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

**A Needs Assessment for
HSE Dublin/Mid-Leinster
and HSE Dublin/North-East**

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Foreword

A child's needs are very different from those of an adult. This is also true of the child with a life-limiting illness who is approaching the end of life. What most families want in these circumstances is for their child to be able to die at home in his or her own bed, surrounded by loved ones, family pets and familiar toys.

This needs assessment has been completed to assist with the implementation of the Government's recently published policy document, *Palliative Care for Children with Life-Limiting Conditions – a National Policy* (Department of Health & Children, 2010), and in particular, that document's recommendation that a comprehensive children's palliative care service needs to operate within a cooperative model, with close liaison between all stakeholders and relevant service providers. Another key recommendation is the establishment of a National Development Committee for Children's Palliative Care. It is envisaged that the development and monitoring of an implementation plan to carry the findings of this needs assessment forward will be led by this committee.

Caring for a child with a life-limiting illness is inevitably a huge challenge for parents and siblings, who themselves need all the support they can get. An essential element of carer support for these families is access to respite services, both within the home, and, when needed, outside of the home, in a dedicated unit with appropriate paediatric palliative care facilities and skilled staff.

This report, prepared by Prospectus Consulting with the support of a broad-ranging advisory group, represents a first step in identifying the respite care needs of the 1,400 children and their families coping with a life-limiting condition in Ireland. While confined to a specific geographic area, its findings have relevance for the country as a whole. We believe that it provides evidence and guidance for policy makers and service providers throughout Ireland. We hope that it will contribute to the development of a fully comprehensive and cohesive nationwide palliative care service for children in Ireland.

We would like to thank the members of the Project Team and Advisory Group, together with all who participated in the consultation process, for their valued contribution to this project. Our thanks also to Julie Ling for acting as special advisor to the project and for her editorial input.

We take this opportunity to re-state the hospice movement's commitment to ensuring that the needs of all children with life-limiting conditions in Ireland, and their families, are addressed.

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Executive Summary

In 2010, the Department of Health and Children published *Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy*¹. Adopted by Government, this policy provides the foundation upon which children's palliative care services should be developed in Ireland.

Respite is a significant component of care for many children with life-limiting conditions and their families. This is reflected in the policy document, which proposed that:

- A range of respite services should be developed for children with life-limiting conditions who have palliative care needs.
- 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.
- Each HSE administrative area 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 existing respite facilities. In response, and in order to assist with the implementation of the policy, the Children's Sunshine Home and the Irish Hospice Foundation set out to identify existing services and to assess current and future need within two administrative areas of the Health Service Executive (HSE). This report documents the findings of that exercise, which specifically focused on the HSE's Dublin Mid-Leinster and Dublin North-East areas.

The need for a palliative respite service for children with life-limiting conditions is projected to steadily grow over the period analysed: 2010-2021. A range of respite care programmes, developed in a structured and coordinated way, will be required to meet the needs of 411 children currently and up to 478 children in the areas studied 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 €10m per annum, rising to €12m-plus by 2021. This assumes a 70:30 ratio between in-the-home and out-of-home respite.

Caring for a child with a life-limiting condition at home can be challenging for the whole family, often proving both physically and emotionally demanding. Regular respite provides temporary relief from the daily demands of care-giving and allows parents to spend time with their other children. Respite services may obviate the need for parents to consider full-time residential care for their child.

The respite care needs of children and families are dynamic, changing over time, so that service plans and delivery need to be flexible and responsive. Respite care should therefore be available both within the family home and outside of it, for example in a children's hospice.

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 the point where hospitalisation becomes necessary, and because many tests and procedures may be completed as part of a respite programme.

¹ Department of Health & Children (2010), *Palliative Care for Children with Life-Limiting Conditions in Ireland, A National Policy*. Stationery Office, Dublin

Glossary & Definitions

ACT

The Association for Children with Life-threatening or Terminal Conditions and their Families

RCPCH

The Royal College of Paediatrics and Child Health

Child

Person below the age of 18 years²

Children's palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite, and care through death and bereavement³.

Life-limiting conditions

Life-limiting conditions are those for which there is no reasonable hope of cure, from which children or young people will die⁴.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail (e.g. cancer). Children in long-term remission or following successful curative treatment are not included.

Palliative care

Palliative care improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual⁵.

Specialist palliative care

Specialist palliative care services are those whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs which require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services⁶.

² Government of Ireland (2001), *Children's Act*. Stationery Office, Dublin

³ Association for Children with Life-Threatening or Terminal Conditions and their Families/Royal College of Paediatrics and Child Health (ACT/RCPCH) (2003), *A Guide to the Development of Children's Palliative Care Services*. Bristol.

⁴ Department of Health & Children (2009), *Palliative Care for Children with Life-limiting Conditions in Ireland – a National Policy*. Stationery Office, Dublin

⁶ Department of Health and Children (2001), *Report of the National Advisory Committee on Palliative Care*. Stationery Office, Dublin

Respite care

Care provided by appropriately trained individual(s) for a specified period of time for children with life-limiting conditions, thus providing temporary relief to their usual care-giver⁷.

For the purposes of this needs assessment, **respite care** is further defined as intermittent care provided on an-going basis by individual(s) contracted to do so.

In-the-home respite involves the provision of supports to care-givers in a home setting (e.g. as provided by the Jack & Jill Foundation)

Out-of-home respite involves the provision of supports to care-givers in settings outside of the home (e.g. residential facility, hospice)

Carer-delivered respite

Carer-delivered respite involves the provision of help and support to parents by another person, usually a relative or friend. A carer will typically tend to the needs of the child when his/her parents are otherwise occupied and generally help with daily living requirements.

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 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 management⁸.

Levels of palliative respite care⁹

- *Level 1* – Respite care where palliative care principles are appropriately applied by all health care professionals and carers
- *Level 2* – This intermediate level of care is delivered by health care professionals who, although not engaged full-time in palliative care, have had some additional training and experience in palliative care.
- *Level 3* – The final level of care involves the provision of specialist palliative care by health care professionals whose core activity is limited to the delivery of palliative care

⁷ Horsburgh, M., Trenholme, A. and Huckle, T. (2002), Paediatric respite care: a literature review from New Zealand. *Palliative Medicine* 16:99-105

⁸ Department of Health and Children (2001), *Report of the National Advisory Committee on Palliative Care*. Dublin: Stationery Office, Dublin.

⁹ Department of Health & Children/Irish Hospice Foundation (2005) *A Palliative Care Needs Assessment for Children*. Stationary Office, Dublin

Section 1: Defining and describing respite care in children's palliative care

1.1 Introduction

One of the challenges in discussing children's palliative care is that definitions used can be ambiguous. Defining what constitutes a life-limiting condition is challenging and requires more than a simple diagnosis. There is a dearth of accurate data on the number of children living with a life-limiting condition who require respite services. In some cases there is an overlap between children's palliative care services and disability services, and it is therefore sometimes unclear whether the respite care that children are receiving is 'palliative' or part of a regular disability respite service. This poses challenges both for service users and for planners and providers of respite care for children with life-limiting conditions.

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 service provision. Issues to be considered in responding to the respite needs of children with life-limiting conditions are referred to. 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

1.2.1 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. While the majority of children with such a condition are unlikely to live beyond 18 years, some, whose diagnosis is made in childhood, will survive unexpectedly into early adulthood¹⁰. Life-limiting conditions in children can be diagnosed either prior to birth or during childhood, with the anticipation that the condition will lead to premature death.

The Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) in the United Kingdom (UK) defines a life-limiting condition as "one for which there is currently no cure available and the likelihood is that the condition will lead to the child dying prematurely"¹¹. Four broad categories of condition have been identified (Table 1). However, ACT points out that diagnosis is only part of the process of defining a child as having a life-limiting condition, suggesting that the severity and spectrum of the disease, subsequent complications and the impact on and needs of the child and family also need to be considered.

¹⁰ Association for Children with Life-Threatening or Terminal Conditions and their Families/Royal College of Paediatrics and Child Health (ACT) (2003), *A Guide to the Development of Children's Palliative Care Services*, Bristol.

¹¹ ACT (2007), *A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*. Bristol

Table 1. ACT categories of life-limiting conditions

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: <i>cancer, irreversible organ failures of heart, liver, kidney.</i>
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: <i>cystic fibrosis.</i>
3.	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: <i>Batten Disease, muscular dystrophy, mucopolysaccharodosis.</i>
4.	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: <i>severe cerebral palsy; multiple disabilities, such as follow brain or spinal cord injury.</i>

ACT has detailed the recommended range of service delivery options for families where a child has been diagnosed with a life-limiting condition. Care plans are developed on the basis of a multi-agency 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. (ACT Care Pathway, Appendix 7)

1.2.2 Children’s palliative care

Palliative care for children is a small 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 therefore professionals and care-givers supporting children require specific training and expertise to deal with their unique needs. Ideally, support for children 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 marked overlap between the needs of children requiring palliative care and those with disabilities and other complex care needs¹². 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 require care (including respite care) over several 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 the child’s personal and nursing care. Respite is a key component of this care.

1.2.3 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 care-giver*”¹³. Respite is an essential

¹² Department of Health UK (2005), *Palliative care services for children and young people in England: an independent review for the Secretary of State for Health.* Department of Health.

¹³ Horsburgh, M., Trenholme, A. and Huckle, T. (2002), Paediatric Respite Care: A Literature Review from New Zealand. *Palliative Medicine* 16, 99-105.

element of a comprehensive palliative care service for children with life-limiting conditions and their families, providing a break for both child and family. (See Appendix 8, *Case Histories*, for an insight into the day-to-day life of children with life-limiting conditions and their families.)

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.

Respite needs are dynamic and likely to change over time, posing challenges for the providers of respite care.

Caring for a child at home with complex care needs can be challenging for the whole family, with many parents finding care provision to be both physically and emotionally stressful¹⁴. Often, despite initial reluctance to use respite services, they find respite beneficial,¹⁵ enabling them to have a break from the routine of caring and to spend more time, for example, with their other children.

ACT UK (2009) gives seven examples of the type of short breaks families may require to enable them to care for their life-limited child (Table 2.)

Table 2. Short break provision (ACT, 2009)¹⁶

Hospice/hospice at home – help 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.

¹⁴ Llewellyn, G., Dunn, P., Fante, M., Turnbull, L., Grace, R. (1999), Family Factors Influencing Out-of-Home Placement Decisions. *Journal of Intellectual Disability Research*, 43, 219-233

¹⁵ Eaton, N. (2008), “I Don’t Know How We Coped Before”: A Study of Respite Care for Children in the Home and Hospice. *Journal of Clinical Nursing*, 17, 3196-3204

¹⁶ ACT (2009), *A Guide to the Development of Children’s Palliative Care Services*, Bristol

1.2.4 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 actual provision of respite care for children with life-limiting conditions. The international literature has established that respite care is insufficient and yet essential in addressing the palliative care needs of children. A study to establish the incidence and prevalence of children with palliative care needs in Wales¹⁷ found that respite care was one of the key needs reported by paediatricians. In the UK¹⁸, 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. Both in-the-home and out-of-home respite were found to have many benefits, especially if services are designed with flexibility in mind to meet the changing needs of individual families and their children.

The European Association of Palliative Care (EAPC) has produced standards¹⁹ for the development of children's palliative care. These standards suggest that:

- Respite for family carers and the child is 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.

They also suggest that: "Every family shall have access to flexible respite care in their own home and in a home-from-home setting, with appropriate paediatric multidisciplinary care."

1.2.5 Irish policy background, and types of respite care

The essential role of respite in the provision of palliative care for children with life-limiting conditions and their families has been recognised in the following two Department of Health and Children publications.

¹⁷ Hain, R.D.W. (2005), Palliative Care in Children in Wales: A Study of Provision and Need. *Palliative Medicine* 2005; 19:137-142

¹⁸ Eaton, N. (2008), 'I don't know how we coped before': a study of respite care for children in the home and hospice. *Journal of Clinical Nursing*, 17, 3196-3204.

¹⁹ Craig, F., Abu-Saad Huijjer, H., Benini, F., Kuttner, L., Wood, C., Feraris, P.C. and Zernikov, B. (2008), IMPaCCT: Standards of Paediatric Palliative Care in Europe. *European Journal of Palliative Care* 14(3), 109-114.

1.2.5.1 A Palliative Care Needs Assessment for Children (2005)²⁰

An assessment of the palliative care needs of children in Ireland was published in 2005 by the Department of Health & Children/Irish Hospice Foundation. It was based on the findings of a research project undertaken by a team of researchers from University College Dublin²¹. The project 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 9)
- ACT categories of life-limiting conditions (See Table 1)
- UK data on the prevalence of children with life-limiting conditions

By using these data, in 2002 it was estimated that on average 370 children died in Ireland each year from a life-limiting condition, the majority (57%) in the first year of life. It was also estimated that the number of children living with a life-limiting condition and thus requiring ongoing support was 1,369, with an estimated rise to 1,610 by the year 2021. (A proviso warned that these figures were likely to be underestimates.) A prevalence rate of 12 children per 10,000 was used to provide these figures.

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, differing 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 the children's palliative care 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 (p. 50) that: "*locally based, child-friendly and readily accessible respite facilities must be a priority in the development of a 'seamless' system of care.*"

1.2.5.2 Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2010)²²

Building on the findings of the afore-mentioned needs assessment, the Department of Health and Children went on to develop a policy, documented in the report, *Palliative Care for Children with*

²⁰ Department of Health & Children/Irish Hospice Foundation (2005), *A Palliative Care Needs Assessment for Children* (2005), Stationery Office, Dublin

²¹ Quin., S, Clarke, J. and Murphy-Lawless, J. (2005), *Report of a Research Study of the Palliative Care Needs of Children in Ireland*, unpublished. See: http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=242&Itemid=112

²² Department of Health & Children (2010), *Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy*. Stationery Office, Dublin.

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. Its recommendations include the appointment of a consultant paediatrician with a special interest in palliative care and a national network of eight children's palliative care outreach nurses.

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

- Inpatient hospice beds specifically for respite should be developed as part of the children's palliative care service.
- 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.

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 needs assessment, in-the-home respite has been further broken down 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 purposes of this needs assessment, out-of-home respite has been 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. It 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 recommends that: “a range of respite services should be developed for children with life-limiting conditions and palliative care needs”.

Specialist respite

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.

At present, specialist respite care is not available in Ireland but is in other countries and jurisdictions. However, it is suggested in the national policy that there is a need for new or extended services to be developed, including statutory/voluntary partnerships.

1.3 National overview of existing respite services

In Ireland, children with life-limiting conditions are usually cared for at home, with their parents as the main carers. Additional supports, including respite, are often provided by statutory and voluntary care providers. Some providers of respite care for children with life-limiting conditions are national organisations, such as the Jack and Jill Foundation and the Brothers of Charity; while others are locally-based. Both of the Irish national reports on children’s palliative care – *A Palliative Care Needs Assessment for Children* and *Palliative Care for Children with Life-limiting Conditions: A National Policy* – found that there was a dearth of information on the provision of respite care, so that 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, usually from clinicians caring for the child and his or her family. Ideally the need for respite care should be assessed, and a programme of respite tailored to meet the individual needs of the child and family. Where available, respite 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. Currently, the HSE fulfils a limited coordination and direct-delivery role in the provision of respite care to some children with life-limiting conditions.

1.3.1 Respite services and disability services

There is a marked overlap between the needs of children requiring palliative care and those who have disabilities and other complex care needs²³. Not all children with a disability have a life-limiting condition requiring palliative care, but some do, depending on the degree of complexity and urgency attached to their care and the support needs of their families²⁴. A number of centres, both public and voluntary, provide respite care for children with intellectual disabilities who also have a life-limiting condition; however, the majority of these would not consider their service as providing respite care as part of palliative care. It is uncertain how many children currently availing of respite care provided by disability services also have a life-limiting condition and require palliative care services.

The Disability Act 2005 includes provision for the establishment of an 'Assessment of Need' process that focuses on disability and education needs (see Appendix 6). 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 five years of age. This has assisted families to access a range of services, including respite care, in accordance with their specific needs including in the HSE's Dublin Mid-Leinster and the Dublin North-East administrative areas.

1.4 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:-

- 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.

²³ Department of Health UK (2005), *Palliative care services for children and young people in England: an independent review for the Secretary of State for Health*. Department of Health

²⁴ ACT (2009), *A Guide to the Development of Children's Palliative Care Services*, Bristol.

Both in-the-home and out-of-home respite should be available, or a combination of both, and within an appropriate care setting. Respite care needs are dynamic, changing over time; the planning and delivery of services therefore needs to be flexible and responsive in order to meet these needs. Respite services may obviate the need for parents to consider full-time residential care for their child.

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.

1.5 Clinical governance in children's respite care services

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 supports.

It is recommended that each organisation providing respite care should develop a clinical governance framework which will enable the delivery of safe and robust services to children, young people and their families.

The framework 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.

1.6 Conclusion

Caring for a child with a life-limiting illness at home is potentially 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 disabilities and children with palliative care needs (and 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: Respite services for children with life-limiting conditions in the HSE Dublin Mid-Leinster and Dublin North-East administrative areas

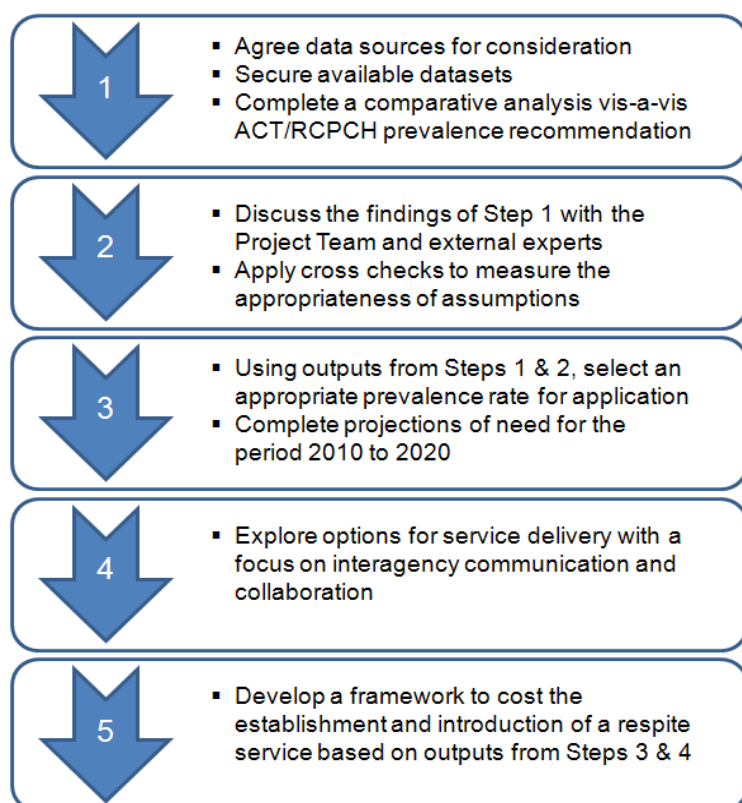
2.1 Introduction

In Section 2, the methodology of this respite needs assessment is described. Demographic data for the HSE Dublin Mid-Leinster and Dublin North-East areas are presented, and findings on respite services as currently provided within these areas for children with life-limiting conditions are presented. Providers of both in-the-home and out-of-home respite care are described.

2.2 Methodology

A five-step approach was used to complete this needs assessment as outlined below. In order to support the completion of all required outputs, a Project Team (Appendix 1) and Project Advisory Group (Appendix 2) were established. The methodology employed was supported by a total of four Advisory Group meetings and eight meetings of the Project Team throughout the duration of the project. The work of the group took place between September 2009 and March 2010, and the findings reflect service provision at this time.

Figure 1. Needs assessment methodology



2.3 Overview of the catchment area

This assessment set out to identify the need for respite care for children with life-limiting conditions in two specific administrative areas of the Health Service Executive:

- **HSE Dublin North-East**, comprising North County Dublin and Counties Cavan, Monaghan, Louth and Meath.
- **HSE Dublin Mid-Leinster**, comprising South County Dublin and Counties Wicklow, Kildare, Laois, Offaly, Westmeath and Longford.

According to the 2006 Census, a total of 516,535 children reside within the boundaries of the two areas under scrutiny. The child populations for each county are shown in Figure 3.

Dublin is the largest city in the Irish Republic and this is reflected in the child population figures, with over 50% of the total for the two HSE administrative areas being resident in Dublin city and county.

At present there are three tertiary paediatric hospitals in Ireland, and all are in Dublin. There is a concentration of services in the capital, including some providers of out-of-home respite care to children with life-limiting conditions.

Figure 2. Catchment area, with counties

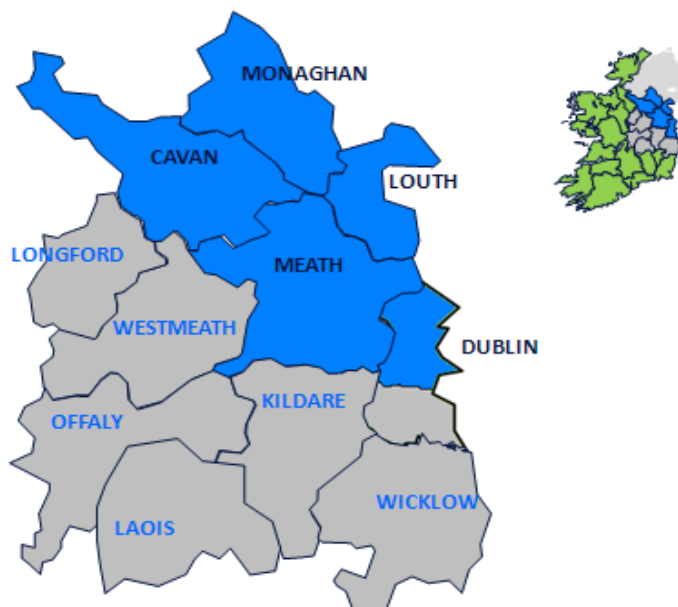
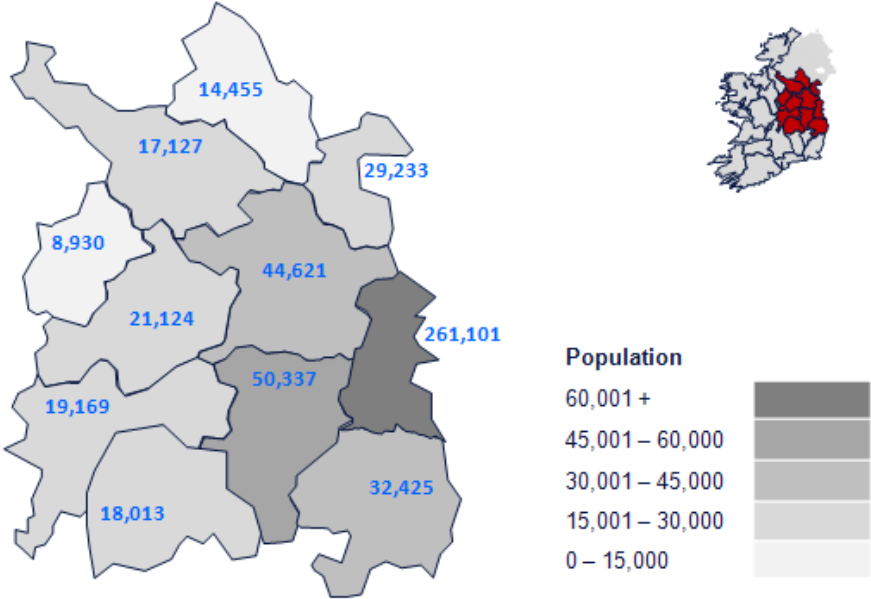


Figure 3. Child population of catchment area, by county



Source: CSO Census 2006

2.4 Respite services in the catchment area

One of the significant findings of *A Palliative Care Needs Assessment for Children* was that services (including respite care) for children with life-limiting conditions and their families were inequitable, varying according to diagnosis and the location of the family home. While the provision of respite care varies both within and between Dublin Mid-Leinster and Dublin North-East, appropriate respite care is not available to all families of a child with a life-limiting condition.

Whilst defining a life-limiting condition is not as simple as just using a diagnosis, certain services, including some respite services, are 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) living in HSE Dublin Mid-Leinster and Dublin North-East 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. Families of children with other conditions or without a definitive diagnosis may find accessing respite services particularly challenging.

Where respite care is provided to families of children with life-limiting conditions in the HSE Dublin Mid-Leinster and Dublin North-East areas, 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.

2.4.1 In-the-home respite care

In the HSE Dublin Mid-Leinster and Dublin North-East areas, in-the-home respite for children with life-limiting conditions is often 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. This can involve the provision of care by a registered children's nurse or registered general nurse, a hospice-at-home nurse or 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. One national voluntary organisation providing respite care is the Jack and Jill Foundation.

The Jack and Jill Foundation

The Jack & Jill Foundation is a national voluntary organisation providing early-intervention home respite to families with children up to the age of four who have severe neurological developmental delay and palliative conditions requiring extensive medical and nursing care at home. The Foundation provides direct funding to these families to enable them to purchase in-the-home respite care. Families of children meeting these criteria are allocated a Liaison Nurse. The nurse supports the families in an advisory capacity and reviews their respite requirements on an ongoing basis. Jack and Jill has played a significant role in the provision of respite care to families within both the HSE Dublin Mid-Leinster and Dublin North-East areas. The service provided is, however, restricted at present to children up to the age of four.

Currently, Jack and Jill provide respite service funding to 126 children within the area under scrutiny, as detailed in Table 3. (See also Appendix 8, *Case Histories*).

Table 3. Jack and Jill Foundation activity data, 2008/09

County	2008 Referrals	2009 Referrals (Jan-Oct)	Total open/active cases (Oct 2009)	Open/active respite cases
Cavan	1	3	10	10
Monaghan	4	1	6	6
Louth	3	2	5	5
Meath	3	3	11	11
Kildare	5	4	14	14
Wicklow	3	1	7	7
Westmeath	1	2	5	5
Longford	0	2	2	2
Laois	1	0	2	2
Offaly	1	2	3	3
Dublin	24	17	61	61
Total	46	37	126	126

2.4.2 Out-of-home respite care

Within the catchment area of this needs assessment, there are currently two centres in the Dublin area specifically providing out-of-home respite to children with life-limiting conditions: the Children's Sunshine Home in Leopardstown 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.

Table 4. Suzanne House respite activity profile, 2008

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

The Children's Sunshine Home

The Children's Sunshine Home was founded in 1925 and today provides transitional care from maternity and acute children's hospitals; home support; respite; and residential services to children with life-limiting and life-threatening conditions. The service works in partnership with the HSE and related voluntary agencies. The Children's Sunshine Home operates a multidisciplinary service that includes a Medical Director, Consultant Paediatrician, a nursing team and a range of allied health professionals. It takes referrals from both the HSE Dublin Mid-Leinster and Dublin North-East areas. (See Appendix 8, *Case Histories*.)

Table 5. Children's Sunshine Home activity data, 2008/09

County	2008 Referrals	2009 Referrals (Jan-Oct)	Total open/active cases (Oct.)	Open/active respite cases
Cavan	1	-	-	0
Monaghan	-	-	-	0
Louth	-	1	2	2
Meath	-	-	4	4
Kildare	-	1	5	5
Wicklow	-	2	2	2
Westmeath	1	-	-	0
Longford	-	-	-	0
Laois	-	-	-	0
Offaly	-	-	1	1
Dublin	12	19	28	28
Total	14	23	42	42

Since March 2010, the Children's Sunshine Home has opened Hazel House to expand its respite and transitional care programme for children with life-limiting conditions. The programme on offer at Hazel House is designed to facilitate all children with life-limiting and life-threatening conditions who require palliative care, in advance of the opening of the new children's hospice, LauraLynn House, anticipated in mid-2011.

The children supported at Hazel House have complex healthcare and medical needs. Many require continuous oxygen support, nippy ventilation and tracheostomy care and thus require round-the-clock support, seven days a week. The programme is designed around the individual needs of the child and his/her family, so families can avail of as little or as much out-of-home respite as is required to support their specific situation. The Transitional Care programme offers step-down placements for children from the acute hospital to home, and can then offer respite and crisis care as required. The children follow a care pathway from the moment of referral to discharge or exit from the service, and relevant aftercare is available for families following the death of a child. A multidisciplinary team supports the children and their families to ensure that all aspects of the child's care needs are holistically met through an integrated care plan. The team comprises nurses, healthcare assistants, physiotherapist, occupational therapist, speech and language therapist, dietician and paediatrician.

2.4.3 Other respite options

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

2.5 Conclusion

The provision of respite care services varies both within and between the two HSE administrative areas under study, but is available in neither area to *all* families who have a child with a life-limiting illness. 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.

Section 3: Future development of services to meet the respite needs of children with life-limiting conditions in HSE Dublin Mid-Leinster and Dublin North-East

3.1 Introduction

This section seeks to quantify and cost the projected need for respite services in the HSE Dublin Mid-Leinster and Dublin North-East administrative areas up to 2021. Child population projections for Ireland are used, based on CSO data; and national and international approaches to estimating the prevalence of children with life-limiting conditions are considered in order to arrive at likely rates for the area under study and assess future service need.

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 Projections²⁵ suggest that the child population of each of the two HSE areas under study is set to rise in the years up to and including 2021 (Table 6). That within the Dublin North-East area is projected to increase by approximately 15%; that within Dublin Mid-Leinster is projected to grow by 16% during the period 2011-2021.

Table 6. Child population projections, by HSE administrative area & constituent counties

Area	2006	2011	2016	2021
Dublin North	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
Total, Dublin North-East	213,406	233,556	253,464	268,365
Dublin South	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
Total, Dublin Mid-Leinster	303,129	336,686	368,979	390,967
Grand TOTAL	516,535	570,242	622,443	659,331

²⁵ Central Statistics Office (2008), Regional Population Projections 2011-2026. Ref: 235/2008

3.3 Quantifying the need for respite care

In order to provide a responsive and appropriate respite service to meet future need, information is needed both on the potential number of families likely to require respite services and on the care location, i.e. within the home or outside the home. In order to estimate these figures the following sources of data 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 assessment²⁶.

3.3.1 CSO data on childhood deaths

An analysis of CSO data relating to childhood deaths (0-17 yrs) registered in Ireland during 2008 was completed. The deaths were categorised using International Classification of Disease codes identified by ACT to define life-limiting conditions (Appendix 9). Diseases in any of the four ACT categories of life-limiting conditions (Table 1) were included²⁷. Upon completion of this exercise, a total of 75 children were identified as having died from a life-limiting condition.

3.3.2 Prevalence of children with life-limiting conditions

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.

3.3.2.1 Prevalence rates – Ireland

The children's palliative care needs assessment undertaken in 2002 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 similarity between UK and Irish prevalence rates, the figures might be higher.

3.3.2.2 Prevalence rates – UK

In the UK, the first edition (1997) of the *Guide to the Development of Children's Palliative Care Services*²⁸ 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 rate of 10 children with life-limiting conditions per 10,000 of child population. A number of local studies completed later suggested that this was an underestimate.

A second edition of the Guide was released in 2003²⁹. 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 in need of palliative care to be at least 12 per

²⁶ Department of Health & Children/Irish Hospice Foundation, *A Palliative Care Needs Assessment for Children*, Stationery Office, Dublin

²⁷ Association for Children with Life-Threatening or Terminal Conditions and their Families/Royal College of Paediatrics and Child Health (ACT/RCPCH) (2003), *A Guide to the Development of Children's Palliative Care Services*. Bristol. 2nd ed.

²⁸ ACT/RCPCH (1997), *A Guide to the Development of Children's Palliative Care Services*. Bristol. 1st ed.

²⁹ ACT/RCPCH (2003), *A Guide to the Development of Children's Palliative Care Services*. Bristol. 2nd ed.

10,000 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.

In the third and latest edition of this publication, ACT³⁰ suggests that the prevalence of children with life-limiting conditions ranges from 12 to 17 children per 10,000 population.

3.3.2.3 Prevalence rates – Wales

A study undertaken by Hain in Wales in 2005³¹ 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.

3.3.2.4 Prevalence rates – New Zealand

Prevalence rates in New Zealand were estimated by Jones *et al* (2002)³² through a combination of hospitalisation data and mortality data for all children aged 0-17 years during the period 1996 to 1998. Cases were classified as either 'palliative' or 'not palliative'. This element of the study was further supplemented by a separate analysis comparing international estimates of paediatric palliative care need.

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.

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 9). 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 favourably with the UK rate of 1 per

³⁰ ACT/RCPCH (2009), *A Guide to the Development of Children's Palliative Care Services*, Bristol. 3rd ed.

³¹ Hain, R.D.W. (2005) Palliative Care in Children in Wales: A Study of Provision and Need. *Palliative Medicine* 2005; 19:137-142

³² Jones, R., Trenholme, A., Horsburgh, M., Riding, A. (2002), The Need for Paediatric Palliative Care in New Zealand. *The New Zealand Medical Journal*. Vol 115, No 1163

10,000 (at the time of study completion). This 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.

3.3.2.5 Prevalence rates – Northern Ireland

The Northern Ireland Children's Hospice completed an *Assessment of Need of Life-limited Children in Northern Ireland* in 2000³³, 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 population.

3.4 Location of respite care (i.e. within the home/outside of home)

In line with the Irish national policy on palliative care for children with life-limiting conditions³⁴, this needs assessment has been completed on the basis that home is the care setting of choice for respite care. Influenced by consideration of practice to date in Northern Ireland, and following discussions by the Project Team and Project Advisory Group, a 70:30 split (i.e. 70% in-the-home respite; 30% out-of-home respite) has been agreed and applied to guide the quantification of future service delivery requirements. Although a clear preference for in-the-home respite care 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. 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, in the absence of accurate and contemporaneous data, estimates of the prevalence of life-limiting conditions in children have been used. These are based on both national and international experience, and aim to provide policy makers and service planners with a guide to the future need for respite services for children with a life-limiting condition.

The following assumptions have been accepted by the Project Team and Project Advisory Group in order to calculate projected respite need:

- For the purposes of this needs assessment, a prevalence rate of 14.5 per 10,000 has been agreed. This is the mid-point of the range, 12-17 per 10,000, as discussed above (3.3.2.2).
- 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.
- This analysis excluded children where death was recorded within six days of birth. It is assumed for the purposes of this cross-check that the families of these children would not have availed of or requested respite care, given the prognosis.
- The ACT/RCPCH 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.

³³ Northern Ireland Hospice Care (2000), *Assessment of Need of Life-Limited Children in Northern Ireland*

³⁴ Department of Health & Children, *A Palliative Care for Children with Life-Limiting Conditions: A National Policy*, Stationery Office, Dublin

- 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

Tables 7 and 8 provide a breakdown of the child population for all counties included in this respite needs assessment, along with estimated numbers of children with life-limiting conditions. These have been calculated using the application of the mid-point prevalence rate (14.5 children per 10,000 population) as recommended by ACT/RCPCH and agreed by the Project Advisory Group. ACT further recommend that approximately 50% of all children will have an 'active palliative care requirement' at any given time. This has been used to estimate the number of children who may require respite care at any given time. Future projections up to 2021 are also calculated in this way, but are coupled with CSO projections of child population changes.

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 2010 to 2021, including those already in place. Where respite services are already provided (by disability services, for example) it is envisaged that this will continue.

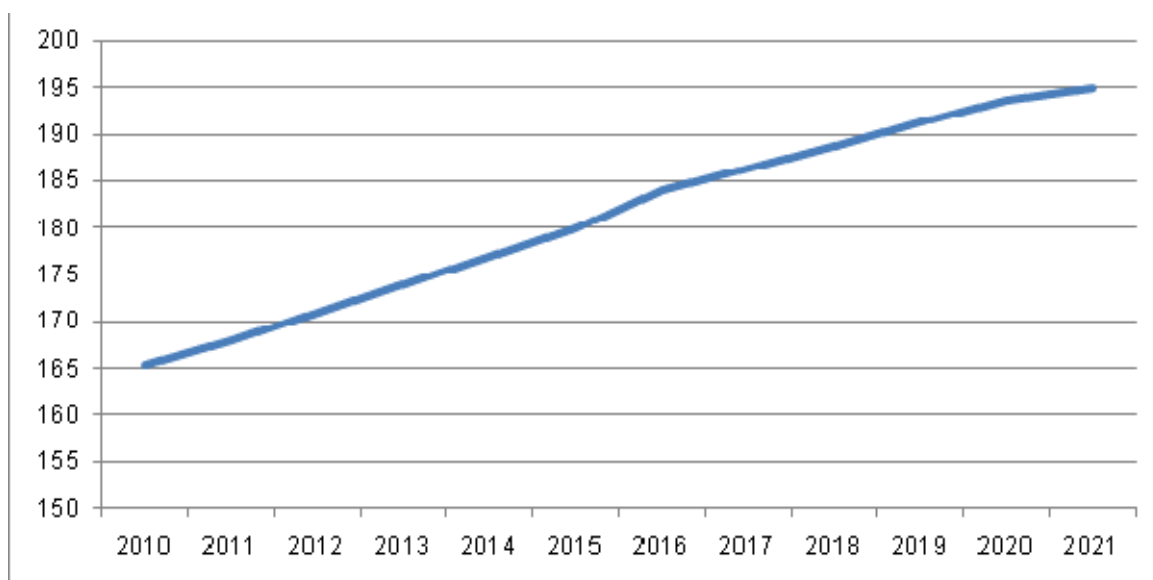
3.6.1 Projected need for respite services, Dublin North-East, 2010-2021

Table 7. Projected need for respite services, Dublin North-East

Area	Child population (Census '06)	Children with life-limiting conditions	Children with active palliative care requirement 2011	Children with active palliative care requirement 2016	Children with active palliative care requirement 2021
Dublin North	107,970	157	85	94	100
Louth	29,233	42	22	23	24
Meath	44,621	65	37	42	45
Cavan	17,127	25	13	14	14
Monaghan	14,455	21	11	11	12
Total	213,406	310	168	184	195

The graph below provides a year-by-year projection of the number of children living with a life-limiting condition in the HSE Dublin North-East area who are likely to require active palliative care. It is assumed that all 195 children will require some form of respite care by 2021.

Figure 4. Projected no. children with active palliative care requirement, Dublin North-East



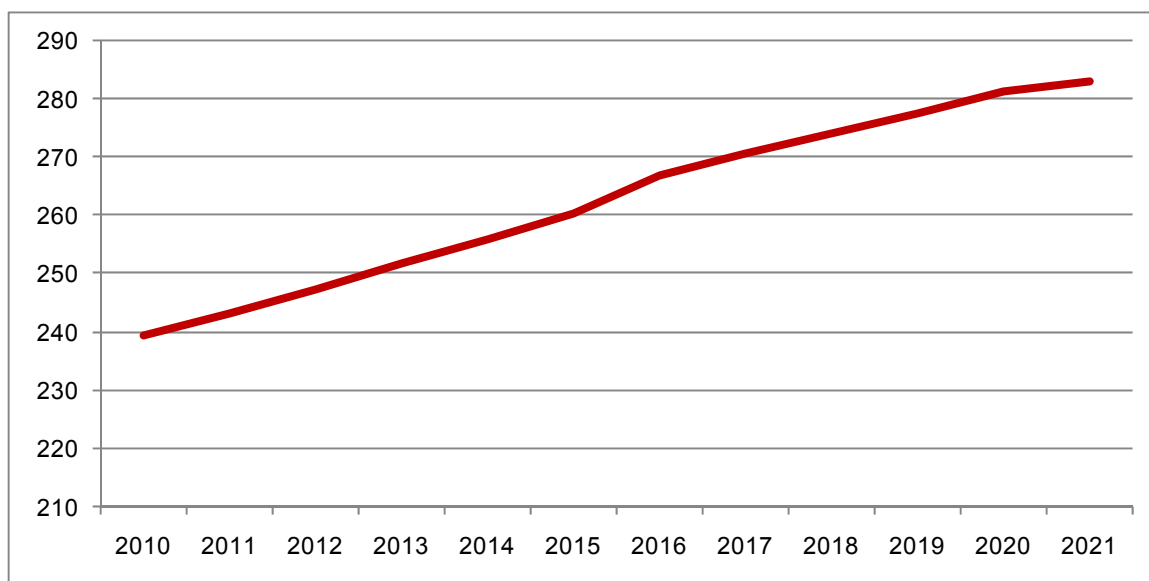
3.6.2 Projected need for respite services, Dublin Mid-Leinster, 2010-2021

Table 8. Projected need for respite services, Dublin Mid-Leinster

Area	Child population (Census '06)	children with life-limiting conditions	Children with active palliative care requirement 2011	Children with active palliative care requirement 2016	Children with active palliative care requirement 2021
Dublin South	153,131	222	121	133	142
Wicklow	32,425	47	27	30	33
Kildare	50,337	73	42	47	51
Westmeath	21,124	31	17	18	18
Longford	8,930	13	7	8	8
Laois	18,013	26	14	15	15
Offaly	19,169	28	15	16	16
Total	303,129	440	243	267	283

The graph below provides a year-by-year projection regarding the number of children living with a life-limiting condition in the HSE Dublin Mid-Leinster area who are likely to require active palliative care. On this basis, it is assumed that all 283 children will require some form of respite care by 2021.

Figure 5. Projected no. children with active palliative care requirement, Dublin Mid-Leinster



3.7 Cross-check of data with international findings

In order to validate the findings and thus the projected need and costings in this respite needs assessment, the following cross checks were made.

Wales

Using the suggested calculation from the Welsh study (prevalence is ten times greater than mortality) and applying this to the 75 childhood deaths in Ireland in 2008, gives a prevalence of 750 children living with a life-limiting condition.

Applying the mid-point prevalence rate of 14.5 children per 10,000 to the population of both Dublin Mid-Leinster and Dublin North-East results in a total of 749 children with a life-limiting condition.

Northern Ireland

In *Assessment of Need of Life-limited Children in Northern Ireland*³⁵ published in 2000, a prevalence rate of 17.2 children per 10,000 of population was used, and identified approximately 860 children living in Northern Ireland with a life-limiting or life-threatening condition, exceeding the estimates reached when applying the ACT/RCPCH formula (500 children)³⁶. In the Northern Ireland needs assessment, cystic fibrosis was identified as the most common life-limiting condition (249 children, or 29%). Advances in research and the treatment of cystic fibrosis have resulted in a significant increase in the number of children with the condition surviving into adulthood; therefore, while technically living with a life-limiting condition, these children may remain well and may not require respite services designed for children with other life-limiting conditions.

The Northern Ireland needs assessment also includes a total of 77 children with cerebral palsy, representing 9% of all children included in this study. Criteria for inclusion did not specifically

³⁵ Northern Ireland Hospice Care (2000), *Assessment of Need of Life-Limited Children in Northern Ireland*

³⁶ In 2000 the ACT/RCPCH formula recommended a prevalence rate of 10 children per 10,000 population. The formula was updated in 2003 and remains at a range between 12-17 children per 10,000 population.

differentiate between levels of the 'Gross Motor Function Classification System' (GMFCS), the standard five-level classification system now used to assess children with cerebral palsy. For the purposes of the present respite needs assessment, the Project Advisory Group suggested that only children within Level 5 of the GMFCS should be included when estimating the number of children with cerebral palsy who would require active palliative care.

3.8 Financial projections

Currently funding for respite services for children with life-limiting conditions is allocated to a range of different services *within* the HSE (e.g. disability services, palliative care services, etc.), and to other service providers *by* the HSE (e.g. Jack and Jill Foundation, Brothers of Charity, etc). It has not been possible to quantify the precise extent of this funding during the process of this respite needs assessment. The financial projections which follow are based on delivering a respite service for all children identified within 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, which are listed below.

In-the-home and out-of-home respite care are further categorised as follows:

Types of 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.

Types of 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. It 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.

Assumptions underpinning the calculated costs of delivering a range of respite services across the two settings are:

- All costs are calculated on the basis of a weekly allocation of up to 8 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 loosely based on current practice in the Jack and 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 the Jack and Jill Foundation
 - 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 within a service provider delivering respite care for children with life-limiting conditions
 - Category 2 represents the average hourly rate for general respite at the Children's Sunshine Home
 - Category 3 out-of-home respite costs are based on the projected costs of planned specialist delivery within the Children's Sunshine Home

Tables 9 and 10 provide a breakdown of the projected annual costs of delivering respite care to children with an active palliative care requirement as a result of a life-limiting condition living in Dublin Mid-Leinster and Dublin North-East. More detailed financial projections on each of the six sub-categories of respite care are provided in Appendix 4.

Table 9. Projected annual respite care costs, Dublin Mid-Leinster

Year	In-the-Home	Out-of-Home	Total
2010	€5,301,343	€1,010,642	€6,311,986
2011	€5,382,074	€1,026,033	€6,408,107
2012	€5,476,260	€1,043,989	€6,520,249
2013	€5,572,095	€1,062,259	€6,634,354
2014	€5,669,607	€1,080,848	€6,750,455
2015	€5,768,825	€1,099,762	€6,868,588
2016	€5,913,637	€1,127,370	€7,041,007
2017	€5,990,515	€1,142,026	€7,132,540
2018	€6,068,391	€1,156,872	€7,225,263
2019	€6,147,281	€1,171,911	€7,319,191
2020	€6,227,195	€1,187,146	€7,414,341
2021	€6,268,012	€1,194,927	€7,462,940

Table 10. Projected annual respite care costs, Dublin North-East

Year	In-the-Home	Out-of-Home	Total
2010	€3,665,126	€698,716	€4,363,842
2011	€3,720,940	€709,357	€4,430,296
2012	€3,786,056	€721,770	€4,507,827
2013	€3,852,313	€734,401	€4,586,714
2014	€3,919,728	€747,253	€4,666,981
2015	€3,988,323	€760,330	€4,748,653
2016	€4,075,316	€776,913	€4,852,229
2017	€4,128,295	€787,014	€4,915,308
2018	€4,181,963	€797,245	€4,979,207
2019	€4,236,327	€807,609	€5,043,937
2020	€4,291,401	€818,108	€5,109,508
2021	€4,318,948	€823,360	€5,142,308

3.8.1 Limitations of the financial projections

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

- As there is currently a dearth of information regarding where respite services are provided for children with life-limiting conditions, the projections 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 ultimately be significantly less than estimated.
- The projected costs of providing respite care are based on figures provided by the Jack and Jill Foundation and the Children's Sunshine Home and are specific to these organisations.
- Neither the Consumer Price Index or any equivalent measure of inflation has not been applied but may have an impact, especially with 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 in to these financial projections

Section 4: Conclusion and implementation

This needs assessment has identified a requirement for a range of respite care programmes to be developed in a coordinated and structured approach to meet the needs of 411 children currently and up to 478 children by 2021.

It is projected that the need for a palliative respite service for children with life-limiting conditions will grow steadily over the projection period analysed (2010 to 2021). It is strongly recommended that projections of future need should be reviewed and based on accurate Irish datasets. Where updates are released by the Association for Children with Life-threatening or Terminal Conditions and their Families/The Royal College of Paediatrics and Child Health (ACT/RCPCH) as regards the basis on which the prevalence of children with life-limiting conditions may be estimated, these should be considered and applied where deemed appropriate.

It is estimated that the development and operation of the six forms of respite care outlined in this assessment will require a budget in excess of €10m per annum, rising to over €12m by 2021. Through the restructuring of existing respite provision where appropriate and possible, however, it is envisaged that both direct and indirect efficiencies can be gained.

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 procedures³⁷. 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. **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 tests and procedures may be completed as part of a respite programme.**

The findings of this report should underpin the development and planning of responsive respite services for children with life-limiting conditions and their families.

³⁷ York Health Economics Consortium (2007), *Independent Review of Palliative Care Services for Children and Young People: Economic Study*

Appendices

Appendix 1 Members of the Project Team

Name	Position	Organisation
Ms Philomena Dunne	Chief Executive Officer	The Children's Sunshine Home
Ms Shirley Devitt	Clinical Services Manager	The Children's Sunshine Home
Ms Julie Ling	Project Advisor – Palliative Care	School of Nursing and Midwifery, Trinity College Dublin
Ms Marie Lynch	Programme Development Manager	The Irish Hospice Foundation
Mr Eugene Murray	Chief Executive Officer	The Irish Hospice Foundation

Appendix 2 Members of the Project Advisory Group

Name	Position	Organisation
Dr Joanne Balfe	Consultant Paediatrician	The Children's Sunshine Home
Ms Philomena Dunne	Chief Executive Officer	The Children's Sunshine Home
Ms Shirley Devitt	Clinical Services Manager	The Children's Sunshine Home
Dr Owen Hensey	Consultant Paediatrician	Children's University Hospital, Temple Street
Ms Ann Kennelly	Local Health Manager	HSE North Cork
Ms Julie Ling	Project Advisor – Palliative Care	School of Nursing & Midwifery, Trinity College Dublin
Ms Marie Lynch	Programme Development Manager	The Irish Hospice Foundation
Ms Jane McEvoy	Director – Strategic Implementation	St John of God Hospitaller Services
Ms Marion Meany	Local Health Manager	HSE Wicklow
Ms Sinead Moran	Liaison Nurse	The Jack & Jill Foundation
Mr Eugene Murray	Chief Executive Officer	The Irish Hospice Foundation
Dr Maeve O'Reilly	Consultant in Palliative Medicine	Our Lady's Children's Hospital, Crumlin
Ms Anna Plunkett	Director of Programme Development	St John of God Community Services Ltd.
Ms Martina Quelly	Local Health Manager	HSE Dublin South-East
Mr Bevan Ritchie	Children's Outreach Nurse (Life Limiting Conditions)	Children's University Hospital, Temple Street
Ms Sharon Vard	Co-Founder	Anam Cara

Appendix 3 External Consultation

Discussions were held with the following individuals during the course of completing this needs assessment. The purpose of this additional consultation was to validate the chosen approach regarding the quantification of need in the catchment areas and to attain background in relation to service planning and provision in other jurisdictions.

Name	Position	Organisation
Ms Karen Bleakley	Children's Palliative Care Nurse Lecturer	Northern Ireland Children's Hospice
Dr Lynda Brook	Macmillan Consultant in Paediatric Palliative Care	Alder Hey Children's Hospital
Dr Mary Devins	Consultant in Paediatric Palliative Care	IWK Health Centre in Halifax, Nova Scotia, Canada
Dr Alan Finnan	Consultant Paediatrician	Cavan General Hospital
Ms Mary Joe Guilfoyle	Liaison Nurse	The Jack & Jill Foundation
Dr Richard Hain	Senior Lecturer in Paediatric Palliative Care	University of Wales College of Medicine
Ms Hilary Maguire	Clinical Services Manager	Northern Ireland Children's Hospice
Ms Penny O'Connell	Respite Care Coordinator	HSE Dublin North-East
Ms Katie Riggs	Nurse Consultant - Children's and Young People's Palliative Care	ACT / Scottish Children's and Young People's Palliative Care Network

Appendix 4 Projected Annual Costs

The following tables provide a breakdown of the projected **annual** costs of delivering respite care to all children with active palliative care needs as a result of a life-limiting condition(s).

Table 1 Projected respite care costs: HSE Dublin Mid-Leinster

Year	In-the-Home Respite			Out-of-Home Respite			Total
	Nurse-delivered	Carer-delivered	Specialist	General	General 'Plus'	Specialist	
2010	€2,498,229	€2,455,014	€348,100	€573,533	€339,788	€97,321	€6,311,986
2011	€2,536,273	€2,492,400	€353,401	€582,267	€344,963	€98,803	€6,408,107
2012	€2,580,657	€2,536,017	€359,586	€592,457	€351,000	€100,532	€6,520,249
2013	€2,625,819	€2,580,398	€365,878	€602,825	€357,142	€102,292	€6,634,354
2014	€2,671,771	€2,625,555	€372,281	€613,374	€363,392	€104,082	€6,750,455
2015	€2,718,527	€2,671,502	€378,796	€624,108	€369,751	€105,903	€6,868,588
2016	€2,786,769	€2,738,563	€388,305	€639,775	€379,033	€108,562	€7,041,007
2017	€2,822,997	€2,774,165	€393,353	€648,092	€383,961	€109,973	€7,132,540
2018	€2,859,696	€2,810,229	€398,466	€656,517	€388,952	€111,403	€7,225,263
2019	€2,896,872	€2,846,762	€403,647	€665,052	€394,008	€112,851	€7,319,191
2020	€2,934,531	€2,883,770	€408,894	€673,697	€399,131	€114,318	€7,414,341
2021	€2,953,766	€2,902,672	€411,574	€678,113	€401,747	€115,067	€7,462,940

Table 2 Projected respite care costs: HSE Dublin North East

Year	In-the-Home Respite			Out-of-Home Respite			Total
	Nurse-delivered	Carer-delivered	Specialist	General	General 'Plus'	Specialist	
2010	€1,727,170	€1,697,294	€240,662	€396,517	€234,915	€67,284	€4,363,842
2011	€1,753,472	€1,723,141	€244,327	€402,555	€238,493	€68,309	€4,430,296
2012	€1,784,158	€1,753,296	€248,602	€409,600	€242,666	€69,504	€4,507,827
2013	€1,815,381	€1,783,979	€252,953	€416,768	€246,913	€70,720	€4,586,714
2014	€1,847,150	€1,815,198	€257,380	€424,061	€251,234	€71,958	€4,666,981
2015	€1,879,475	€1,846,964	€261,884	€431,482	€255,631	€73,217	€4,748,653
2016	€1,920,470	€1,887,250	€267,596	€440,893	€261,206	€74,814	€4,852,229
2017	€1,945,436	€1,911,784	€271,075	€446,625	€264,602	€75,787	€4,915,308
2018	€1,970,727	€1,936,637	€274,599	€452,431	€268,042	€76,772	€4,979,207
2019	€1,996,346	€1,961,813	€278,168	€458,313	€271,526	€77,770	€5,043,937
2020	€2,022,299	€1,987,317	€281,785	€464,271	€275,056	€78,781	€5,109,508
2021	€2,035,281	€2,000,074	€283,593	€467,251	€276,822	€79,287	€5,142,308

Appendix 5 Projected Annual Costs, Weekly Allocation of Service Hours Increased/Decreased

Weekly allocation of 5 hours:

Table 1 Projected Respite Care Costs: HSE Dublin Mid-Leinster

Year	In-the-Home Respite			Out-of-Home Respite			Total
	Nurse-delivered	Carer-delivered	Specialist	General	General 'Plus'	Specialist	
2010	€1,561,393	€1,534,384	€217,563	€358,458	€212,368	€60,826	€3,944,991
2011	€1,585,170	€1,557,750	€220,876	€363,917	€215,602	€61,752	€4,005,067
2012	€1,612,911	€1,585,011	€224,741	€370,285	€219,375	€62,833	€4,075,156
2013	€1,641,137	€1,612,749	€228,674	€376,765	€223,214	€63,932	€4,146,471
2014	€1,669,857	€1,640,972	€232,676	€383,359	€227,120	€65,051	€4,219,034
2015	€1,699,079	€1,669,689	€236,748	€390,068	€231,095	€66,190	€4,292,867
2016	€1,741,730	€1,711,602	€242,691	€399,859	€236,896	€67,851	€4,400,629
2017	€1,764,373	€1,733,853	€245,846	€405,057	€239,975	€68,733	€4,457,837
2018	€1,787,310	€1,756,393	€249,042	€410,323	€243,095	€69,627	€4,515,789
2019	€1,810,545	€1,779,226	€252,279	€415,657	€246,255	€70,532	€4,574,495
2020	€1,834,082	€1,802,356	€255,559	€421,061	€249,457	€71,449	€4,633,963
2021	€1,846,104	€1,814,170	€257,234	€423,821	€251,092	€71,917	€4,664,337

Table 2 Projected respite care costs: HSE Dublin North-East

Year	In-the-Home Respite			Out-of-Home Respite			Total
	Nurse-delivered	Carer-delivered	Specialist	General	General 'Plus'	Specialist	
2010	€1,079,481	€1,060,809	€150,414	€247,823	€146,822	€42,052	€2,727,401
2011	€1,095,920	€1,076,963	€152,704	€251,597	€149,058	€42,693	€2,768,935
2012	€1,115,099	€1,095,810	€155,377	€256,000	€151,667	€43,440	€2,817,392
2013	€1,134,613	€1,114,987	€158,096	€260,480	€154,321	€44,200	€2,866,696
2014	€1,154,469	€1,134,499	€160,862	€265,038	€157,021	€44,974	€2,916,863
2015	€1,174,672	€1,154,353	€163,677	€269,676	€159,769	€45,761	€2,967,908
2016	€1,200,294	€1,179,531	€167,247	€275,558	€163,254	€46,759	€3,032,643
2017	€1,215,897	€1,194,865	€169,422	€279,141	€165,376	€47,367	€3,072,068
2018	€1,231,704	€1,210,398	€171,624	€282,769	€167,526	€47,982	€3,112,005
2019	€1,247,716	€1,226,133	€173,855	€286,445	€169,704	€48,606	€3,152,461
2020	€1,263,937	€1,242,073	€176,115	€290,169	€171,910	€49,238	€3,193,443
2021	€1,272,050	€1,250,047	€177,246	€292,032	€173,014	€49,554	€3,213,943

Weekly Allocation of 10 Hours:

Table 3 *Projected respite care costs: HSE Dublin Mid-Leinster*

Year	In-the-Home Respite			Out-of-Home Respite			Total
	Nurse-delivered	Carer-delivered	Specialist	General	General 'Plus'	Specialist	
2010	€3,122,786	€3,068,768	€435,125	€716,916	€424,735	€121,652	€7,889,982
2011	€3,170,341	€3,115,501	€441,751	€727,834	€431,204	€123,504	€8,010,134
2012	€3,225,822	€3,170,022	€449,482	€740,571	€438,750	€125,666	€8,150,311
2013	€3,282,274	€3,225,497	€457,348	€753,531	€446,428	€127,865	€8,292,942
2014	€3,339,713	€3,281,943	€465,352	€766,717	€454,240	€130,102	€8,438,068
2015	€3,398,158	€3,339,377	€473,495	€780,135	€462,189	€132,379	€8,585,735
2016	€3,483,461	€3,423,204	€485,381	€799,718	€473,792	€135,702	€8,801,259
2017	€3,528,746	€3,467,706	€491,691	€810,115	€479,951	€137,466	€8,915,675
2018	€3,574,620	€3,512,786	€498,083	€820,646	€486,190	€139,253	€9,031,579
2019	€3,621,090	€3,558,452	€504,558	€831,315	€492,511	€141,064	€9,148,989
2020	€3,668,164	€3,604,712	€511,117	€842,122	€498,913	€142,898	€9,267,926
2021	€3,692,208	€3,628,340	€514,468	€847,642	€502,184	€143,834	€9,328,675

Table 4 *Projected respite care costs: HSE Dublin North-East*

Year	In-the-Home Respite			Out-of-Home Respite			Total
	Nurse-delivered	Carer-delivered	Specialist	General	General 'Plus'	Specialist	
2010	€2,158,963	€2,121,617	€300,827	€495,646	€293,644	€84,105	€5,454,802
2011	€2,191,841	€2,153,926	€305,408	€503,194	€298,116	€85,386	€5,537,871
2012	€2,230,198	€2,191,620	€310,753	€511,999	€303,333	€86,880	€5,634,783
2013	€2,269,226	€2,229,973	€316,191	€520,959	€308,641	€88,400	€5,733,392
2014	€2,308,938	€2,268,998	€321,725	€530,076	€314,043	€89,947	€5,833,726
2015	€2,349,344	€2,308,705	€327,355	€539,353	€319,538	€91,521	€5,935,817
2016	€2,400,587	€2,359,062	€334,495	€551,117	€326,508	€93,518	€6,065,287
2017	€2,431,795	€2,389,730	€338,843	€558,281	€330,753	€94,733	€6,144,135
2018	€2,463,408	€2,420,796	€343,248	€565,539	€335,052	€95,965	€6,224,009
2019	€2,495,433	€2,452,267	€347,711	€572,891	€339,408	€97,212	€6,304,921
2020	€2,527,873	€2,484,146	€352,231	€580,339	€343,820	€98,476	€6,386,885
2021	€2,544,101	€2,500,093	€354,492	€584,064	€346,028	€99,108	€6,427,885

Appendix 6 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 5 years with effect from the 1st of 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.

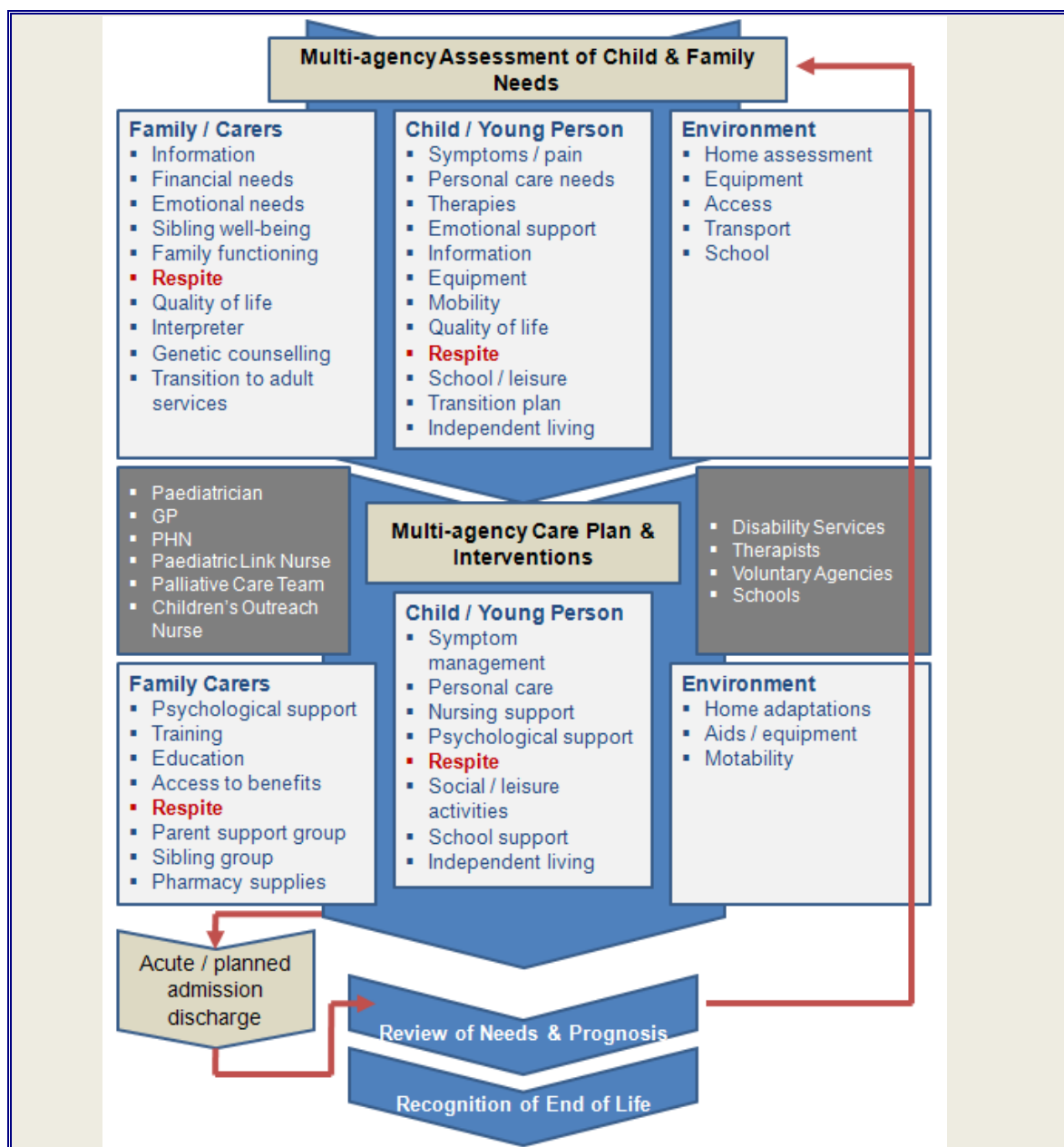
Each person found to have a need for disability related health and/or education services, as a result of the Assessment Report, will be given a Service Statement. The Service Statement will set out the health and education services that will be provided to the person taking account of:

- 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.



The ACT pathway describes the recommended range of service delivery options for families where a child has been diagnosed with a life-limiting condition. Care plans are developed on the basis of a multi-agency assessment, which includes consideration of the needs of both the child and his/her 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.

³⁸ Association for Children with Life-Threatening or Terminal Conditions and their Families/Royal College of Paediatrics and Child Health (ACT/RCPCH), 2003, *A Guide to the Development of Children's Palliative Care Services*, Bristol

Appendix 8 Case Histories

The following two case histories have been included to provide an insight into the day-to-day life of a child with a life-limiting condition and their family.

Vicky (8 years old)

Vicky is eight years of age and lives with her parents and two siblings, Rachel (14) and Colm (11) in Co Monaghan.

Shortly after her birth, it was discovered that she had a heart murmur. Upon closer examination and following the completion of specific tests, Vicky was diagnosed with severe heart problems. Within the first month of her life she underwent her first major heart surgery.

Following this initial surgery, Vicky continued to struggle and her condition was not progressing as had been hoped. A few months later she travelled to Birmingham Children's Hospital for open heart surgery. She successfully underwent the planned procedure and was making good progress thereafter, including saying her first words.

Following her first birthday, however, Vicky suffered a major stroke. After a period on life-support her condition stabilised and she came out of a coma. The stroke had caused Vicky to suffer some neurological damage, and as a result she now has cerebral palsy and epilepsy. In addition, Vicky lost her sight and the ability to swallow.

The medical team supporting Vicky have done all that is possible for her condition. It is most likely that the damage to her heart will significantly limit her life. She is extremely prone to infection and relies on a large quantity of different medications on a daily basis. Her parents provide her with round-the-clock care, and avail of regular, out-of-home, respite care from the Children's Sunshine Home. She also receives night nursing support, as provided by the HSE when available. Vicky's family have also developed and maintained links with the local hospice team.

As Vicky has grown older her respite requirements have increased. Services have been challenged to respond to these needs and have adopted some innovative approaches to provide support to the family in the absence of a sufficiently resourced respite service. The proposed introduction of specialist respite care in Ireland would significantly benefit Vicky and her family.

Cara (3 years old)

Cara was diagnosed at 22 weeks gestation with a fatal bone condition. At the time of initial diagnosis, the medical team felt that if Cara was born alive that she would live for a few hours at best. Following Cara's birth and some further tests she was diagnosed with Osteogenesis Imperfecta (severe brittle bone disease), her medical team at that point suggesting that she could live for a period of a few months but would not see her first birthday.

After about six weeks of hospital care, it was recommended to Cara's parents that they consider moving her to the Children's Sunshine Home. Despite their initial hesitation to avail of this service, it was obvious that Cara's parents would have severe difficulties meeting her needs while at the same time rearing her two older sisters.

For the next year Cara spent each week at the Children's Sunshine Home and returned home to Kildare for weekends with the help of nursing care provided by the Jack and Jill Foundation. Shortly after her first birthday, Cara went home for good, returning occasionally to the Children's Sunshine Home for respite care.

Cara is now three years old. She attends an Enable Ireland play-school three mornings a week. She has fractured her femur a total of six times and has had rods inserted in her upper and lower legs that have enabled her to walk with the assistance of a little zimmer-type frame. She is permanently on pain killers and has infusions every few months to help strengthen her bones.

The prognosis for Cara is now far more positive, but there are a range of complications that could pose problems for her in the years to come. As a result, Cara and her family need to take stringent precautions incessantly, but continue to aim to live a life as close to normality as possible.

Looking back now, Cara's parents have both reflected that her time at the Children's Sunshine Home provided the whole family with the necessary foundation upon which to build the rest of their lives. They have developed strong relationships with staff at the Children's Sunshine Home and are most comfortable placing Cara in the centre for respite care.

As Cara gets older is it likely that she will need significant additional support, given her condition and the increased strain that her bone structure will be placed under. All service providers assisting Cara - respite providers included - need to possess a specific understanding of her condition and the associated requirements. Therefore, service providers require a high level of expertise and experience to ensure Cara's needs are met.

Appendix 9 International classification of disease (ICD) codes used to define life-limiting conditions

ICD codes and categories identified by ACT³⁹

Code	Category
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 460 – 487)
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

³⁹ Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT)



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