LauraLynn

IRELAND'S CHILDREN'S HOSPICE

ADVANCING OUR VISION

Extending our Community of Care

STRATEGIC PLAN

2024–2028

CONTENTS

A NEW CHAPTER WELCOME FROM THE CHAIR AND CEO

We are in equal measure proud and excited to present to you LauraLynn's new five-year Strategic Plan - "Advancing our Vision: Extending our Community of Care." As the title suggests, this strategy aims to progress the work of our last strategic plan "Building a Community of Care" (2019-2023) but it is also built on our refreshed vision which imagines a society where *children and their families have the care and support they need at all stages of their journey.*

During the lifetime of this new strategy, The Children's Sunshine Home will reach its 100th anniversary. Over the years, we have seen and achieved amazing innovation and positive change – change that has seen the inception and growth of LauraLynn House, Ireland's first and only children's hospice. Through it all, we have remained rooted in the values that shape us: Compassion, Collaboration and Excellence. These values will continue to drive us as we embark on the next chapter of our journey.

We know that our success relies upon our ability to listen and respond to the needs of those we work with and those who benefit from our service. As such, this strategy was developed through comprehensive consultation with our colleagues across children's health, palliative care and charity sectors, the Department of Health, the Health Service Executive, researchers, educators, our staff and volunteers and most importantly, with those in our care.

The emergent themes of Equity, Access, Quality and Collaboration underpin the strategic ambitions that we now aim to achieve over the next five years. These ambitions will ultimately ensure that, with a renewed commitment to our organisational purpose, LauraLynn can leverage its core strengths, while building additional capacity and capability to further grow and expand supports to children and families across Ireland who need us. With a cornerstone of financial sustainability; Advocacy, Research and Education will feature more prominently in our extended portfolio.

The following pages outline the details of our strategic ambitions and goals, along with the impact that we anticipate from each of our actions, and the enablers that will be critical to our success. To ensure we stay on track, we have developed a detailed implementation plan and are committed to sharing our progress over the lifetime of the strategy.

We would like to take this opportunity to thank all those who gave their time to the creation of our strategy. Your input will ensure that we can focus our efforts in meeting the needs of those we support. Continued collaboration over the next five years will enable us to successfully achieve each of our ambitious strategic objectives and support more children and families than ever before. Thank you for being an integral part of our journey and for your ongoing support.

We look forward with excitement, renewed passion and determination to achieving our strategic objectives and embracing whatever challenges may lie ahead as we strive to Advance our Vision and Extend our Community of Care.

Sandra O'Malley
Chair of the Board

Sandra O'Malley

Kerry McLaverty
Chief Executive Officer

> May it be an exciting, challenging but ultimately successful five years ahead for the children, their families and bereaved families who come into our care… with LauraLynn staff supported and at the heart of this vital journey.
>
> **Staff Member**

EXECUTIVE SUMMARY

LauraLynn, Ireland's Children's Hospice, formerly known as the Children's Sunshine Home has been providing medical care within a residential setting since the 1920s. The service has evolved in line with unmet need and today provides a community of care that includes a small adult disability residential service supporting six adults with severe to profound intellectual disabilities; a specialist Children's Disability Respite Service for children with medical complexity; and Ireland's first and only children's hospice, providing palliative care to children with life-limiting conditions, and their families.

With an estimated 4,000 children in Ireland living with life-limiting conditions, including 2,000 with palliative care needs and over 720 classified as "unstable, deteriorating or dying", specialist hospice supports are crucial (based on UK data, Fraser et al., 2015). We know, that through our last strategy we have started to make a real impact in terms of reaching more of the children and families who need us, but we want to do more.

Despite a global pandemic, which started in the second year of our strategic cycle, we significantly expanded the reach of our Children's Hospice Service, between 2019 and 2023, through a strategy of increasing referrals to our existing service and expanding our presence on the ground nationally. We opened our first hospice Community Team hub in Mallow, to bring care and supports closer to home for children and families in Munster, and we progressed plans to develop a second hospice Community Team hub in Ballinasloe, for the West of Ireland.

We completed intentional work with each of the six residents living in our adult disability residential service, to identify the best way to move forward and enhance their lives. We also spent time investing in financial, human, educational and reputational resources achieving a strong foundation to move into our next strategic cycle to continue our growth and expansion.

The LauraLynn Strategic Plan for 2024-2028 aims to build upon the previous five years of our Growing a Community of Care Strategic Plan (2019-2023) and further extend our care and support to ensure the wellbeing of those who need us.

Our vision is to ensure that ***'children and their families have the care and support they need at every stage of their journey'***. To achieve this, our mission focuses on improving the quality of life for those in our care by delivering accessible and equitable specialist care and support. We will also prioritise advocacy, research, and education, collaborating with healthcare colleagues, statutory bodies, donors and funders, as well as the children and families we serve.

Compassion, collaboration, and excellence are the core values that underpin our work at LauraLynn. These values are supported by character strengths such as kindness, love, hope, teamwork, leadership, honesty, love of learning, and judgement. We bring these values to life through our behaviours, which include placing the children, adults, and families of LauraLynn at the centre of everything we do, treating everyone with compassion, respect, and dignity, paying attention to the details that matter, and actively listening to the needs of our service users and their families. We also emphasise teamwork and collaboration, working together and building strong partnerships.

Our purpose is to provide specialist care and support that positively impacts children with medical complexity and children with palliative care needs, as well as their families. We do this through our dedicated, values-led staff and volunteers.

EXECUTIVE SUMMARY

Strategic Themes

Through extensive consultations with over 200 people, we identified four key strategic themes on which we want to focus:

EQUITY	Care and support is offered in an equitable manner.
ACCESS	Care and support is readily available.
QUALITY	Care and support is always of the highest quality and standard.
COLLABORATION	Care and support is delivered in collaboration with children, families and all our stakeholders.

To respond to the themes that emerged, we identified six strategic ambitions.

Strategic Ambition 1:
Provide an exemplary Children's Hospice Service that is equitable and accessible.

Strategic Ambition 2:
Maximise the impact of our Children's Disability Respite Service.

Strategic Ambition 3:
Successfully support the residents of Willow View to transition to specialist adult disability community provider(s) that will better meet their rights, needs, will and preferences.

Strategic Ambition 4:
Drive Standards of Care through conducting and supporting research and further education, in collaboration with Third Level Institutions, Academics, Clinicians, Research Bodies and through public patient involvement.

Strategic Ambition 5:
Advocate to ensure children and their families can access the cohesive, responsive, specialist care and support they need at all stages of their journey.

Strategic Ambition 6:
Ensure a sustainable financial model to support ongoing service delivery and future growth.

To achieve these Strategic Ambitions, we have detailed 25 high level strategic goals with specific actions and metrics identified to ensure the plan is delivered.

This plan will be enabled by our continued investment in our Strategic Enablers:

1. **People & Culture**
2. **Good Governance**
3. **Resources & Capabilities**
4. **Innovation**

This strategic plan will deliver accessible and equitable specialist care and support for the children and families who need our services, at every stage of their journey.

VISION

Children and their families have the care and support they need, at all stages of their journey.

MISSION

To take a leading role in improving the quality of life of those in our care, by delivering specialist care and support that is accessible and equitable.

Our mission will be underpinned by Advocacy, Research and Education. It will be achieved through collaboration with our healthcare colleagues, statutory bodies, donors and funders, and the children and families in our care.

OUR VALUES

COMPASSION	COLLABORATION	EXCELLENCE
Our Values are underpinned with Character Strengths of:		
Kindness Love Hope	Teamwork Leadership Honesty	Love of Learning Judgement Leadership
We bring our values to life at LauraLynn through our behaviours:		
We hold those in our care at the centre of everything we do. ••••• We are caring and inclusive, treating everyone with compassion, respect and dignity. ••••• We pay attention to the 'little things' because they really matter.	We listen and seek to understand the needs of our service users and their families. ••••• We work together and support each other as best we can. ••••• We work collaboratively with others, building strong partnerships.	We try to always do better. ••••• We strive to develop our learnings and improve our skills. ••••• We raise the bar through initiative, innovation and evidence.

ABOUT US

LauraLynn, Ireland's Children's Hospice was formed in 2011 following the merging of the long-standing Children's Sunshine Home and the LauraLynn Foundation, founded by Jane and Brendan McKenna. It provides a 'Community of Care' that comprises the only children's hospice in Ireland (LauraLynn Hospice Service) as well as two local disability services (LauraLynn Disability Service).

LauraLynn is committed to upholding the highest levels of governance across our clinical, corporate and fundraising activities. We operate to the 'triple lock' standard of good governance and are fully compliant with all required standards including:

- **HSE Compliance Statement**
- **HIQA Regulations**
- **CHKS Accreditation**
- **Charity Regulator**
- **Fundraising Standards**
- **SORP Financial Reporting**

WHAT IS THE LAURALYNN COMMUNITY OF CARE?

The LauraLynn Community of Care includes all strands of its services (LauraLynn Hospice Service and LauraLynn Disability Service) as well as the staff, volunteers, funders and supporters.

The philosophy of the LauraLynn Community of Care is centred around the provision of exemplar, holistic specialist care, within a dynamic culture of compassion, collaboration and excellence.

ADVANCING OUR VISION
Extending our Community of Care

OUR STRATEGIC PLAN AND ITS RELATIONSHIP TO OUR VISION, MISSION AND ANNUAL PLANS

VISION

Approved by the Board of Directors in December 2023 with a reviewed vision statement: ***A world where children and their families have the care and support they need at all stages of their journey.***

MISSION

To achieve this vision, LauraLynn will take a leading role in improving the quality of life of those in our care, by delivering specialist care and support that is accessible and equitable. Our Mission will be underpinned by Advocacy, Research and Education. It will be achieved through collaboration with our healthcare colleagues, statutory bodies, donors and funders, and the children and families in our care.

FIVE-YEAR STRATEGIC PLAN

LauraLynn's five-year strategic plan (2024-2028) with strategic ambitions, goals and actions, developed in 2023 in consultation with key stakeholders, to guide our work.

ANNUAL PLANS & BUDGETS

Annual Plans, tied to activities, strategic actions and budgets, which are approved each year.

STRATEGIC THEMES

Throughout the course of our strategy four key strategic areas of focus will underpin our work. Find further information on page 16.

OUR JOURNEY

1923

Dr Ella Webb, founder of The Children's Sunshine Home in Stillorgan, a convalescent home for tenement children with rickets.

1950's

The foundation stone laid in 1952 by Dr. J. Ryan, Minister for Health, on a new site donated by the Overend family of Airfield.

1970's

Long-term residential care commenced for profoundly disabled children.

2005

The Children's Sunshine Home and The LauraLynn Foundation join forces to fundraise and build a dedicated hospice for children.

2010

Hazel House opens to extend children's disability respite care service.

2011

Mary McAleese, President of Ireland, opens LauraLynn House which was followed by the rebranding of all our children's disability and hospice services under LauraLynn, Ireland's Children's Hospice.

2014

LauraLynn At Home commenced in two HSE regions, providing hospice care for children and their families in their own home.

2019

Growing a Community of Care Strategic Plan 2019-2023 commences.

2020

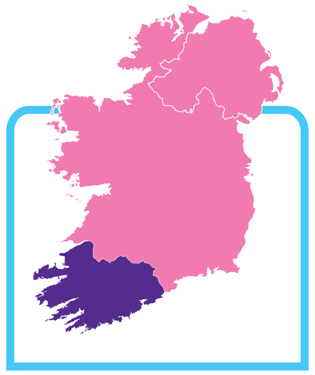
Virtual Children's Hospice launched in response to the Covid-19 pandemic.

2021

LauraLynn marks a Decade of Care and received dedicated statutory funding for the Hospice Service.

CELEBRATING 10 ••• YEARS •••

2022



LauraLynn establishes new hospice Community Team hub in Mallow, expanding care in the home to Cork and Kerry.

2023

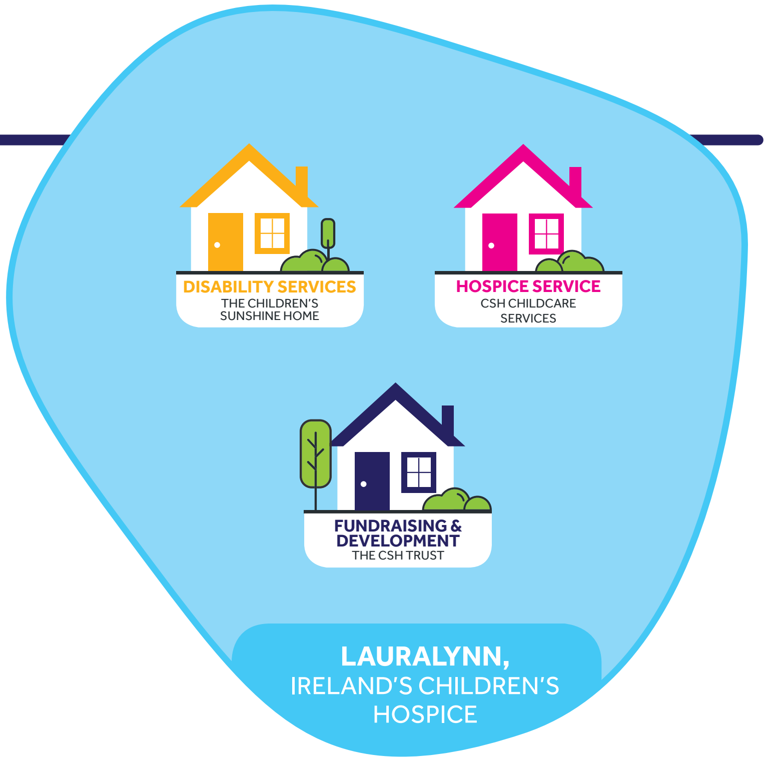
Discovery review completed for Willow View service and Transforming Lives initiative commenced.

Children's Sunshine Home

Growing a Community of Care 2019 – 2023

OUR STRUCTURE

LauraLynn, Ireland's Children's Hospice is made up of three distinct entities all of which are registered charities: The Children's Sunshine Home, CSH Childcare Services and The Children's Sunshine Home Trust, which is the fundraising arm of the charity.



The Children's Sunshine Home (Disability Service)

The Children's Sunshine Home — our Disability Service — provides respite care to children with medical complexity, as well as residential care for six adults with severe to profound intellectual disabilities, who have been in the care of The Children's Sunshine Home since they were children . This was originally overseen by The Children's Sunshine Home Trust until the establishment of The Children's Sunshine Home in 1985. The Disability Service is operated under a Section 38 Service Agreement with the Health Service Executive (HSE). Consequently, the main source of funding for this service is the HSE.

CSH Childcare Services (Hospice Service)

CSH Childcare Services — our hospice — provides specialist high quality hospice and palliative care (including Short Break Stays, In-Home Support, Crisis Care, Symptom Management, End-of-Life care and Bereavement Support) to children with palliative care needs and support for their families. All of the care is provided free of charge to families. The main source of funding for the Hospice Service is The Children's Sunshine Home Trust through its fundraising activities. However, LauraLynn's Hospice Service now receives partial recurring core funding from the State, under a Section 39 Service Agreement with the HSE.

The Children's Sunshine Home Trust

The Children's Sunshine Home Trust ('Trust') was founded in 1925 and its primary objective was to provide care for sick children. Today, the Trust raises and invests funds to enable the continued operation of LauraLynn services. The trustees act as guardians of the organisation's assets and are entrusted with the land and buildings on its campus on Leopardstown Road, Foxrock, Dublin 18.

Further information about LauraLynn can be found at **www.lauralynn.ie.**

WHAT DIFFERENTIATES US

Our Community of Care – through almost a century-long heritage of addressing the emerging healthcare needs of children, we have developed expertise and specialism in caring for children with medical complexity and for children with palliative care needs and their families, supported by a community of skilled staff, dedicated volunteers and committed donors.

Our Children's Hospice – is the first and only specialist hospice for children with palliative care needs and their families in Ireland.. Initially delivered in our purpose-built facility in Leopardstown, Dublin 18, our care and support is now also offered through our community-based teams, our virtual hospice and our in-reach to the children's hospitals and paediatric units.

We Make Moments that Matter – we care for some of Ireland's most vulnerable children, many of whom are not expected to reach adulthood. We cannot change their prognosis, but we can help make every day the best it can be. No matter the reason a child is availing of our care and support, we focus on the little things; the little moments, and family time. Because moments matter, and one day they become memories that last forever.

GROWING A COMMUNITY OF CARE 2019-2023 – REVIEW AND SUCCESS

In 2019, we published our five-year strategic plan; Growing a Community of Care, 2019-2023. This plan set out a roadmap to expand and grow our services to reach more children and families in need of our specialist supports – particularly those living outside the greater Leinster region.

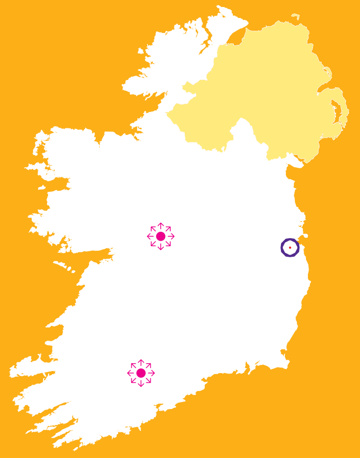
Whilst setting these as our ambitions for the coming years, we could not have anticipated a global pandemic. Our staff pivoted to deliver hospice services online, we became the first Virtual Children's Hospice in Ireland, enjoying numerous activities online, from Music Therapy to Play Therapy.

Our volunteers went virtual and continued to provide their invaluable services through online platforms. Throughout the pandemic, staff and volunteers demonstrated their commitment to 'make every day better for those in our care'.

Despite the challenges we continued to achieve our strategic goals and just some of our successes are captured here:

1. **Expand our children's hospice and palliative care services nationwide in line with unmet need.**
   - The reach of our hospice community of care grew to 575 families in 2023, more than double the number in 2018 (258 families).
   - We increased the number of children with palliative care needs cared for per year from 204 in 2018 to 310 in 2023, 52% growth. While the number of bereaved families in our service grew to 322 in 2023.
   - We launched our first regional community service in Mallow, providing nursing and family supports to children and their families closer to home.
   - We progressed the establishment of a second Community Team hub in Ballinasloe, to provide support to the West of Ireland.
2. **Extend our Children's Disability Respite Service in the Greater Dublin Area to serve more children and families.**
   - We completed a large-scale refurbishment of Hazel House to single occupancy rooms with the addition of a dedicated sensory room, new laundry, storage facilities and an upgraded family room.
   - We expanded the number of children who have access to our children's disability respite by more than 50%, by increasing our catchment area to include CHO7 and CHO9, with 54 children accessing respite in 2023.
3. **Enhance our adult disability service to ensure it's an exemplar service and the best possible home for our residents.**
   - The Discovery Project commenced in 2020 and continued throughout the course of the past three years. Its focus was to support the people living in the service to live their best possible lives in line with their will and preference.
   - Building on our discovery learnings, each resident received an enhanced, tailored programme of social engagements and opportunities.
4. **Build the financial, human, educational and reputational resources necessary for us to achieve these ambitions.**
   - Through the course of the last strategy the numbers of people involved in delivering our services rose from 132 to 176. We rolled out a range of measures to support staff wellbeing and professional development including the LauraLynn Wellbeing at Work programme.
   - We secured partial recurring core statutory funding for our Children's Hospice Service in 2021, the year that marked the 10th anniversary of the opening of the service.
   - In 2022, we completed our accreditation programme for our Hospice Service, under CHKS Accreditation and Quality Assurance Framework and were found to be 97% compliant on the first attempt. We received a commendation from the HSE at the 2023 HSE Excellence Awards for this achievement.
   - We were awarded Good Governance Awards in both 2019 and 2020 in recognition of the significant investment we made to achieve an excellent standard of governance and compliance.
   - We created a new three-year funded scholarship, the McKenna scholarship, to support the expansion of the knowledge base of Children's Palliative Care.

OUR IMPACT IN NUMBERS



2

additional Hospice Community Team hubs established

124%

growth in reach of our hospice community of care

2021

the year recurring core statutory funding was secured for LauraLynn Hospice

33%

growth in our Workforce which increased from

132 to 176

NEW STRATEGIC PLAN
KEY FINDINGS AND THEMES

Despite significant growth in our Children's Hospice and Children's Disability Services over the past five years, we know that there are many children and families who need our services who may not be able to access us. The overwhelming message received through our new strategic planning process was "Do more of what you do, for more children and families, keep doing it really well and work with others to do it".

In addition to extending our reach in the next five years, the continuation of work to shape policy and standards of care for children with palliative care and medical complexity also emerged as a key theme.

In line with providing the highest quality support and standards and in the context of the findings of the Disovery Project, national policy and legislation, the adults living in Willow View will, during the first years of this strategic cycle, be supported to transition to an altenative service provider that can better meet their rights, needs, will and preference.

Strategic Themes

Through extensive consultations with over 200 people, we identified four key strategic themes on which we want to focus:

EQUITY	Care and support is offered in an equitable manner.
ACCESS	Care and support is readily available.
QUALITY	Care and support is always of the highest quality and standard.
COLLABORATION	Care and support is delivered in collaboration with children, families and all our stakeholders.

STRATEGIC AMBITIONS
2024-2028

1. Provide an Exemplary Children's Hospice Service that is equitable and accessible.
2. Maximise the impact of our Children's Disability Respite Service.
3. Successfully support the residents of Willow View to transition to specialist adult disability community service provider(s) that can meet their rights, needs, will and preferences.
4. Drive standards of care through conducting and supporting research and further education, in collaboration with third level institutions, academics, clinicians, research bodies and through public patient involvement.
5. Advocate to ensure children and their families can access the cohesive, responsive, specialist care and support they need at all stages of their journey.
6. Ensure a sustainable financial model to support ongoing service delivery and future growth.

STRATEGIC AMBITIONS

1

Provide an Exemplary Children's Hospice Service that is Equitable and Accessible

Strategic Goals

1. **Ensure** the full range of hospice supports is available to children and families in every county in Ireland.
2. **Determine** the need and potential location(s) for additional in-patient hospice beds based on ECHPI data. (ECHPI is Ireland's first baseline study of children with palliative care needs.)
3. **Further develop** medical services to ensure 24/7 specialist support for in-patient care.
4. **Plan and develop** a perinatal hospice care pathway for Infants with palliative care needs, in collaboration with key stakeholders, such as the HSE, Children's Health Ireland and Neonatal Services.
5. **Increase** the range of practical supports offered to families of children with palliative care needs in line with their requirements.
6. **Expand** in-reach support as part of LauraLynn's Model of Care to support other organisations in the provision of palliative care to children and their families.
7. **Facilitate** transition to support continuity of care for those being discharged from the hospice.

Overview

To provide an exemplary Children's Hospice Service nationwide, LauraLynn plans to enhance existing services, and also develop new services that will ensure all specialist supports are both equitable and accessible, with an additional focus on peri-natal supports, through to young people transitioning to adult services.

A key focus of this ambition will be to enhance the existing LauraLynn in the Community Teams and bring care closer to home and increase specialist medical support in LauraLynn House.

Recognising the complex healthcare system in which we operate, service developments will be collaborative and practical in nature, working where appropriate, in partnership with key external stakeholders to ensure greater choice and access to specialist hospice supports.

Outcome

Under a revised and enhanced Model of Care, each of the Five Pillars of Hospice Care (i.e. Direct Care, Family Support, Symptom Management, End-of-Life Care and Bereavement Care) will be extended to offer greater availability to children and their families in every county in Ireland.

Through a collaborative approach to care provision, there will be an increased focus across the continuum of life, in particular recognising the specific needs of both the neonatal population, as well as the distinct needs of young people with palliative care needs transitioning to adult services.

In addition to enhanced, specialist medical support for in-patient hospice care, there will be a clear understanding as to whether increased capacity on a national basis is required, and if so, how and where this need can be best met.

Impact

Infants, children and young people with palliative care needs and their families, living in Ireland, will have an improved quality of life as a result of better access to hospice services.

There will be more comprehensive, responsive and accessible hospice services, across the continuum of life for children with palliative care needs and their families in Ireland, based upon individual need.

Children and their families will have greater opportunity to get the specialist care and support that they need, irrespective of where they live.

STRATEGIC AMBITIONS

2

Maximise the impact of our Children's Disability Respite Service

Strategic Goals

1. **Develop** and implement a Model of Care for Respite for children with medical complexity.
2. **Raise** the internal and external profile of our Children's Disability Respite Service.
3. **Expand** the catchment area of of Children's Disability Respite Service from three Community Healthcare Organisations (CHO's) to three Health Regions to increase occupancy for children with medical complexity.

Overview

Respite can provide a lifeline to families caring for a child with medical complexity 24-hours a day. It gives families a much-needed break whilst also giving the child a positive holiday/ sleep over experience away from home.

LauraLynn has unique expertise in providing high quality respite care for children with medical complexity and an important role to play in addressing unmet need in this vulnerable population.

In 2019, we expanded the reach of our Children's Disability Respite Service from CHO6 to include CHO7 and CHO9. Now, with the impending national restructure to Health Regions, there is an opportunity for LauraLynn to once again widen the catchment area to support even more children with medical complexity.

Outcome

We will maximise the impact of our Children's Disability Respite to support more children with medical complexity and their families. They will be supported through planned and crisis nursing care, support and fun experiences along with enhanced liaison with parents / guardians.

We will develop a Model of Care incorporating best practice in respite services for children with medical complexity globally, as well as the many years' experience of our Children's Disability Respite Service service, to achieve our vision that children and their families have the care and support they need at all stages of their journey.

We will share the Model of Care and liaise with the HSE Children's Disability Managers, Children's Disability Network Teams and other key stakeholders to support awareness and referrals development within the designated Health Regions.

We will embed the Family Liaison and Respite Coordinator role to ensure families remain connected with the Service and supports are appropriate to their needs.

Impact

Hazel House's Model of Care will describe the Care Pathway for children with medical complexity from the referral criteria and process to the range of out of home respite supports based on the child's holistic needs along with the development of outcomes or goals, through to the annual review and discharge process, including transition to adult services and the supports available for parents/guardians.

Children with medical complexity living in the designated Health Regions will have access to short, planned breaks away from the home, where they will have the nursing support that they require and fun breaks with their peers, whilst their parents/guardians get the rest they need in order to continue to care for their child at home.

STRATEGIC AMBITIONS

3

Successfully support the residents of Willow View to transition to specialist adult disability community service provider(s) who can meet their rights, needs, will and preferences.

Strategic Goals

1. **Ensure** we hold each Willow View resident's rights, needs, will and preferences at the centre of all decision-making in the transition process.
2. **Provide** a dedicated Transforming Lives Project Lead, to ensure the transition process is completed successfully for each resident.
3. **Uphold** regulatory, policy and legal requirements by ensuring our HIQA compliance plan is achieved.
4. **Work** with each adult in our care, their family and circle of support, the HSE and other specialist adult disability service providers in implementing the Transforming Lives Project Plan.

Overview

The disability landscape in Ireland has seen significant changes in recent decades. National policies include 'Time to Move on From Congregated Settings: A strategy for Community Inclusion' in 2011 and the 2018 'A Framework for Person Centered Services'. These policies along with legislative pieces have been the foundation for change in Disability Services in Ireland during this time.

Through the work of our previous strategy, we have discovered that our disability service, while providing excellent physical and medical care to the residents, is in contravention of prevailing national policy, legislation and also failing to meet the rights of the residents as laid out in the UN Convention for Human Rights for Persons with a Disability.

Therefore, a transformational process is underway that will see LauraLynn support each person in Willow View to transition to an alternative specialist service provider that can better meet their rights, needs, will and preferences. This transition process commenced in June 2023, and it is expected to be concluded by the end of 2025. In the interim, day-to-day operations in Willow View are continuing as normal.

Outcome

Working closely with each resident, their family and circle of support throughout the Transforming Lives Project, we will develop a detailed biography for each person, to inform and guide their individual transition plans and our Transforming Lives work.

We will ensure all tools are in place to enable the residents of Willow View to drive their decision making and express their will and preference so that this is at the heart of our work throughout the coming years.

Partnering with the HSE throughout this process will ensure the successful transition of the residents to alternate service providers.

Our ultimate goal is to find the right solutions to ensure that each person has the supports to live life to their full potential, through the delivery of quality services whilst promoting their roles as active citizens in the community.

Impact

The six adults currently living in Willow View will be actively and effectively supported to live full, inclusive lives at the heart of family, community and society with an established disability service provider experienced in supporting people with disabilities.

STRATEGIC AMBITIONS

Drive standards of care through conducting and supporting research and further education, in collaboration with third level institutions, academics, clinicians, research bodies and through public patient involvement.

Strategic Goals

1. **Develop and implement** an organisational-wide Research and Education Strategy to grow our clinical research activity and increase our internal education capacity to meet the needs of our growing workforce.
2. **Provide** funding opportunites for postgraduate education and research to encourage skills development and promote research.
3. **Take a leading role** in the development of a National Research Strategy for Children's Palliative Care in collaboration with researchers in Ireland.

Overview

Education of healthcare professionals is a key factor in ensuring the provision of safe, high-quality care to children with life-limiting conditions and their families. However research indicates that healthcare professionals often lack the education, training, competence and confidence to provide care to children with life-limiting conditions.

LauraLynn as an employer of healthcare professionals, and the professionals themselves, are obligated to continuously strive to identify and meet their education and training needs. Ongoing education and continuous development of our staff is a critical focus for us strategically.

The provision of high-quality care is dependent on the development of evidence-based policies, guidelines and treatment protocols. As a relatively new paediatric speciality, there is a dearth of research in Children's Palliative Care and LauraLynn has a key role to play in conducting and supporting research to expand our knowledgebase in the area.

Outcome

Through supporting the ongoing development of education and research Strategy, LauraLynn will support the training and upskilling of healthcare professionals both within the organisation and nationally.

This increase in trained healthcare professionals (HCPs) will contribute to improving the current significant deficit in the number of HCPs available to provide care to children with life-limiting conditions in Ireland.

LauraLynn staff will be encouraged and enabled to pursue post-graduate education and engage in research projects through the provision of funding opportunities.

A National Research Strategy in Children's Palliative Care will support the identification of priority research projects, establishment of research collaborations and development of pathways towards a sustainable funding model for Children's Palliative Care research.

Impact

Infants, children and young people with palliative care needs and their families will have improved access to appropriately trained healthcare professionals.

The evidence base in Children's Palliative Care will expand and improve, with associated improvement in the quality of life of children with life-limiting conditions and their families.

STRATEGIC AMBITIONS

5

Advocate to ensure children and their families can access the cohesive, responsive, specialist care and support they need at all stages of their journey.

Strategic Goals

1. **Lobby** for policy, services and funding to ensure that children with palliative care needs and their families have the Right Care, at the Right Time, from the Right Team in the Right Place.
2. **Bring** evidence-based, solution-focussed positions to policymakers and funders.
3. **Position** LauraLynn as the Voice of Children's Palliative Care in the voluntary sector.
4. **Build** a network to support and promote Action and Change.

Overview

Families of children with life-limiting conditions and palliative care needs face enormous challenges and require equitable and timely access to specialist services from LauraLynn and the broader palliative care sector to care for their child and enjoy the best possible quality of life.

As Ireland's only children's hospice, LauraLynn is uniquely placed to understand and represent the issues and policy priorities of these children and families, enabling them to have a voice in influencing policy development and service planning.

While we are not a primary disability service, our extensive expertise in supporting children with medical complexity will be leveraged in lending our voice to relevant topical discussions and agendas.

Outcome

Ensuring that children with palliative care needs and their families are supported to drive conversations about their lived experience will improve political and public understanding of their issues, drive the changes they need and alleviate feelings of isolation and stigma.

Maximising the evidence of our families, our expert team of healthcare professionals and our research function, together we will work closely and constructively with sectoral allies and key stakeholders to advance our vision that children and their families have the care and support they need at all stages of their journey.

By creating strong, evidence-based submissions, LauraLynn aims to be seen as the voice of Children's Palliative Care in the voluntary sector and play an important role in influencing much needed public policy and funding in the area of Children's Palliative Care, improving quality and equity of access to care nationally.

Impact

Policy development that is informed by the lived experience of children with life-limiting conditions and their families and underpinned by relevant data and evidence, will ensure that Children's Palliative Care services will be available when and where children and families need them.

Access to and between services and clinicians will be child and family centred ensuring continuity, cohesion, integration and flexibility.

Ultimately, the desired impact is that children with palliative care needs and their families will be enabled to live well, in their family home throughout their journey.

STRATEGIC AMBITIONS

6

Ensure a sustainable financial model to support ongoing service delivery and future growth.

Strategic Goals

1. **Continue to maximise** our fundraising capability through growing our supporter revenue and fostering an organisational wide fundraising culture.
2. **Demonstrate** efficient and effective use of funding in the delivery of our services.
3. **Sustain** Section 38 statutory funding to ensure the Children's Disability Respite Service can provide respite to children with complex disabilities across Regional Health Areas A, B and C.
4. **Continue to engage** with the Department of Health and the HSE to achieve a sustainable funding model for the Hospice Service.

Overview

LauraLynn provides all services free of charge to the children and families we support.

LauraLynn's Children's Disability Respite Service is fully funded by the HSE as a Section 38 service. Our Children's Hospice Service is funded partially by the HSE, but relies heavily on fundraised income and faces annual economic uncertainty that could impact its long term sustainability.

A sustainable funding model is imperative in order to plan and provide consistent, equitable, reliable, ongoing support to those who need us.

Outcome

By further growing our fundraising capability coupled with building on our strong relationships with the HSE and Department of Health, we believe that we can ensure a financial model that will sustain and secure our Hospice and Children's Disability Respite Services for years to come.

Impact

A funding model empowers us to match the most appropriate sources of income to suitable areas of expenditure, optimising all income sources. This will ensure that those in our care can continue to receive the support they require, free of charge, on a consistent and ongoing basis.

STRATEGIC ENABLERS

To ensure that we can support our ongoing service delivery and future growth, we are committed to continue investing in four, foundational strategic enablers:

1 People & Culture

- **Support** staff with the required competencies, continuous professional development and leadership opportunities.
- **Enhance** our organisational culture to ensure the recruitment and retention of the best possible staff and volunteers within the sector.
- **Grow** our diversity and inclusion.
- **Build** on our wellbeing focus.

2 Good Governance

- **Ensure** all practices and operations are underpinned by good governance including:
  - statutory and regulatory compliance;
  - accreditation of services;
  - management of risk; and
  - promotion of sustainability and positive social impact.

3 Resources & Capability

- **Maintain and Develop** our campus, facilities and equipment to ensure they are fit-for-purpose, and of a quality and specification to provide the highest standards of service for our families and staff.

4 Innovation

- **Establish** an Innovation Environment across the organisation to help improve the way we operate and deliver our service.
- **Collaborate** with key stakeholders on innovation initiatives and encourage knowledge exchange.
- **Be Digital First** and embrace technological developments.

STRATEGY METHODOLOGY

The strategic planning process commenced in May 2023 with the selection of external consultants following a competitive tendering process. A Strategy Steering Group, comprising members of the Executive Management Team and Board, was formed to lead the six-month initiative.

Extensive consultation took place with families, healthcare colleagues, researchers, educators, funders, staff and volunteers, through a mix of workshops, surveys, interviews and focus groups. Each of these consultations gathered feedback on what we need to do over the coming years and the direction we need to go in, and ultimately, they contributed to the shape of this new strategy. As a part of these consultations, our Vision and Mission were reviewed and renewed, and our Values were affirmed.

The Executive Management Team met regularly to analyse all stakeholder inputs, conduct a comprehensive policy review and SWOT analysis and develop a strategic framework for consideration by the Strategy Steering Group. Through this extensive process, six high level Strategic Ambitions were identified, resulting in key actions to be achieved in the next five years and the operational actions that will be required to achieve these actions.

This ambitious plan to deliver quality, accessible services equitably and in collaboration with stakeholders, most particularly the children and families, was then approved and adopted by the Board in December 2023. We now look forward, with excitement, to bringing it to life over the coming years.

We would like to take this opportunity to thank everyone who contributed to the production of this document.

ENGAGEMENT

Broad stakeholder consultation took place with internal stakeholders (staff, volunteers, families and the Family Engagement Committee); with healthcare colleagues including CHI (Children's Health Ireland), Children's Palliative Care providers and consultants, adult hospices, disability consultants and UK children's hospices; other voluntary organisation working in the sector including Jack & Jill Foundation, Cancer Fund for Children, Barretstown and the Irish Hospice Foundation; statutory bodies in particular our funders, the HSE and Department of Health; and finally researchers and educators within the Children's Palliative Care space.

In total over 200 individuals contributed to the process:

21 external stakeholders were met with

5 surveys were conducted

with responses from:

7	Researchers and Educators
5	Adult Palliative Care Providers
9	Children's Palliative Care Providers
37	Family Members and
16	Staff Members

96 staff members participated in person focus groups

3 intensive 'away day' workshops took place

- 1 with the Executive Management Team
- 1 with the Board and
- 1 joint workshop with the Board and EMT.

17 Executive Management Team Meetings with **9** people

5 Strategy Steering Group Meetings

This was an extensive, robust process involving hundreds of hours of preparation, consultations and analysis, leading to an informed, ambitious strategy for the next five years.

ADVANCING OUR VISION
Extending our Community of Care

STRATEGY STEERING GROUP

The Strategy Steering Group comprised Board Members and members of the Executive Management Team who met both virtually and in person to review all information received through the strategic planning consultation and progress the strategic plan based on this feedback.

Sandra O'Malley, Chair

Jacinta Quigley, Vice-Chair

Tony McPoland, Board Member

Angie Kinane, Board Member

Kerry McLaverty, CEO

Bevan Ritchie, Head of Operations

Sarah O'Callaghan, Head of Marketing and Communications

Katie Devlin, Head of Finance

The Steering Group met on five occasions, twice virtually and three in person. In addition, there were ten individual meetings (virtual and in person) with members of the Steering Group with the external consultant working with the steering groups and a number of telephone calls to support the process. Members of the Steering Group also participated in workshops and led specific stakeholder consultations.

In addition, extensive work was completed by the full Executive Management Team through weekly meetings throughout the process.

WHAT WE HEARD

> Supporting every child and every family who needs us where and when they need our support. Really hearing the needs of our service users and ensuring they can access our care, ideally no more than one hour from their own home.
>
> **Staff Member**

> Bespoke to the unique needs of each child and their family - taking place in the right place for them (home, local community or further afield), at the right time in their palliative care journey for their family circumstances and taking into consideration the needs of the whole family system e.g. siblings.
>
> **Children's Palliative Care Provider**

> Ability to offer more families more time in respite. It's life changing for families and siblings of children with complex needs. Until you experience it you cannot understand what respite means to families and experiencing the norm that others get daily.
>
> **Hazel House Family**

> I think LauraLynn is ideally placed due to staff competence and skills in the area to deliver further external education offerings to support the provision of Children's Palliative Care.
>
> **Research & Education**

> The smiles and joy you see in LauraLynn! I wish that every child with palliative care needs and their family can experience their special care and memory making.
>
> **Volunteer**

> Notwithstanding the continued need for care services to be developed further, there is also a need for increased education and meaningful clinically relevant research needs to be a priority.
>
> **Research & Education**

> Continued engagement in independent research that meets rigorous academic standards will help to advance how policy and services in Children's Palliative Care are developed, funded, and delivered.
>
> **Staff Member**

> There are so many children with palliative care [needs] in Ireland... its hugely stressful... and whatever can be done to give a break to the carers needs to be done.
>
> **Hospice Family**

> The ongoing challenges and changes that face families with children with severe and complex disabilities. The worry and fear about the future for these children after the age of 18.
>
> **Hazel House Family**

> Dependency on fundraising to meet the majority of it's running costs. This makes us very vulnerable if there is an economic down turn.
>
> **Staff Member**

LauraLynn
IRELAND'S CHILDREN'S HOSPICE

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