivery of services therefore needs to be flexible and responsive in order to fully meet these needs.

Out-of-home respite should be delivered in an environment that replicates a normal home setting as far as possible and avoids any association with traditional institutional living or hospital environments. Future models of out-of-home respite care should also provide modern family accommodation on-site, enabling parents to remain close to their child while he/she avails of high-quality care and support.

ACT has detailed the recommended range of service delivery options for families where a child has been diagnosed with a life-limiting condition – see *Act Care Pathway*, Appendix 4. Care plans should be developed on the basis of a detailed assessment which includes consideration of the needs of both child and family. Consideration of the appropriateness of respite care is recommended, with the further suggestion that this is revisited and reviewed on a structured and continuous basis.

## 1.4 Clinical governance in children's respite care services

As in all areas of healthcare, international and national best practice dictates that good clinical governance mechanisms be put in place. The over-arching purpose of introducing a clinical governance framework is to support the creation of an open and participative environment, where a commitment to high-quality, safe, holistic, child and family-centred clinical care and support is shared by all professionals delivering, coordinating and managing respite care.

Good practice recommends that each organisation providing respite care should develop a clinical governance framework that will facilitate the delivery of safe and robust services to children, young people and their families.

The framework (IHF/CSH, 2011) should outline:

- A standardised approach to seeking and responding to the views of children, young people and their families, respecting their diverse needs, choices and preferences.
- The delivery of effective clinical outcomes and supports for each child or young person, based on evidence-based practice guidelines and standards.
- How the respite service enhances the safety of clinical care by using healthcare processes, clear working practices and systematic activities that prevent or reduce the risk of harm to each child and young person.
- Procedures for reviewing the effectiveness of clinical services and healthcare supports through evaluation, audit or research.
- How health records and information will be integrated and used to enhance the quality and safety of service delivery, and to plan for quality improvement activities.
- Strategies for the promotion of continuing professional development and clinical supervision.
- Competence assurances, including clear lines of responsibility and accountability for the overall quality of respite care.

Service providers should nominate a lead clinician to take responsibility for the coordination of clinical governance requirements within their associated service, as outlined in the agreed framework.

## 1.5 Conclusion

Caring for a child with a life-limiting illness at home is stressful for families. Respite care confers important benefits and is an essential component of a comprehensive children's palliative care service. Problems with the use of definitions, and some overlap between children with needs arising from disability and those with palliative care needs, and between corresponding services, have contributed to a lack of accurate national data on children with life-limiting conditions and their respite needs, and continue to pose challenges for service planners. The key role of respite care is acknowledged internationally, and the Irish Government's national policy on children's palliative care includes a number of respite-specific recommendations. Both in-the-home and out-of-home respite services are essential, and a range of issues need to be considered in developing them.

## SECTION 2

# Estimation of the prevalence of life-limiting conditions in children, and overview of current respite service provision

### 2.1 Introduction

In Section 2, the methodology for this respite needs assessment is described. Demographic data for each of the existing HSE administrative regions are presented. The issue of estimating the number of children with life-limiting conditions is discussed in the context of available data. In order to put this in context, international estimates of the prevalence of children with life-limiting conditions are presented. Respite services for such children as currently provided in each of the four HSE regions are described, and the work of providers of both in-the-home and out-of-home respite care is illustrated.

### 2.2 Methodology

This respite needs assessment set out to identify the level of need for respite care for children with life-limiting conditions in all four administrative regions of the Health Service Executive, building on the needs assessment previously undertaken in two of these regions, HSE Dublin Mid-Leinster and HSE Dublin North-East (IHF/CSH, 2011).

In order to compile this national report, a steering committee was formed to oversee the project and guide the project team (see Appendix 1). To ensure that the information collected from HSE South and HSE West was reflective of the range of locally-based services, a separate support group was established in each of these two regions (Appendix 2).

The original respite needs assessment was undertaken between September 2009 and March 2010; the work on the HSE South and HSE West regions was undertaken during August-November 2012. The report findings therefore reflect these time periods except where specified.

The original needs assessment was updated as far as possible – services in Dublin Mid-Leinster and Dublin North-East that had provided information in 2010 were given the opportunity to update their figures – and the information was incorporated with the new data on HSE South and West.

### 2.3 National overview of child population

This project set out to identify the level of need for respite care for children with life-limiting conditions in all four administrative regions of the HSE. Using data from the 2006 census, the child population per county was calculated. (A further census was conducted in 2011, but the data required was not available at the time of compiling this report.) According to the 2006 census, a total of 1,036,034 children resided in the Republic of Ireland. The child population for each county is shown in Table 4.

**TABLE 4 Child population by county and HSE region (CSO Census, 2006)**

<b>County*</b>	<b>Child population</b>	<b>County</b>	<b>Child population</b>
Clare	28,565	Cork	11,6241
Limerick	43,507	Kerry	33,036
North Tipperary	16,769	Carlow	12,668
Galway	55,306	Kilkenny	22,882
Roscommon	14,503	South Tipperary	21,162
Mayo	30,969	Waterford	27,009
Sligo	14,610	Wexford	34,851
Leitrim	7,133		
Donegal	40,288		
<b>HSE West</b>	<b>251,650</b>	<b>HSE South</b>	<b>267,849</b>
Dublin North	107,970	Dublin South	153,131
Louth	29,233	Kildare	50,337
Meath	44,621	Laois	18,013
Cavan	17,127	Longford	8,930
Monaghan	14,455	Offaly	19,169
		Westmeath	21,124
		Wicklow	32,425
<b>HSE Dublin-North East</b>	<b>213,406</b>	<b>HSE Dublin-Mid Leinster</b>	<b>303,129</b>
<b>NATIONAL TOTAL</b>			<b>1,036,034</b>

\*Counties Dublin and Tipperary are split in two by HSE region boundaries

## 2.4 Prevalence of life-limiting conditions in children

There is currently an absence of robust data regarding the number of children living with and dying from life-limiting conditions in Ireland. This is not an exclusively Irish issue: several countries (including Ireland) have undertaken work aimed at establishing prevalence rates, but currently there is no established formula for estimating these figures, and comparison between countries is challenging – for example, age categorisation differs between countries, some of which collect data on the population aged 0-19 (UK) and others 0-17 (Ireland). The sub-sections below describe findings and review various reports on prevalence rates from a number of different countries, including Ireland. These reports demonstrate the range of and difficulty in estimating prevalence rates for children with life-limiting conditions, and therefore the challenges involved in estimating the need for respite services.

### **Prevalence rates – Ireland**

The children's palliative care needs assessment undertaken in 2002 and published in 2005 used a prevalence rate of 12 children with life-limiting conditions per 10,000 children (aged 0-17 years), producing a figure of 1,369 children living with a life-limiting condition. This was based on 2002 UK prevalence rates and was thought, even at the time of publication of the Irish report in 2005, to be an underestimate. A proviso warned that for a number of reasons, including the assumption of a similarity in prevalence between the UK and Ireland, the figures might be higher.

### **Prevalence rates – UK**

In the UK, the first edition of the *Guide to the Development of Children's Palliative Care Services* (ACT, 1997), produced by the Association for Children with Life-Threatening or Terminal Conditions (ACT) and the Royal College of Paediatrics and Child Health, included an estimated prevalence of 10 children with life-limiting conditions per 10,000 of child population.

The second edition of the Guide was released in 2003 (ACT, 2003). This report estimated the annual mortality rate for children aged 0-19 with life-limiting conditions to be within the range 1.5 to 1.9 children per 10,000 of population. ACT further refers to district-based data that indicates the prevalence of severely ill children with life-limiting conditions and in need of palliative care to be at least 12 per 10,000 of child population. Taking a range of factors and studies into account, ACT recommends that for the purposes of planning future services, a prevalence range of 12 to 17 per 10,000 of population be used as the measure to estimate the number of children with a life-limiting condition. ACT estimates that approximately 50% of these children will need active palliative care at any one time. The third edition (ACT, 2009) also suggests a prevalence rate of children with life-limiting conditions ranging from 12 to 17 children per 10,000 population.

ACT recently merged with Children's Hospices (UK) to become *Together for Short Lives*. Following new research, a briefing report from this organisation gives a figure of 49,000 children living with a life-limiting condition who may benefit from a palliative care approach (Together for Short Lives, 2012). This information is based on research (Fraser et al., 2012) which now estimates that the prevalence of children with life-limiting conditions may be as high as 32 per 10,000, more than double the earlier ACT estimates.

### **Prevalence rates – Wales**

A study undertaken by Hain in Wales (Hain, 2005) to establish the incidence and prevalence of children needing palliative care examined data from three different sources:

1. Paediatricians using the Welsh Paediatric Surveillance Unit.
2. Referrals to the specialist palliative medicine service based in Cardiff.
3. The two principal children's hospices serving Wales.

Data pertaining to children referred/reported to these services during the period January 2001 to December 2002 was used to evaluate service provision and estimate need. During the study period a total of 226 children were identified in Wales. All children were categorised according to the four ACT categories outlined in Table 1.

According to Hain, there are a number of approaches to test and validate estimations of incidence and prevalence. Incidence of life-limiting conditions in children is typically determined using mortality data. Hain comments that since by definition all children with a life-limiting condition are likely to die from it, incidence is the same as or very similar to mortality. Childhood mortality is currently 1-2 per 10,000. Hain refers to a number of studies that suggest that prevalence is approximately 10 times that of mortality, and notes that this formula is generally suitable for application as a guide to service development but should be subject to continuous review.

### **Prevalence rates – New Zealand**

Prevalence rates in New Zealand were estimated by Jones et al through a combination of hospitalisation data and mortality data for all children aged 0-17 years during the period 1996 to 1998 (Jones et al., 2002). Cases were classified as either 'palliative' or 'not palliative'.

According to the New Zealand study, out of 2,122 childhood deaths, 16% were classified as being 'appropriate for palliative care' leading to a prevalence of 1.14 per 10,000 children per year. 37% of deaths were due to cancer; 11% were cardiac; 24% were congenital; and 28% were classified as 'other'. Of all the deaths recorded, 28% were of children under the age of one year.

In the same study, a second analysis of deaths in the population 1-17 years old was also undertaken, comparing prevalence rates for New Zealand with other countries, using the International Classification of Disease codes to define life-limiting conditions (Appendix 3). In total 28% of cases were classified as requiring palliative care. As a result, it was calculated that 0.99 children per 10,000 of population in the 1-17 age group require palliative care. This compared closely with the UK rate of 1 per 10,000 (at the time of study completion). The New Zealand study found that 29% of childhood deaths occurred in hospital, the authors suggesting that this may reflect gaps in palliative care services rather than a preference for care within the acute setting.

### **Prevalence rates – Northern Ireland**

The Northern Ireland Children's Hospice completed an *Assessment of Need of Life-limited Children in Northern Ireland* in 2000 (Northern Ireland Hospice Care, 2000), when there were approximately 500,000 children living in Northern Ireland. An analysis of quantitative and qualitative data was used to reach a prevalence rate of 17.2 children with life-limiting conditions per 10,000 of population.

### **Summary of prevalence rates, Ireland and UK**

Table 5 provides a summary of the prevalence of children with life-limiting conditions in Ireland and the UK, and also separately in Wales and Northern Ireland. Estimates of prevalence rates range from 10 per 10,000 of child population in 1997 (with a caveat that this is an underestimate) to the more recent UK estimate of 32 per 10,000 and rising.

**TABLE 5 Prevalence of children with life-limiting conditions in Ireland and the UK, per 10,000 of child population**

Country	Year	No. children (per 10,000)
Ireland	2005	12
UK	1997	10
	2003	12
	2009	12-17
	2012	32
Wales	2005	10-12
Northern Ireland	2000	17.2

**A prevalence rate of 14.5 per 10,000 will be used for the purposes of this study.**

## 2.5 National overview of respite services

In Ireland, the majority of children with life-limiting conditions are cared for at home, with their parents as their primary carers. Additional supports, including respite, are often provided by statutory and voluntary care providers; however, as a result of the overlap between children with disabilities and those with life-limiting conditions, it is not possible to clearly separate and identify the funding and services provided to children with life-limiting conditions and their families.

The provision of respite care for children with life-limiting conditions varies both between and within HSE regions. One of the significant findings of *A Palliative Care Needs Assessment for Children* (DoHC/IHF, 2005) was that the provision of services (including respite care) was inequitable, varying according to diagnosis and the location of the family home.

While defining a life-limiting condition is not as easy as simply using a diagnosis, access to certain services, including some respite services, is diagnosis dependent. In Ireland, children with conditions in ACT Categories 3 and 4 (see Table 1) are frequently cared for through the disability services and often receive respite care through these services. Children with cancer (ACT Category 1) are under the care of specialist cancer services at Our Lady's Children's Hospital in Crumlin, and receive the support of an Oncology Liaison Nurse who links services, including respite care, for the child and family. Children with cancer may be admitted to the Oncology Unit for respite care, and families may be eligible for a night-nursing service provided by the Irish Cancer Society, although this is usually restricted to care at the end of life rather than respite care. Although the Irish Hospice Foundation provides a similar service for families of children with life-limiting conditions other than cancer, again the main focus is on end-of-life care, and accessing respite services may prove particularly challenging for families of children without a definitive diagnosis.



Where respite care is provided to families of children with life-limiting conditions it falls into three categories:

- In-the-home respite care
- Out-of-home respite care
- Other.

In-the-home and out-of-home respite care are not mutually exclusive and are often combined as part of a respite care plan for a child.

### **In-the-home respite care**

Across all four HSE regions, in-the-home respite for children with life-limiting conditions is supported by a combination of voluntary and statutory funding. Home is the location of choice for the care of a child with a life-limiting condition, especially when adequate supports are available, and planned respite care in the child's own home is therefore a common option. Care is often provided by a registered children's nurse or registered general nurse, or by a trained care assistant/carer. The role of this healthcare professional or carer is to undertake the normal duties and tasks required to support the child, often those usually provided by the child's family.

### **Out-of-home respite care**

Out-of-home respite involves the provision of supports to care-givers in settings outside of the home. This care can be provided in a variety of settings, including respite centres, residential care facilities and where available, in a children's hospice.

### **Other respite options**

Respite care is also occasionally provided within acute settings, when no other more suitable location for respite is available.

### **Respite services and disability services**

There is a marked overlap between the needs of children requiring palliative care and those with disabilities and other complex care needs (UK DH, 2008). Not all children with a disability have a life-limiting condition requiring palliative care, but for those who do, the need for respite depends on the degree of complexity and urgency attached to their care and on the support needs of their families.

A number of both statutory and voluntary centres provide respite care for children with intellectual disabilities who also have a life-limiting condition; however, the majority of these centres would not consider their service to be providing respite care as part of palliative care. It is uncertain how many of the 698 children who availed of respite care provided by disability services in 2011 also had a life-limiting condition and may have required palliative care services.

The Disability Act 2005 (Government of Ireland, 2005) includes provision for the establishment of an 'Assessment of Need' process that focuses on disability and education needs (See Appendix 5). This process aims to ensure that assessed needs are matched with appropriate services where available. In 2007, this Act was extended to include children under the age of five. Although this has assisted families to access a range of services, including respite care, in accordance with their specific needs, it does not automatically entitle them to these services.

## **Providers of respite care for children with life-limiting conditions and their families**

Some providers of respite care for children with life-limiting conditions are national organisations, such as the Jack & Jill Foundation, LauraLynn, Ireland's Children's Hospice and the Brothers of Charity, while others, such as COPE (Cork), are locally-based. The HSE fulfils a limited coordination and direct-delivery role in the provision of respite care to some children with life-limiting conditions, and also provides respite funding through HSE Service Arrangements.

Both of the Irish national reports on children's palliative care – *A Palliative Care Needs Assessment for Children* (DoHC/IHF, 2005) and *Palliative Care for Children with Life-limiting Conditions: A National Policy* (DoHC, 2010) – found that there was a dearth of information on the provision of respite care, and as a result, it is unclear where or how services are accessed or provided.

Where respite services are provided, the most common route of referral is from within the acute hospital sector at the time of diagnosis, which can be as early as birth. Referrals are usually from clinicians caring for the child and family, and ideally, the need for respite care should be assessed and a programme of respite tailored to meet their individual needs.

Where available, respite care can be provided in a variety of locations, both in the home (including overnight respite care if needed), and away from the home. However, appropriate respite services are not available to all children with life-limiting conditions, and access depends on a range of criteria including the child's age, diagnosis and prognosis, and where the child and family live.

## **Examples of national organisations providing respite care**

### **■ The Jack & Jill Foundation**

The Jack & Jill Foundation is a voluntary organisation providing early-intervention home respite to families with children who have severe neurological developmental delay and palliative conditions requiring extensive medical and nursing care. The Foundation provides direct funding to these families to enable them to purchase in-the-home respite care.

Families of children meeting the above criteria are allocated a Liaison Nurse who supports the families in an advisory capacity, reviews their respite requirements on an ongoing basis and provides 'hands-on' care when necessary. The Jack & Jill Foundation has played a significant role in the provision of respite care to families in Ireland, however, services are restricted at present to children up to the age of four.

Figure 2 Jack & Jill Foundation activity data, 2008-2012

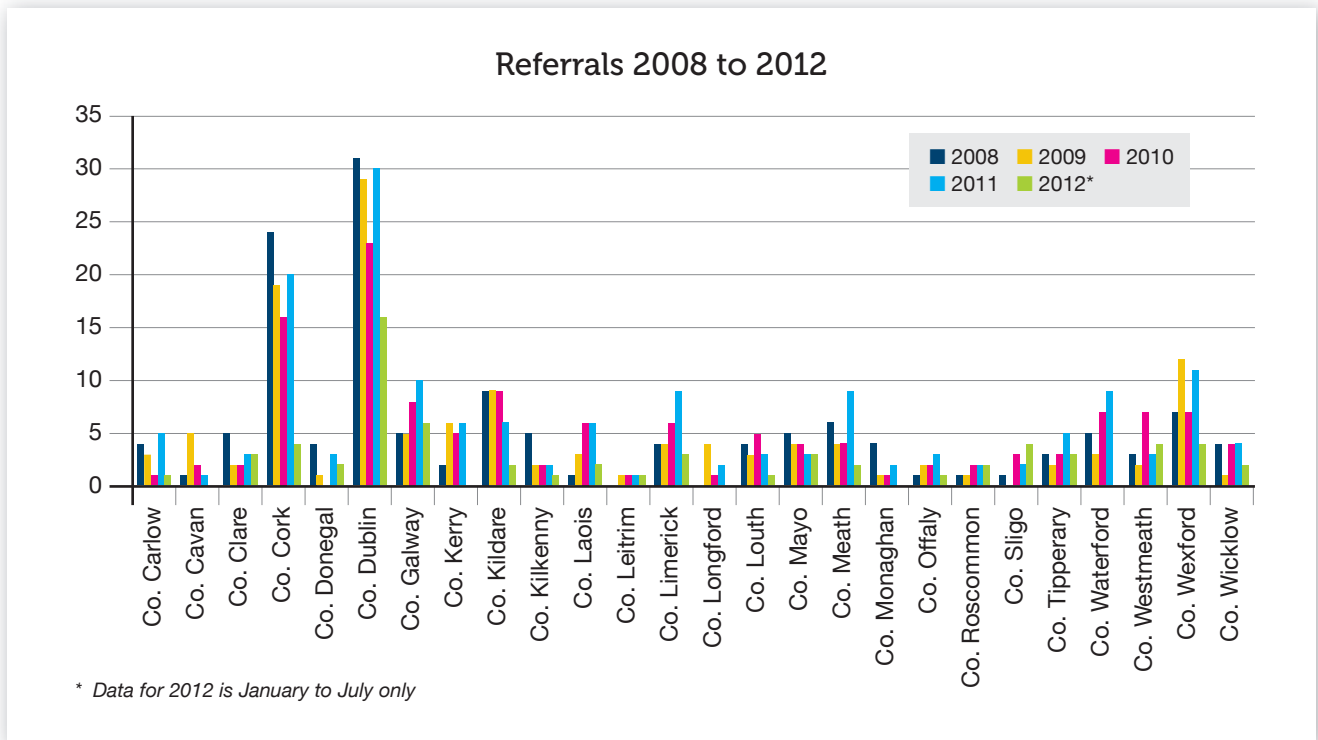
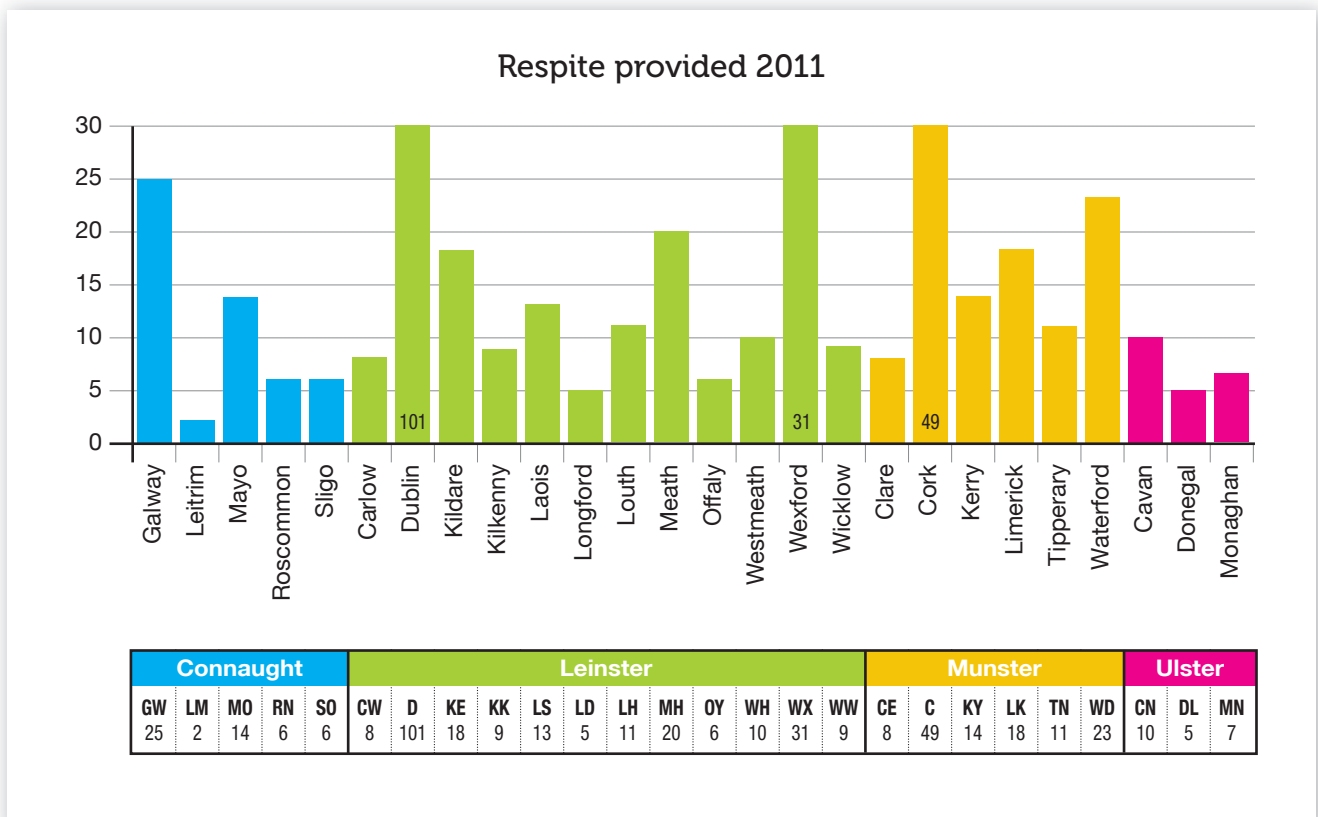


Figure 3 Respite provided by Jack & Jill Foundation, 2011, by region



### ■ LauraLynn, Ireland's Children's Hospice

The Children's Sunshine Home has been in existence since 1925 and has recently been renamed *LauraLynn, Ireland's Children's Hospice*. This incorporates both the services previously operated as the Children's Sunshine Home and a new purpose-built hospice unit opened in September 2011. As the first children's hospice in the Republic of Ireland, LauraLynn provides the following services to children and families with life-limiting and life-threatening conditions:

- transitional care from maternity and acute children's hospitals
- home support
- respite and crisis care
- end-of-life care.

Prior to 2011, services were provided predominantly to families in the HSE Dublin Mid-Leinster region; however, Figure 4 below testifies to the fact that LauraLynn currently provides services to families from all four HSE regions, while Figure 5 reflects a steady increase in the number of referrals.

Figure 4 **LauraLynn, Ireland's Children's Hospice: Families cared for in 2012**

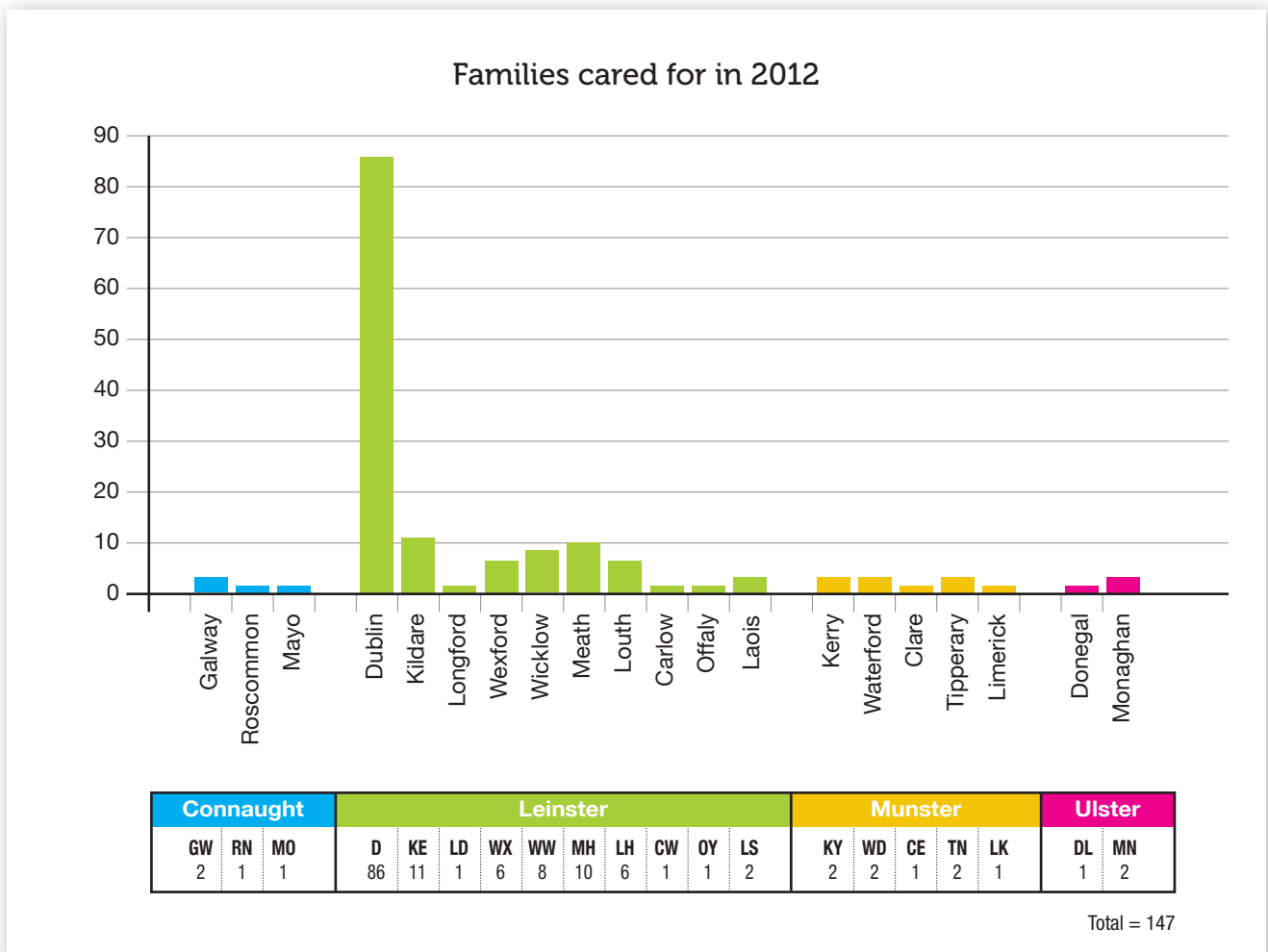
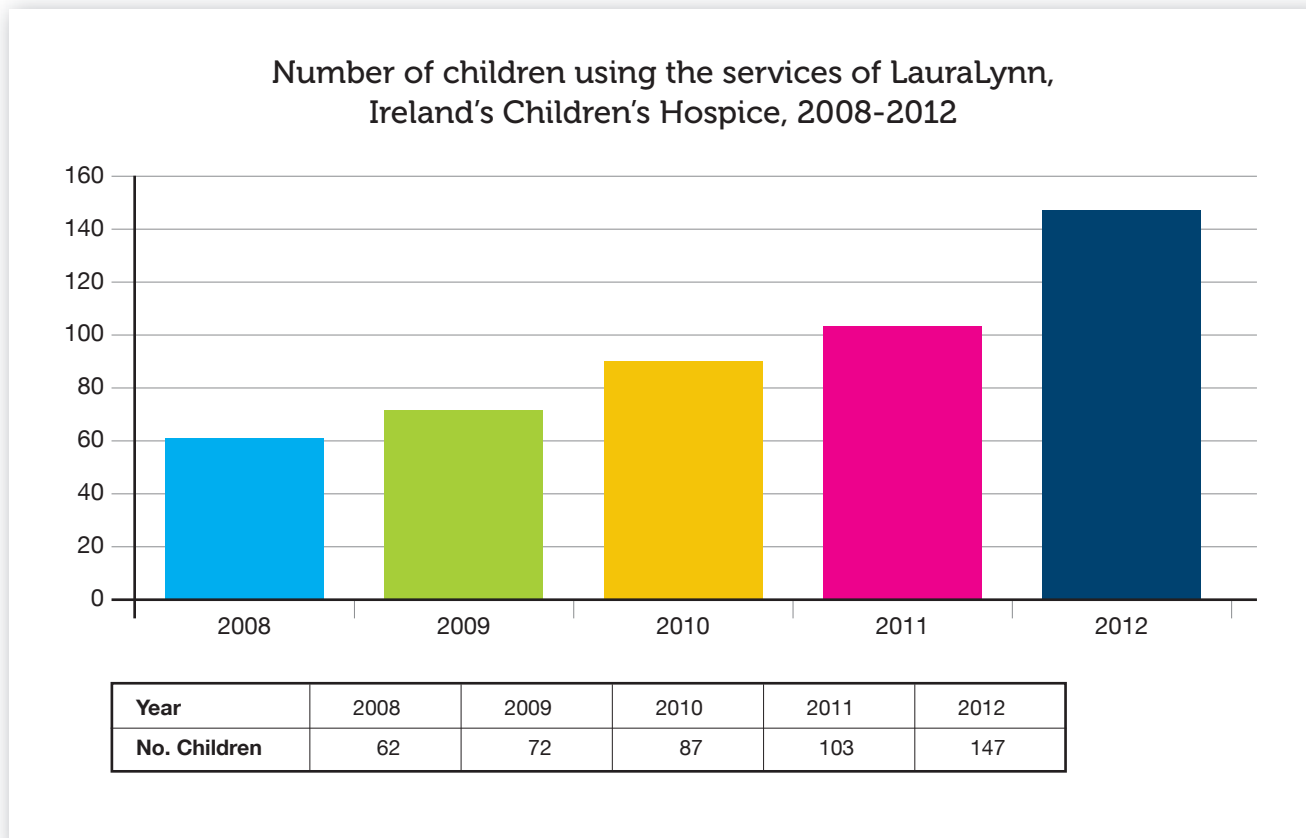


Figure 5 Number of children using LauraLynn services, 2008-2012



LauraLynn works in partnership with the HSE and other relevant voluntary agencies. It incorporates a multidisciplinary service that includes a Medical Director, Consultant Paediatrician, a nursing team, a range of allied health professionals and support services.

A strategic plan, in line with national policy, has been developed by LauraLynn for 2012-2017. In order to provide high-quality child and family-centred care LauraLynn recognises the essential role of education and research and is committed to staff development. Services are developing with the aim of providing responsive family-centred care to children with life-limiting conditions and their families.

### Examples of local respite services in each HSE area

Respite services to children with life-limiting conditions and their families vary within and between HSE regions. Services are available to some children and their families, but accessing them can be challenging and often depends on diagnosis and geographical location. Establishing accurate data on current service levels and location of care and identifying the gaps in local service provision has proved very challenging for the project team. As noted previously, because of the overlap between the respite needs of children with disabilities and other complex care needs and those requiring palliative care, some service providers do not identify themselves as providing respite care to children with life-limiting conditions. Identifying providers of respite care for this patient population has therefore been difficult. This section presents examples of some of the services provided in each of the four HSE areas.

## HSE Dublin Mid-Leinster and HSE Dublin North-East

Within the Dublin Mid-Leinster and Dublin North-East catchment areas, there are currently two centres specifically providing out-of-home respite to children with life-limiting conditions, both located in Dublin: LauraLynn, Ireland's Children's Hospice in Leopardstown (described above) and Suzanne House in Tallaght.

### ■ Suzanne House

Suzanne House, part of St. John of God Community Services, provides day care, support and a respite service for children who have a terminal illness or who are medically fragile. The service has a total of three beds available for planned respite and one bed for emergency situations such as end-of-life care.

**TABLE 6 Suzanne House respite activity data, 2011**

No. respite nights	177
No. children supported	10
No. respite days	319
No. children supported	12

## HSE South and HSE West – Overview

The project team held meetings with key stakeholders in both HSE South and HSE West (Appendix 2). These two HSE regions have their own unique services which currently cater for this patient population. Key stakeholders were asked to provide any information available on respite provision for children with life-limiting conditions and their families in their area.

While every effort was made to ensure that as much information as possible was made available to the project team, the information acquired in no way represents the total number of hours / amount of funding being provided by the HSE or various partners to support the respite needs of children with life-limiting illness and their families. This support is often drawn from other community funding streams and released to families when a crisis occurs. The respondents to the research noted that this 'crisis' funding can cover a substantial period of time, may have irregular review periods and is not supported by a standardised national assessment process. The data provided for each of the two regions is summarised separately below.

## HSE South

In the HSE South region there are several statutory and voluntary organisations that provide respite services to children with life-limiting conditions and their families. Some examples are given below.

### ■ St Joseph's Foundation, Charleville, Cork

St Joseph's provides centre-based day and overnight respite to children from South County Limerick and North Cork who have a physical/ sensory disability, intellectual disability and autism. Seven children with life-limiting conditions availed of services in 2011

### ■ The COPE Foundation

COPE Foundation provides a comprehensive range of services to people with intellectual disability and/or autism through a network of community-based supports at over 65 locations in Cork city and county. These supports include early intervention; education; training; leisure, sports and arts activities; and supported employment, as well as residential supports. Five children availed of in-home respite provision, with a total of 340 hours, in 2010/2011

**TABLE 7 COPE Foundation activity profile, 2011**

No. respite nights	84
No. children supported	4
No. respite days	84
No. children supported	4
Hospital admission support	16 hrs per week

### ■ St Rita's (Brothers of Charity Services), South Tipperary

St Rita's offers respite breaks to children with intellectual disabilities from the South Tipperary area, including those who have life-limiting conditions. This part-time service includes mid-week and weekend planned breaks. St Rita's also organises in-the-home respite which offers the family a flexible use of hours. The Brothers of Charity Services are currently examining the feasibility of providing alternative respite options within the current agreed allocation.

### ■ In-the-home respite services

In-the-home respite services are provided in all areas of the HSE South region by a combination of voluntary organisations and the HSE, but are dependent upon assessed need and funding.

## HSE West

### ■ San Joseph House (Daughters of Charity), Limerick

San Joseph House is a five-bedded house staffed by nurses providing overnight respite care to children aged 0-6 with a disability from the former HSE Mid-West region, i.e. Clare, Limerick and North Tipperary. It also provides overnight respite to children aged 6-18 with a disability from the East Limerick/ North Tipperary region. This service does not specifically provide services to children with life-limiting conditions. San Joseph currently provides a service to 36 children through a range of day and overnight respite.

### ■ Claddagh House (Daughters of Charity), Roscrea, Co. Tipperary

Claddagh House is a three-bedded house staffed by nurses and care staff. It takes children who attend St Anne's Special School in Roscrea with moderate, severe/ profound learning disability and autism. It also provides respite to the children in the East Limerick/ North Tipperary catchment area attending the early intervention and school age disability teams. There are currently 15 children attending for day and overnight respite, although only one child is currently defined by staff as life-limited.

### ■ Donegal

An example of a HSE region having unique services is Donegal. The following are examples of the respite services provided:

- Play breaks (day outings for children, e.g. bowling, cinema, concerts, etc.)
- Teen breaks (overnight trips to concerts, football matches, 3-4 night breaks in one of the respite houses)
- Use of respite houses for family breaks (currently there are 59 families on the books)
- There are four respite houses in Donegal with approximately six beds in each house.

### ■ In-the-home respite services

In-the-home respite services are provided in all areas of the HSE West region through a combination of voluntary organisations and the HSE, but these are dependent on assessed need, local protocol and funding. Some examples of in-the-home services provided to children in the Co. Clare area – many of whom may have a life-limiting condition – are presented below.

Co. Clare area – In-home respite	Enable Ireland	Brothers of Charity
Number of respite nights	125	156
Number of children supported	8	8
Number of respite days	205	17
Number of children supported	8	3



### **Other respite options**

Respite care is also occasionally provided within acute settings, where no other more suitable location for respite is available. While most adult specialist palliative care teams will extend support to families of children with life-limiting conditions, this study found they do not have a specific role in the provision of respite care for children.

## **2.6 Conclusion**

The provision of respite care services varies both within and between HSE administrative regions. Limited in-the-home and out-of-home services are provided, often supported by a combination of voluntary and statutory funding. Some services are diagnosis dependent or age dependent (e.g. confined to babies/ very young children). Families whose child does not have a definitive diagnosis may find access to respite particularly challenging. It is likely that the voluntary sector will continue to be key service providers, with significant funding provided through HSE Service Arrangements.

This report indicates that there is a dearth of information regarding where and by whom respite care is provided. Examples of centres known to provide respite for some children with life-limiting conditions are presented. Further work is needed, however, to establish the number of services providing respite care, the quantum of service being provided and the number of families accessing this care. The quality of the care being provided also needs to be assessed.

## ↘ SECTION 3

# Future development of services to meet the respite needs of children with life-limiting conditions

### 3.1 Introduction

This section seeks both to quantify projected need and to estimate the cost of providing respite services in each of the four HSE administrative regions up to 2021. Using child population projections for Ireland, CSO data, and national and international approaches to estimating the prevalence of children with life-limiting conditions, as described in Section 2, future service need is estimated.

### 3.2 Population projections

In order to plan and develop respite services for children with life-limiting conditions, it is important to have an estimation of the future child population of Ireland. The CSO's regional population projections suggest that the child population of each HSE region is set to rise in the years up to and including 2021 (Table 8). In HSE Dublin North-East, this is projected to increase by approximately 15%; in HSE Dublin Mid-Leinster by 16%; in HSE West by 11% and in HSE South by 10%.

### 3.3 Quantifying the need for respite care

In order to provide a responsive and appropriate respite service to meet future need, information is required on both the potential number of families likely to require respite care and on where that care should be provided, i.e. within the home or outside the home. In order to estimate these figures, the following data / data sources have been used: an analysis of child death data from the CSO; national and international prevalence rates; and the findings of the Irish children's palliative care needs assessment (DoHC/IHF, 2005)

**TABLE 8 Child population projections, by HSE administrative region and constituent counties (CSO, 2006)**

HSE region & counties*	2006	2011	2016	2021
<b>HSE West</b>				
Clare	28,565	30,278	32,035	32,835
Limerick	43,507	46,117	48,792	50,011
North Tipperary	16,769	17,775	18,806	19,276
Galway	55,306	59,177	64,503	69,018
Roscommon	14,503	15,518	16,914	18,098
Mayo	30,969	33,136	36,119	38,647
Sligo	14,610	15,632	16,258	16,583
Leitrim	7,133	7,632	7,937	8,096
Donegal	40,288	43,108	44,832	45,729
<b>Total</b>	<b>251,650</b>	<b>268,373</b>	<b>286,196</b>	<b>298,293</b>
<b>HSE South</b>				
Cork	11,6241	125,540	134,327	139029
Kerry	33,036	35,678	38,176	39512
Carlow	12,668	13,744	14,638	15004
Kilkenny	22,882	24,826	26,444	27101
South Tipperary	21,162	22,960	24,453	25064
Waterford	27,009	29,304	31,209	31989
Wexford	34,851	37,813	40,271	41277
<b>Total</b>	<b>267,849</b>	<b>289,865</b>	<b>309,518</b>	<b>318,976</b>
<b>HSE Dublin North-East</b>				
North County Dublin	107,970	117,903	129,104	138,270
Louth	29,233	30,841	31,982	32,654
Meath	44,621	51,493	57,826	62,163
Cavan	17,127	18,069	18,738	19,131
Monaghan	14,455	15,250	15,814	16,146
<b>Total</b>	<b>213,406</b>	<b>233,556</b>	<b>253,464</b>	<b>268,365</b>
<b>HSE Dublin Mid-Leinster</b>				
South County Dublin	153,131	167,219	183,105	196,105
Kildare	50,337	58,089	65,234	70,126
Laois	18,013	19,814	21,063	21,315
Longford	8,930	9,823	10,442	10,567
Offaly	19,169	21,086	22,414	22,683
Westmeath	21,124	23,236	24,700	24,997
Wicklow	32,425	37,418	42,021	45,172
<b>Total</b>	<b>303,129</b>	<b>336,686</b>	<b>368,979</b>	<b>390,967</b>
<b>NATIONAL TOTAL</b>	<b>1,036,034</b>	<b>1,120,528</b>	<b>1,218,157</b>	<b>1,276,600</b>

\*Counties Dublin and Tipperary are split in two by HSE region boundaries

## CSO data on childhood deaths

An analysis of CSO data relating to childhood deaths (0-17 yrs) registered in Ireland during 2010 was completed. The deaths were categorised using the International Classification of Disease codes identified by ACT to define life-limiting conditions (Appendix 3). Diseases in any of the four ACT categories of life-limiting conditions (Table 1) were included. Upon completion of this exercise, a total of 348 children were identified as having died from a life-limiting condition (CSO, 2012).

### 3.4 Location of respite care (home/outside of home)

In line with Irish national policy on palliative care for children with life-limiting conditions, this respite needs assessment has been completed on the basis that home is the setting of choice for respite care. However, although this clear preference is accepted as best international practice, a child's home is not always the most suitable location for care, and therefore an alternative, or a combination of respite settings, may be required.

Based on both national and international findings and on the clinical experience of its members, the project advisory group (see Appendix 6) for the HSE Dublin Mid-Leinster/Dublin North-East respite needs assessment (IHF/CSH, 2011), established a 70:30 split between in-the-home and out-of-home respite as a guideline for quantifying future service needs. This guideline has been adopted for the present needs assessment also. All respite care should be flexible, person-centred and aimed at meeting the individual needs of the child and family.

### 3.5 Project assumptions

In this respite needs assessment, and in the absence of accurate and contemporaneous data, estimates of the prevalence of life-limiting conditions in children have been used, following the example of the HSE Dublin Mid-Leinster/Dublin North-East needs assessment (IHF/CSH, 2011). These are based on both national and international experience, and aim to provide policy makers and service planners with a guide to future need for respite services for children with life-limiting conditions.

In order to calculate projected respite need, the following assumptions adopted for the previous study will serve as the basis upon which all calculations and projections have been arrived at in this respite needs assessment also:

- A prevalence rate of 14.5 children with life-limiting conditions per 10,000 of child population. This was the mid-point of the range, 12-17 per 10,000, as discussed in Section 2.<sup>1</sup>
- A number of studies suggest that prevalence is approximately 10 times that of mortality; the application of this figure provides a guide to the level of service development needed. This has been applied for the purposes of this respite needs assessment.

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<sup>1</sup> It is clear, however, from the recent work of Fraser et al. (2012) that this is likely to be an underestimate

- The ACT recommendation that approximately 50% of all children with a life-limiting condition will need active palliative care at any one time is also accepted as applicable to the Irish environment.
- All children classified as having an ‘active palliative care requirement’ will benefit from and will require some form of respite care, although some children with life-limiting conditions access respite care through services other than palliative care, in particular, through intellectual disability services.
- Projections of respite care demand to 2021 assume a constant rate of use of palliative respite care during the period 2010 to 2021. As a result, population changes will serve as the sole contributing factor to variances in demand during the period under review.

These assumptions serve as the basis upon which all calculations and projections have been made.

### **3.6 Projected future need for respite services**

Table 9 shows the projected need for respite services across Ireland up to 2021. The child population for each county, along with the estimated overall number of children with life-limiting conditions, have been used to estimate the number of children with life-limiting conditions who may require respite services.

Applying the mid-point prevalence rate of 14.5 children per 10,000 to the total child population of all HSE regions gives a total of 1,503 children living with a life-limiting condition. As noted above, ACT point out that approximately 50% of all children with such a condition will have an ‘active palliative care requirement’ at any given time. This has been used to estimate how many will need respite care at any given time. Future projections up to 2021 are calculated in this way, but are coupled with CSO projections of child population changes. On this basis, it is assumed that 925 children will require some form of respite care in 2021.

**TABLE 9 Projected need for respite services, 2011-2021, by HSE administrative region and constituent counties**

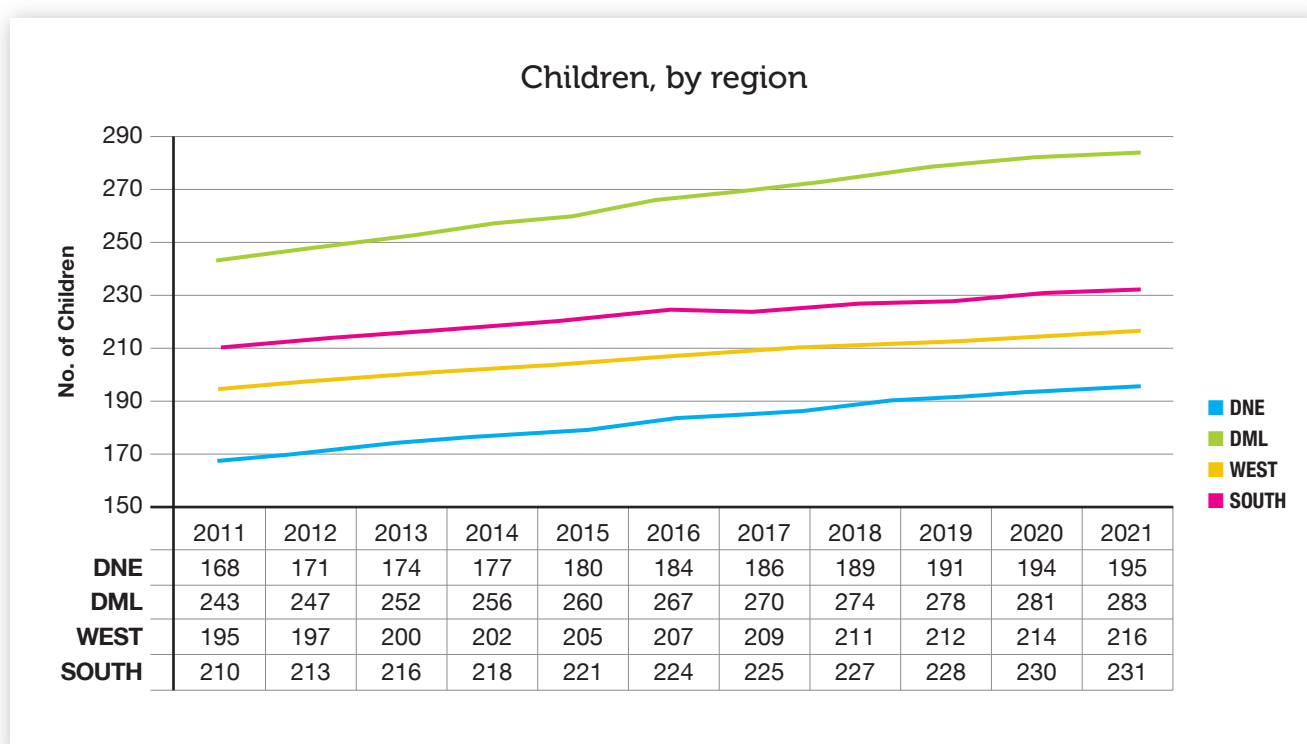
HSE region & constituent counties*	Child pop. (2006 Census)	Children with life-limiting conditions	Children with active palliative care needs		
			2011	2016	2021
<b>HSE West</b>					
Clare	28,565	41	22	23	24
Limerick	43,507	63	33	35	36
North Tipperary	16,769	24	13	14	14
Galway	55,306	80	43	47	50
Roscommon	14,503	21	11	12	13
Mayo	30,969	45	24	26	28
Sligo	14,610	21	11	12	13
Leitrim	7,133	10	6	6	6
Donegal	40,288	58	31	33	33
<b>Total</b>	<b>251,650</b>	<b>365</b>	<b>195</b>	<b>207</b>	<b>216</b>
<b>HSE South</b>					
Cork	116,241	169	91	97	101
Kerry	33,036	48	26	28	29
Carlow	12,668	18	10	11	11
Kilkenny	22,882	33	18	19	20
South Tipperary	21,162	31	17	18	18
Waterford	27,009	39	21	23	23
Wexford	34,851	51	27	29	30
<b>Total</b>	<b>267,849</b>	<b>388</b>	<b>210</b>	<b>224</b>	<b>231</b>
<b>HSE Dublin North-East</b>					
Dublin North	107,970	157	78	94	100
Louth	29,233	42	21	23	24
Meath	44,621	65	32	42	45
Cavan	17,127	25	12	14	14
Monaghan	14,455	21	10	11	12
<b>Total</b>	<b>213,406</b>	<b>310</b>	<b>168</b>	<b>184</b>	<b>195</b>
<b>HSE Dublin Mid-Leinster</b>					
Dublin South	153,131	222	111	133	142
Kildare	50,337	73	36	47	51
Laois	18,013	26	13	15	15
Longford	8,930	13	6	8	8
Offaly	19,169	28	14	16	16
Westmeath	21,124	31	15	18	18
Wicklow	32,425	47	24	30	33
<b>Total</b>	<b>303,129</b>	<b>440</b>	<b>243</b>	<b>268</b>	<b>283</b>
<b>NATIONAL TOTAL</b>	<b>1,036,034</b>	<b>1,503</b>	<b>816</b>	<b>883</b>	<b>925</b>

\*Counties Dublin and Tipperary are split in two by HSE region boundaries

Identifying the gap between supply and demand in relation to respite services has been challenging, as comprehensive information regarding the location and type of respite care currently being provided is not available. Therefore, this respite needs assessment focuses on projecting the *total* need for respite services for the period up to 2021, including those which are already in place. Where respite services are already provided (by disability services, for example) it is envisaged that this will continue.

Figure 6 provides a graphic illustration of the projected year-by-year growth in the numbers of children with life-limiting conditions who are likely to require active palliative care over the period 2011-2021 in each HSE region.

Figure 6 Projected number of children with active palliative care requirement, 2011-2021, by HSE region



### 3.7 Financial projections

HSE funding for respite services for children with life-limiting conditions is currently provided through a range of different HSE services, e.g. disability services, palliative care, community services, etc. The HSE also provides respite funding to external service providers (e.g. Jack & Jill Foundation, Brothers of Charity, etc.) Because of the complexities involved in the provision of respite funding, it has not been possible to quantify the precise extent of this allocation in the process of undertaking this needs assessment. The financial projections which follow are based on delivering a respite service for all children identified in the previous section, and *do not take account of existing respite budgets*. They present the annual projected cost of providing a range of respite services across the two respite care settings – within the home and outside of the home – and are underpinned by a number of assumptions as listed on page 38.

### 3.8 Categorising respite care

As indicated in Section 1, for the purposes of this needs assessment, in-the-home and out-of-home respite care have been further categorised as follows:

#### In-the-home respite care

- **Category 1:** The provision of in-the-home care for a child with a life-limiting condition in order to enable parents and/or other regular carers to tend to other requirements/activities. This type of respite is typically provided by a trained/accredited healthcare assistant or a family member/friend.
- **Category 2:** The provision of care by an appropriately qualified and experienced registered nurse with the requisite skills to care for a child with a life-limiting condition in the child's own home.
- **Category 3:** The provision of an extended range of respite services to a child with a life-limiting condition. Care is delivered by an appropriately qualified and experienced registered nurse with specific expertise/qualifications in palliative care and paediatrics.

#### Out-of-home respite care

- **Category 1:** The provision of support to a child with a life-limiting condition at a non-specialist unit by appropriately trained healthcare staff.
- **Category 2:** The provision of respite care to a child within a specialist unit. This involves the provision of care/support to children by appropriately trained healthcare staff, with access to specialist care as necessary.
- **Category 3:** The provision of an extended range of respite services to children with life-limiting conditions. Care is delivered by a registered nurse with specific expertise /qualifications in palliative care and paediatrics within a specialist unit.

### 3.9 Assumptions underpinning the calculated costs

The assumptions underpinning the calculated costs of delivering a range of respite services across the two settings are taken from the HSE Dublin Mid-Leinster/Dublin North East needs assessment (IHF/CSH, 2011). These were based on national and international reports and the recommendation of a multi-professional steering committee. The assumptions are:



- All costs are calculated on the basis of an average weekly allocation of up to eight hours of respite care per child (1.44 days per month).
- Total respite provision has been allocated on the basis of a 70:30 ratio between in-the-home and out-of-home respite care.

**The allocation of in-the-home respite provision is further sub-divided as follows:**

- Category 1: 48.25%
- Category 2: 44.25%
- Category 3: 7.5%.

**The allocation of out-of-home respite provision is further sub-divided as follows:**

- Category 1: 60%
- Category 2: 32.50%
- Category 3: 7.5%

- The allocations assigned to each sub-category of in-the-home care above are approximately based on current practice in the Jack & Jill Foundation, with specific allowances incorporated based on the planned introduction of specialist respite care.
- Carer-delivered and nurse-delivered in-the-home respite costs have been estimated on the basis of an average hourly rate, as per HSE consolidated salary scales.
- Costs associated with specialist in-the-home respite were calculated on the basis of the annual salary (plus expenses/PRSI/pension entitlements) of a Specialist Community Palliative Care Nurse.
- Category 1 out-of-home respite costs are based on the average hourly rate for the provision of respite care by a service provider delivering respite care for children with life-limiting conditions.
- Category 2 out-of-home respite costs are based on the average hourly rate for general respite at LauraLynn, Ireland's Children's Hospice.
- Category 3 out-of-home respite costs are based on the projected costs of specialist care within LauraLynn, Ireland's Children's Hospice.

### **3.10 Cost of respite options**

Tables 10-13 provide a breakdown of the projected annual cost of delivering respite care to children with life-limiting conditions, both within and outside of the home, in each of the four HSE administrative regions for the period 2011-2021.

The calculations for in-the-home respite are based on the HSE's mid-point hourly pay rates for three categories of staff: (a) healthcare assistants – €19; (b) registered nurses – €24; and (c) Clinical Nurse Specialists (CNS) – €37.

**TABLE 10 Projected cost (€) of respite care, 2011-2021 – HSE DUBLIN MID-LEINSTER**

Year	In-the-home respite (70% of total hours)				Out-of-home respite (30% of total hours)*				Overall Total €
	Delivered by healthcare assistant/ carer (Cat. 1)	Delivered by registered nurse (Cat. 2)	Specialist respite, delivered by CNS (Cat.3)	Total €	General (Cat. 1)	General plus (Cat. 2)	Specialist (Cat. 3)	Total €	
2011	648,707	751,488	196,363	1,596,559	345,721	236,546	84,156	666,423	2,262,981
2012	662,055	766,951	200,404	1,629,410	352,835	241,413	85,887	680,135	2,309,545
2013	675,403	782,414	204,444	1,662,261	359,948	246,280	87,619	693,847	2,356,108
2014	688,751	797,876	208,485	1,695,112	367,062	251,148	89,351	707,560	2,402,671
2015	702,098	813,339	212,525	1,727,963	374,175	256,015	91,082	721,272	2,449,235
2016	715,446	828,802	216,565	1,760,814	381,289	260,882	92,814	734,985	2,495,798
2017	723,455	838,079	218,990	1,780,524	385,557	263,802	93,853	743,212	2,523,736
2018	731,464	847,357	221,414	1,800,235	389,825	266,723	94,892	751,440	2,551,674
2019	739,473	856,635	223,838	1,819,945	394,093	269,643	95,931	759,667	2,579,612
2020	747,481	865,912	226,262	1,839,656	398,362	272,563	96,970	767,894	2,607,550
2021	755,490	875,190	228,687	1,859,367	402,630	275,484	98,009	776,122	2,635,488

**TABLE 11 Projected cost (€) of respite care. 2011-2021 – HSE DUBLIN NORTH-EAST**

Year	In-the-home respite (70% of total hours)				Out-of-home respite (30% of total hours)*				Overall Total €
	Delivered by healthcare assistant/ carer (Cat. 1)	Delivered by registered nurse (Cat. 2)	Specialist respite, delivered by CNS (Cat.3)	Total €	General (Cat. 1)	General plus (Cat. 2)	Specialist (Cat. 3)	Total €	
2011	448,489	519,547	135,757	1,103,794	239,017	163,538	58,182	460,737	1,564,530
2012	456,497	528,825	138,182	1,123,504	243,285	166,458	59,221	468,964	1,592,468
2013	464,506	538,103	140,606	1,143,215	247,553	169,379	60,260	477,192	1,620,406
2014	472,515	547,380	143,030	1,162,925	251,821	172,299	61,299	485,419	1,648,344
2015	480,524	556,658	145,454	1,182,636	256,090	175,219	62,338	493,646	1,676,282
2016	491,202	569,028	148,687	1,208,917	261,780	179,113	63,723	504,616	1,713,533
2017	496,541	575,213	150,303	1,222,057	264,626	181,060	64,416	510,101	1,732,158
2018	504,550	584,491	152,727	1,241,768	268,894	183,980	65,454	518,329	1,760,097
2019	509,889	590,676	154,343	1,254,908	271,740	185,927	66,147	523,814	1,778,722
2020	517,898	599,954	156,768	1,274,619	276,008	188,847	67,186	532,041	1,806,660
2021	520,567	603,046	157,576	1,281,189	277,430	189,821	67,532	534,784	1,815,973

\* Out-of-home respite costs do not include overheads, e.g. water, light, heat, cleaning, catering, etc., nor administration or management costs.

**TABLE 12 Projected cost (€) of respite care, 2011-2021 – HSE WEST**

Year	In-the-home respite (70% of total hours)				Out-of-home respite (30% of total hours)*				Overall Total €
	Delivered by healthcare assistant/ carer (Cat. 1)	Delivered by registered nurse (Cat. 2)	Specialist respite, delivered by CNS (Cat.3)	Total €	General (Cat. 1)	General plus (Cat. 2)	Specialist (Cat. 3)	Total €	
2011	520,567	603,046	157,576	1,281,189	277,430	189,821	67,532	534,784	1,815,973
2012	525,906	609,231	159,192	1,294,329	280,276	191,768	68,225	540,269	1,834,598
2013	533,915	618,509	161,616	1,314,040	284,544	194,688	69,264	548,496	1,862,536
2014	539,254	624,694	163,232	1,327,180	287,389	196,635	69,957	553,981	1,881,161
2015	547,263	633,972	165,656	1,346,891	291,658	199,555	70,996	562,208	1,909,099
2016	552,602	640,157	167,273	1,360,031	294,503	201,502	71,688	567,693	1,927,725
2017	557,941	646,342	168,889	1,373,172	297,348	203,449	72,381	573,178	1,946,350
2018	563,281	652,527	170,505	1,386,312	300,194	205,396	73,074	578,663	1,964,975
2019	565,950	655,619	171,313	1,392,882	301,617	206,369	73,420	581,406	1,974,288
2020	571,289	661,804	172,929	1,406,023	304,462	208,316	74,112	586,891	1,992,914
2021	576,628	667,990	174,545	1,419,163	307,308	210,263	74,805	592,376	2,011,539

**TABLE 13 Projected cost (€) of respite care, 2011-2021 – HSE SOUTH**

Year	In-the-home respite (70% of total hours)				Out-of-home respite (30% of total hours)*				Overall Total €
	Delivered by healthcare assistant/ carer (Cat. 1)	Delivered by registered nurse (Cat. 2)	Specialist respite, delivered by CNS (Cat.3)	Total €	General (Cat. 1)	General plus (Cat. 2)	Specialist (Cat. 3)	Total €	
2011	560,611	649,434	169,697	1,379,742	298,771	204,422	72,727	575,921	1,955,663
2012	568,620	658,712	172,121	1,399,453	303,039	207,343	73,766	584,148	1,983,601
2013	576,628	667,990	174,545	1,419,163	307,308	210,263	74,805	592,376	2,011,539
2014	581,968	674,175	176,161	1,432,304	310,153	212,210	75,498	597,861	2,030,164
2015	589,976	683,452	178,586	1,452,014	314,421	215,130	76,537	606,088	2,058,102
2016	597,985	692,730	181,010	1,471,725	318,689	218,051	77,576	614,316	2,086,040
2017	600,655	695,822	181,818	1,478,295	320,112	219,024	77,922	617,058	2,095,353
2018	605,994	702,007	183,434	1,491,435	322,957	220,971	78,615	622,543	2,113,978
2019	608,663	705,100	184,242	1,498,006	324,380	221,944	78,961	625,285	2,123,291
2020	694,090	804,061	210,101	1,708,252	369,907	253,094	90,043	713,045	2,421,297
2021	616,672	714,378	186,666	1,517,716	328,648	224,865	80,000	633,513	2,151,229

\* Out-of-home respite costs do not include overheads, e.g. water, light, heat, cleaning, catering, etc., nor administration or management costs.

### 3.11 Limitations of the financial projections

There are a number of limitations to the financial projections in this respite needs assessment.

- As there is currently a dearth of financial information regarding the provision of respite services for children with life-limiting conditions, the projections above represent the **total cost** of funding respite services, and *do not take into account services already provided*. Thus, **the cost of providing new funding for respite care may be significantly less than estimated**.
- The projected costs of providing respite care are based on figures supplied by the Jack & Jill Foundation and LauraLynn, Ireland's Children's Hospice. The figures provided by the former are specific to the Jack & Jill Foundation. The figures provided by LauraLynn are based on the average costs at the mid-point of the HSE's consolidated pay scales.
- Neither the Consumer Price Index nor any equivalent measure of inflation has been applied. This may have an impact, especially given the current uncertainty surrounding Irish economic projections.
- The capital expenditure required to upgrade/develop the required out-of-home service locations has not been factored into these financial projections.

# ↘ SECTION 4

## Conclusion and implementation

### 4.1 Introduction

This needs assessment has found that while respite services for children with life-limiting conditions are currently provided in all four HSE administrative regions, access to these services is often dependent on the child's geographical location and diagnosis. The projected need for respite service provision has been clearly identified and, bearing in mind the limitations of the financial projections, the cost of providing these services has been estimated. One of the main challenges to identifying and developing respite services for children with life-limiting conditions and their families is ensuring consistency among services providers regarding the definitions and terminology used in children's palliative care and in respite provision for this group of service users.

The objectives of this study were to:

- Estimate the number of children in the HSE South and HSE West administrative regions who are living with a life-limiting condition and whose families need or have access to respite services.
- Where possible, update the information provided in the previous report on HSE Dublin Mid-Leinster and Dublin North-East.
- Establish as accurately as possible current service levels and location of care.
- Where possible, identify the gap between the projected need for respite services for children with life-limiting conditions (based on age, location and condition) and the current level of respite care provided.
- Estimate the cost of providing appropriate services to such children, based on population estimates.

### 4.2 Current service provision – the main issues

#### Terminology

There is a lack of consistency among service providers and other stakeholders regarding the terminology used in children's palliative care, including the terms 'life-limiting' and 'respite'. This may have resulted in organisations under-reporting available service provision, and thus the findings may not present a complete picture of the respite services that exist in each of the four HSE regions. This lack of clarity may also make it more difficult for families to identify which services they can access and how.

Future work should include a mapping of respite services for children with life-limiting conditions at a regional level.

## **Accessibility**

Although there are a number of known established providers of respite to children with life-limiting conditions and their families, in many cases access to services may be on an ad-hoc basis. There are also services which would not consider themselves to be providers of respite to children with life-limiting conditions, but which may actually provide appropriate services. Further work is needed to establish whether these would be (a) willing and able to identify themselves as providing these services, and/or (b) capable of developing their services to meet the needs of children with life-limiting conditions and their families.

## **Standards**

There are currently no standards for the provision of respite care for children with life-limiting conditions and their families, either nationally or internationally. It is recommended that the National Development Committee for Children's Palliative Care examine the feasibility of developing such standards.

## **Equity of service provision**

The findings of this needs assessment confirm that the provision of respite services to children with life-limiting conditions and their families is still dependent on diagnosis and location rather than on need. Because of the data collection issues discussed above, it is impossible at this time to clearly establish the gap between the projected need for respite services for children with life-limiting conditions (based on age, location, condition) and the current level of respite care provided.

## **Assessment and evaluation processes**

During the data collection process, it became evident that families of children with life-limiting conditions may not undergo assessment and evaluation processes to establish and monitor their respite needs.

It is clear that an assessment process applied across the board for all families would assist in the delivery of equitable, needs-based services. There are a number of assessment tools in development within the health sector which could be used to assess the need for respite care, including the TCD children's framework report (Buckley et al, 2006) and other instruments being developed by the HSE.

## **Quality of services**

An examination of the quality of respite services provided to children with life-limiting conditions and their families was not covered in this study. The development of national standards is required and should include consideration of how high-quality patient and family oriented services, which complement other services, can be developed.

### 4.3 Recommendations and implementation of findings

This needs assessment indicates that if the required appropriate respite services are to be provided, a number of key actions need to be undertaken. The following recommendations are made:

1. The National Development Committee for Children's Palliative Care should progress the following through its programme of work:
  - Oversee the development of national standards for the provision of both in-the-home and out-of-home respite care for children with life-limiting conditions and their families.
  - Examine the feasibility of developing an assessment tool for respite services.
  - Promote understanding of the terminology used in children's palliative care (including respite care) among service providers and stakeholders.
  - Recommend the establishment of regional groups to oversee the development of services for children with life-limiting conditions and their families – see (2) below.
2. A regional group with a remit to further develop the findings of this report should be established in each HSE region. Representation should include paediatrics, disability services, acute and community services and specialist palliative care. Each group should also include a regional outreach nurse for children with life-limiting conditions. Each group should:
  - Map the full range of existing respite services for children with life-limiting conditions and their families.
  - Identify the needs of families for both in-the-home and out-of-home respite.
  - Identify where respite services need to be developed / provided.
  - Plan for the development and provision of respite services.
  - Ensure that national standards, when developed, are implemented across the region.

The children's outreach nurses should play a lead role in this.

3. Where out-of-home respite is required, health services should work with regional service providers (voluntary and statutory) to ascertain:
  - where in-patient respite care is needed
  - whether facilities/services are currently available that may be able to meet the needs of children with life-limiting conditions and their families, and which are willing to ensure that they have both the physical environment and appropriate staff skills and experience to do so.
  - whether additional facilities are required to meet the needs of families.
4. The education and on-going support needs of those organisations providing respite should be considered both national and regionally.
5. It is projected that the need for respite services for children with life-limiting conditions will grow steadily over the period analysed, up to 2021. It is strongly recommended that projections of future need should be reviewed and based on accurate Irish datasets. This needs assessment should be repeated in four years' time.

## 4.4 Conclusion

It is estimated that the development and provision of in-the-home and out-of-home respite care, as outlined in this needs assessment, may require a total budget of approximately €7.6m per annum, rising to approximately €8.62m per annum by 2021. Through a partnership approach, the appropriate re-structuring of existing respite provision and the development of new services over time will ensure that the respite needs of children and their families can be met.

This needs assessment arose from one of the recommendations of the Government's children's palliative care policy, published in 2010 (DoHC, 2010). Since then, a number of that policy's key recommendations have been implemented, including the establishment of the National Development Committee for Children's Palliative Care, which has responsibility for implementing the policy and oversees the development of children's palliative care services across the country. Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine has been appointed, and regionally-based outreach nurses for children with life-limiting conditions have been (and are currently being) appointed. A programme of education / training on caring for children with life-limiting conditions has been established, and the development of a Minimum Data Set is nearing completion.

This study has identified a requirement for a range of respite care services to be developed in a coordinated and structured way to meet the needs of 816 children currently, and up to an estimated 925 children by 2021. Its findings should underpin the development and planning of responsive respite services for children with life-limiting conditions and their families.

It is hoped that an update of this needs assessment in 2017 will identify tangible improvements in the provision of respite services for children with life-limiting conditions and palliative care needs and their families.



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# ➤ Appendices

## APPENDIX 1 Steering Committee and Authors/Project Team

### Steering Committee

Name	Role/organisation
Sharon Foley	Chief Executive Officer, Irish Hospice Foundation
Philomena Dunne	Chief Executive Officer, LauraLynn, Ireland's Children's Hospice
Mary Devins	Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine, Our Lady's Children's Hospital, Crumlin
Sheilagh Reaper-Reynolds	General Manager-Palliative Care, Acute Hospital Services, HSE

### Authors/Project Team

Name	Role/organisation
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Claire Quinn	Head of Education & Research, LauraLynn Ireland's Children's Hospice / Lecturer, NUI Galway
Eugene Murray	Research Consultant

## APPENDIX 2 Regional Support Groups

### HSE South

Sean Abbott	Cope Foundation, Cork
Eileen O’Leary	Regional Support (Palliative Care) HSE South
Suzanne Moloney	Interim Disability Specialist, Cork
Carol Moore	Area Co-ordinator, Disability Services, HSE South, Co. Tipperary
Monica Sheehan	Director of Public Health Nursing, Kerry
Anne Sheehan	A/Care Group Coordinator, Disability Services, Kerry
Eilin Ni Mhurchu	Liaison Nurse, Jack & Jill Foundation

### HSE West

Pat Quinlan	Chief Executive, Milford Care Centre, Limerick
Fergal Flynn	Local Health Manager, HSE West
Jacqueline Gibson	Director of Public Health Nursing, Limerick
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Mary Connor	Clinical Nurse Specialist Paediatric Liaison, Sligo
Brian Malone	Case Manager, Disability Services, Galway

### **APPENDIX 3 International Classification of Disease (ICD) codes used to define life-limiting conditions \***

<b>Code</b>	<b>Category</b>
140 – 239	Neoplasms
240 – 279	Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders
280 – 289	Diseases of Blood and Blood-forming Organs
320 – 389	Diseases of the Nervous System and Sense Organs
390 – 459	Diseases of the Circulatory System
488 – 519	Diseases of the Respiratory System (excluding acute respiratory infections)
520 - 579	Diseases of the Digestive System
580 – 629	Diseases of the Genitourinary System
710 – 739	Diseases of the Musculoskeletal System and Connective Tissue
740 – 759	Congenital Abnormalities
760 - 779	Conditions Originating in the Perinatal Period

\* Codes and categories identified by ACT: Association for Children with Life-Threatening or Terminal Conditions and their Families.

## APPENDIX 4 ACT Care Pathway



## **APPENDIX 5 Disability Act 2005: Assessment of Need**

Part 2 of the Disability Act 2005 establishes a system for the assessment of individual health service needs occasioned by the disability and, where appropriate, education needs for persons with disabilities aged 18 years or over. Part 2 was commenced for children under the age of five with effect from 1<sup>st</sup> June 2007.

Part 2 provides a statutory entitlement to:

- An independent assessment of health and education needs;
- A statement of the services (Service Statement) to be provided;
- A complaints process through an independent redress mechanism if there is a failure to provide these entitlements.

Persons with a disability entitled to the services in Part 2 are those with a “substantial restriction” which is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and gives rise to the need for services to be provided continually to the person, whether or not a child, or, if the person is a child, for services to be provided early in life to ameliorate the disability

Any person who considers that he or she may have a disability is entitled to apply for an independent assessment of need. The assessment will be undertaken without regard to cost or to capacity to provide any services identified in the assessment. The Health Information and Quality Authority (HIQA), has set appropriate standards for carrying out the assessment process.

Arising from the assessment, the person concerned will be given an Assessment Report. The Assessment Report will indicate:

- whether a person has a disability;
- the nature and extent of the disability;
- the health and education needs arising from the disability;
- the services considered appropriate to meet those needs and the timescale ideally required for their delivery;
- when a review of the assessment should be undertaken.

There is provision for a relative, guardian or personal advocate to apply for an assessment on behalf of a person with a disability. Each person with a disability will be encouraged to participate in his/her own assessment while taking account of the nature of his/her disability and his/her age. This will also include taking account of his/her views regarding their needs or preferences in relation to the provision of services.

Each person found to have a need for disability related health and/or education services, as a result of the Assessment Report, will be given a Service Statement. The Service Statement will set out the health and education services that will be provided to the person taking account of:

- the Assessment Report;
- eligibility criteria for services;
- relevant standards and Codes of Practice;
- the practicability of providing the service;
- the financial resources available.

The individual or his/her advocates will be invited to participate in a review of the provision of services specified in the Statement at intervals determined by regulations.

Under Section 12 of the Act there is provision for informing, with the necessary consent of the person concerned, other public bodies about the contents of an Assessment Report so as to facilitate access to assessment for services outside the health and education sectors.

Section 13 of the Act requires the HSE to keep records of assessments and services provided, levels of unmet needs and the numbers of persons involved. The maintenance of these records will be in accordance with the requirements of data protection legislation.



**APPENDIX 6 Project Advisory Group and external consultation for the HSE Dublin Mid-Leinster/Dublin North-East children’s respite needs assessment (2011)**

<b>Project Advisory Group, 2011 report</b>	
<b>Name</b>	<b>Role/organisation</b>
Joanne Balfe	Consultant Paediatrician, Children’s Sunshine Home
Philomena Dunne	Chief Executive Officer, Children’s Sunshine Home
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Sharon Vard	Co-Founder, Anam Cara

### External consultation, 2011 report

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