

Service Adaptation and Learning from COVID-19

Northern Ireland Hospice Family Support Team

Palliative Care

Palliative care for children and young people with life- limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition and throughout the child's life and death

- Together for Short Lives 2008



Paediatric vs Adult Palliative Care

- People who care for ill children know that their needs are very different from those of adult patients.
- Children experience a variety of complex illnesses that are not seen in adults.
- Palliative care can be helpful to all people living with a serious illness and at any stage of their disease. This is particularly the case in children, because they are resilient to illness in ways that adults are not.



Similarities	Differences
Palliative care can start at the beginning of an illness and be given along with treatment meant to cure.	Having a serious illness is not a “normal” condition for most children. This presents unique challenges in caring for the children and their families.
Palliative care aims to improve quality of life by relieving distressing symptoms	Medical decisions for young children are usually made by their family caregivers. Adult patients may make their own decisions.
The team helps with decision making and figuring out care goals. Should always be based on Best Interests.	Pediatric palliative care can also involve a play therapist, child life therapist and/or child behavioral specialist
Palliative care can be medical care, but it also involves a team of different disciplines that includes doctors, nurses, social workers, chaplains, and other professionals.	

Similarities

- Care can start at the beginning of an illness and be given along with treatment meant to cure.
- Improving quality of life by relieving distressing symptoms.
- The team helps with decision making and figuring out care goals. Should always be based on best interests.
- It can be medical care, but also involves a team of different disciplines that includes doctors, nurses, social workers, physios, OTs and others



Differences

- Having a serious illness is not a “normal” condition for most children. This presents unique challenges in caring for the children and their families.
- Medical decisions for young children are usually made by their family caregivers. Adult patients may make their own decisions.
- Paediatric care can also involve a play therapist, child life therapist and/or child behavioral specialist

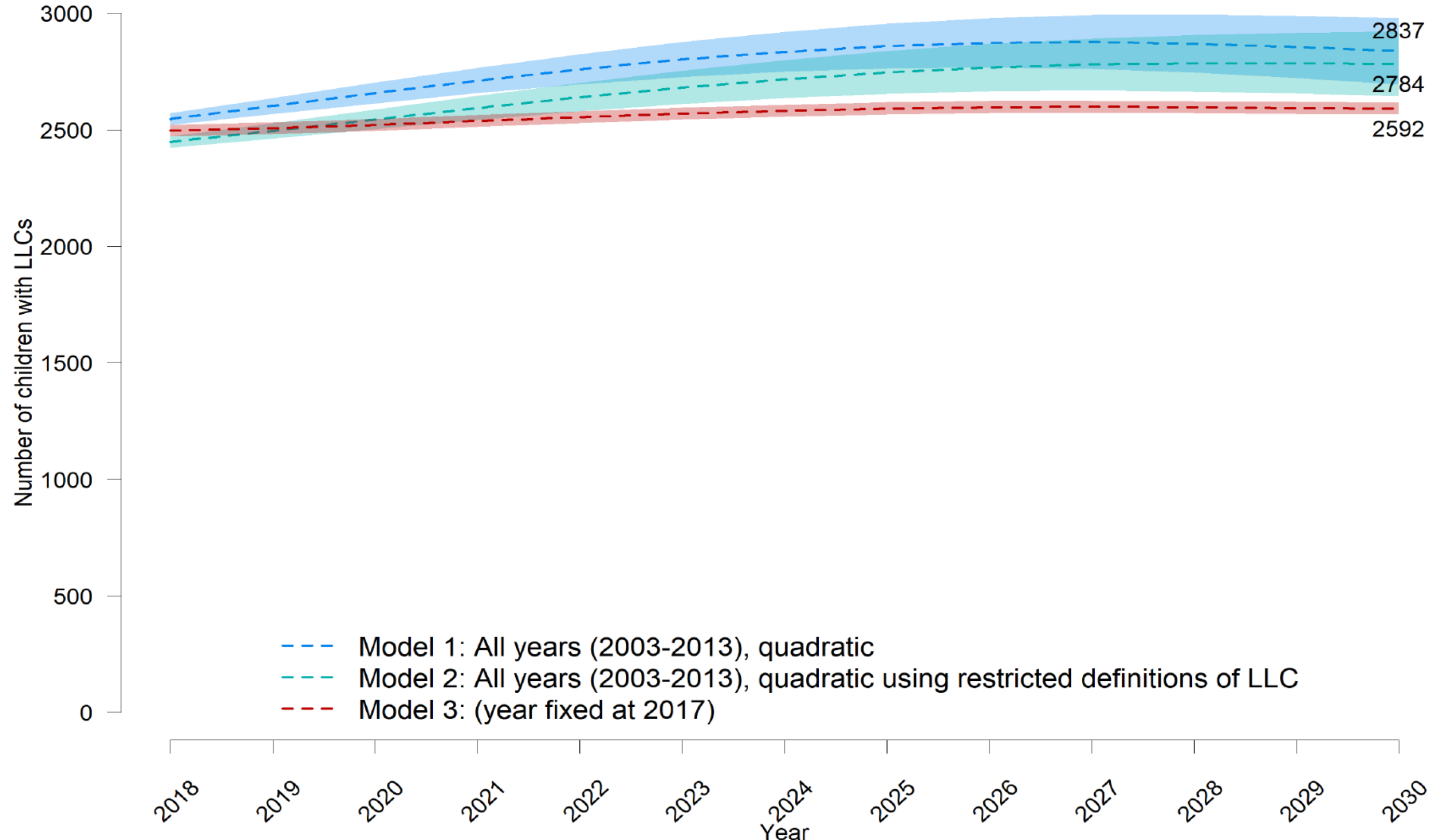


Make Every Child Count Research

- Up to date research on numbers of children and young people with a life limiting or life-threatening illness.
- From this there were able to estimate prevalence in Northern Ireland and make predictions for numbers likely impacted by 2030.

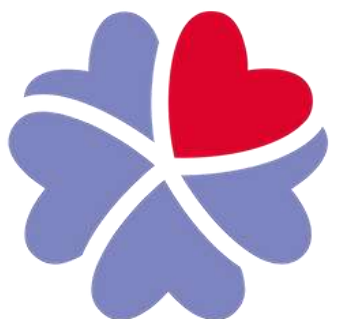


Predicted numbers of children with LLCs in Northern Ireland




What the Research Tells Us...

- Prevalence is higher in boys than girls
- The prevalence of life-limiting conditions was highest for congenital abnormalities.
- Prevalence is by far the greatest in babies under one year of age, as is the number of deaths.
- The number of young people with life-limiting conditions living to age 19 is increasing
- The prevalence of life-limiting conditions is highest among the most deprived groups of the population
- The prevalence of life-limiting conditions is increasing







Palliative care services going forward?





The role of Children's Hospice services for children with a life-limiting or life-threatening condition

Relationship between palliative care and treatments aimed at cure or prolonging life

	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.

Key:

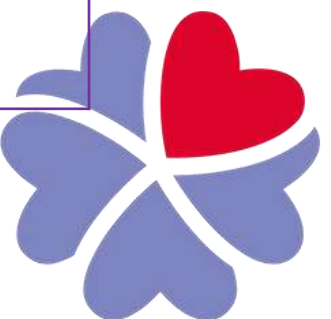


curative



palliative

Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail.
Category 2	Conditions where premature death is inevitable.
Category 3	Progressive conditions without curative treatment options
Category 4	Irreversible but non progressive conditions causing severe disability, leading to susceptibility to health conditions and likelihood of premature death



Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail.</p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
Category 2	<p>Conditions where premature death is inevitable.</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy.</i></p>
Category 3	<p>Progressive conditions without curative treatment options.</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>

What is a Children's Hospice?

Children's Hospices care for babies, children and young people from birth to 18. Services vary depending on the provider, however many offer a wide range of specialist services for children with life limiting and life-threatening conditions. These may include:

- Day care
- Hospice at Home
- Supported short breaks/ respite
- Advance Care Planning
- Key worker visits
- End of Life care
- Bereavement Support
- Education



Northern Ireland Children's Hospice





Northern
Ireland
Children's
Hospice

Supporting the O'Neill Family





In-House Services





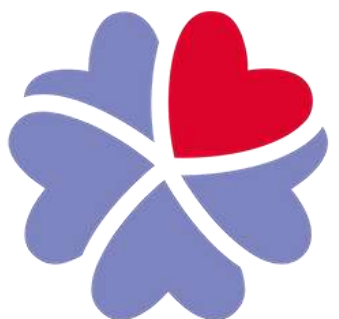
In-House Services



What Children's Hospice Offers

Community Services

- Community Hospice Nurse Specialists
- Hospice at Home



What Children's Hospice Offers

- Hospital Services
- PALLS Nurse
- I'm Coming Home





**Northern
Ireland
Hospice**

What Children's Hospice Offers

- Family Support Services
- When a child in the family is diagnosed with a life limiting or life-threatening condition, it affects the entire family unit.
- The Family Support Service offers specialist support to help families cope with disruption to family life, and minimize the long-term impact on the families emotional wellbeing.



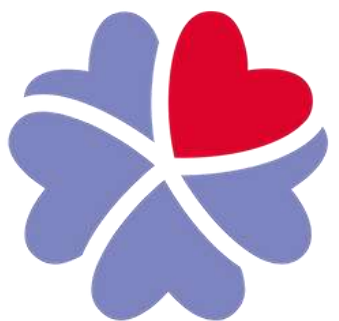
Who is the Family Support Service For?

- The service is for children/young people and their families when a child has been diagnosed with a life limiting or life-threatening condition.
- A family might decide that individual members would benefit from the service, or perhaps the whole family would benefit from using the service together



Aims & Objectives of Family Support Service

- Help families, children and young people untangle complicated feelings and dispel fears
- Provide a support service tailor made to meet the needs of the families
- Offer constructive practical and emotional support when life feels difficult
- Help families find the language to speak to each other
- Provide opportunities for families to meet others in a similar situation and share experiences and feelings
- Support the family to have fun together and to enable them to continue family life



Types of Support

- Family Support Sibling Group
- Coffee Mornings
- Family Fun/Activity Days
- Adult Carers Group
- 1:1 therapeutic work
- Counselling Service for Adults
- Parent & Tots Group
- Facebook Support Groups



THIS IS

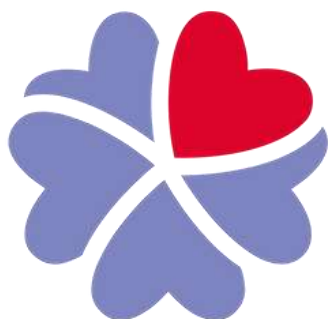


Northern
Ireland
Children's
Hospice

KERRY & GORDON
TALKING ABOUT BEN

Care After Death & Bereavement Support

- Some Children and Families travel to or remain in Horizon House for Care After Death.
- Bereavement Support is offered to the whole family, for up to two years.
- Parent and Sibling Bereavement Support Groups
- Pre-Christmas Bereavement Day
- Forget Me Not annual service.





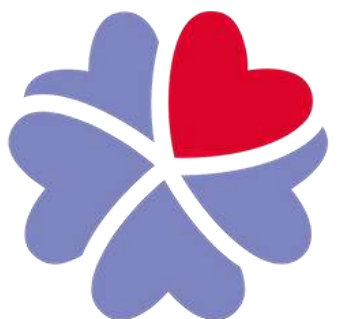
**Northern
Ireland
Hospice**

The Importance of Children's Hospice Week

The Importance of Children's Hospice Week



Children's Hospice Week is the only week in the year dedicated to raising awareness and funds for children's hospice and palliative care services across the UK.



Mothers caring for children with life-limiting conditions

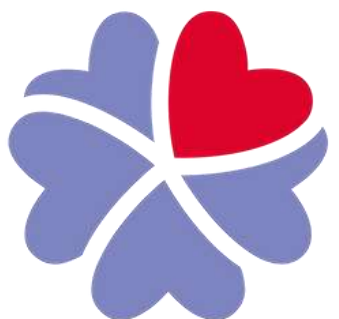
- New research shows that mothers of children with life-limiting conditions are much more likely to develop serious physical and mental health problems and have a premature death, compared to mothers caring for children with no long-term health condition.
- The risk of premature death was more than **50% higher**
- Mothers caring for a seriously ill child have a significantly higher incidence of **depression, anxiety and serious mental illness**, and physical conditions such as **cardiovascular disease, type 2 diabetes, hypertension and obesity**.



A Mother's Perspective

Responding to the research, Karen mother of five said this;

In reflection as to where we find ourselves as a family of five - 2 adults - pretty broken. Both parents suffering carers/compassion fatigue, burnout and with bouts of poor mental health. Our marriage is under constant strain. Our eldest disabled daughter is now 12. What could have made those 12 years any easier - two things would definitely have helped in some way

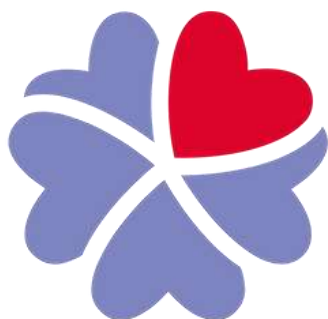


A Mother's Perspective

1: FREE counselling - for as long as you need it!

Our daughters health and progress has changed month on month, year on year. It's like a constant grieving process - a living loss.

A constant source of worry. If we'd both had someone we could regularly check in without a cost, it would have made such a difference to our mental health. I don't feel that this is a huge ask when mental health is such a pressing issue in 2021.



A Mother's Perspective

2: Nursing support once a month at the weekend

Marriages/partnerships are put under extreme pressure when there is full time care required in a household.

The Hospice is in a fantastic location and I know my two children love to come up and play at the hospice whilst Emily is cared for. Supported Short Breaks in Hospice are limited throughout the year due to demand on service and funding.



Lessons we learned
through COVID-19 and
how we responded to
ongoing need

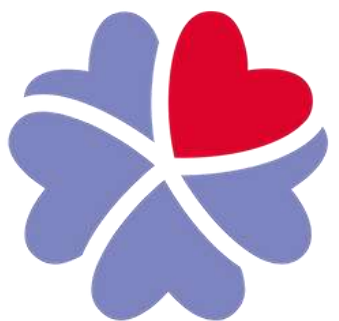
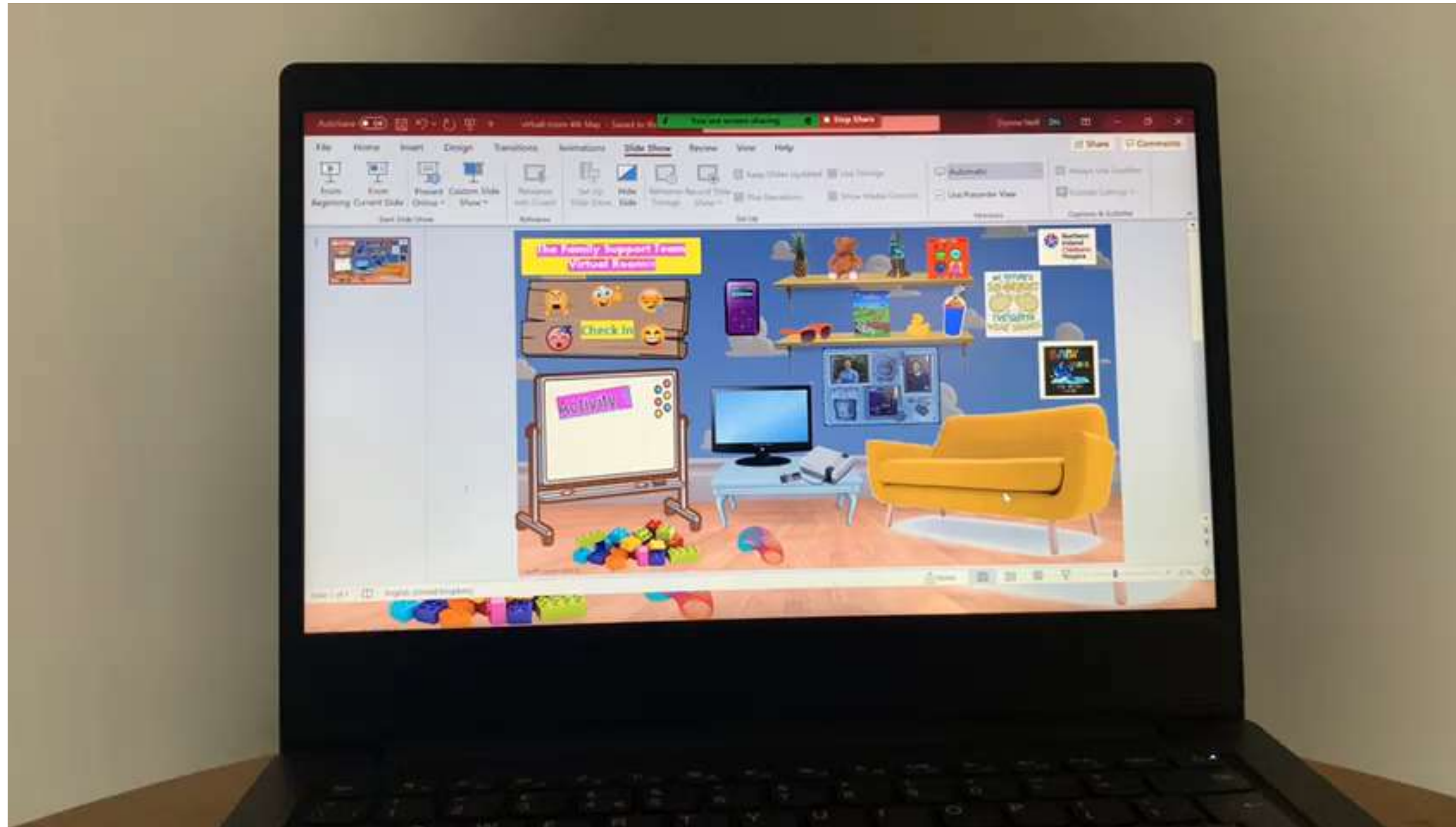
1. Greater Flexibility in Service Delivery

Some examples of this new flexibility include;

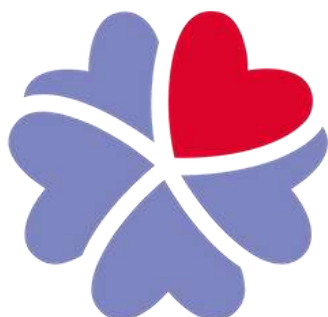
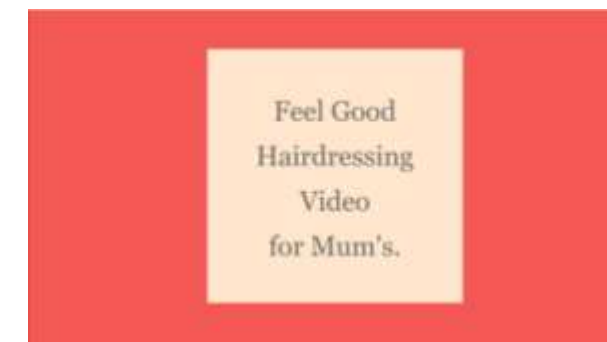
- Development of online work
- Care at Home Model
- PPE adaptation
- Safeguarding



Development of Online Work



Virtual – Facebook Videos





MULTI-SENSORY SCAVENGER HUNT



Search around your house and find things that match the words below and make your very own multi-sensory collage.

Hard

Soft

Sticky

Crunchy

Bumpy

Small

Fluffy

Square

Round



Colourful

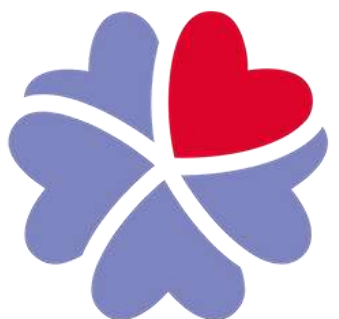


Once you have all these items, stick them onto a piece of paper to make your collage





PPE Adaptations



Care at Home Model

Month	No of Hours
May 2020	26
June 2020	291
July 2020	324.8
August 2020	391.25
September 2020	97
Total no. of hours	1130.05

One Parent reported that the care at home was the first help they got since lockdown. She reported feeling weary with home-schooling and working from home herself. She felt her mental health had been affected with everything and the lack of interaction and has found care at home to be a 'lifeline'.



Safeguarding



- Covid-19: SBNi report "sustained, noticeable drop in child protection referrals during lockdowns – Jan 2021.
- The key concern was that children were no longer visible to services in Northern Ireland when it went into lockdown."
- NICH provided Care at Home, online support and face-to-face support including. doorstep visits to maintain good safeguarding practices during COVID.



2. How intelligence is used and gathered

- Out of necessity everyone accepts that new ways to communicate will be essential going forward.
- Co-production has improved relationships between all those who have a shared interest in the service.
- We cannot have a responsive, individualised and reflective service without this greater trust that co-production brings.



Parent's Feedback

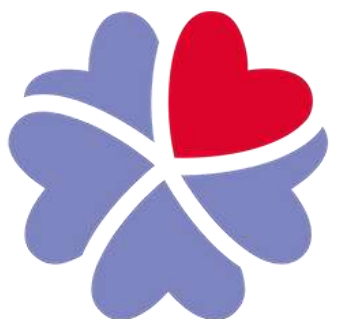
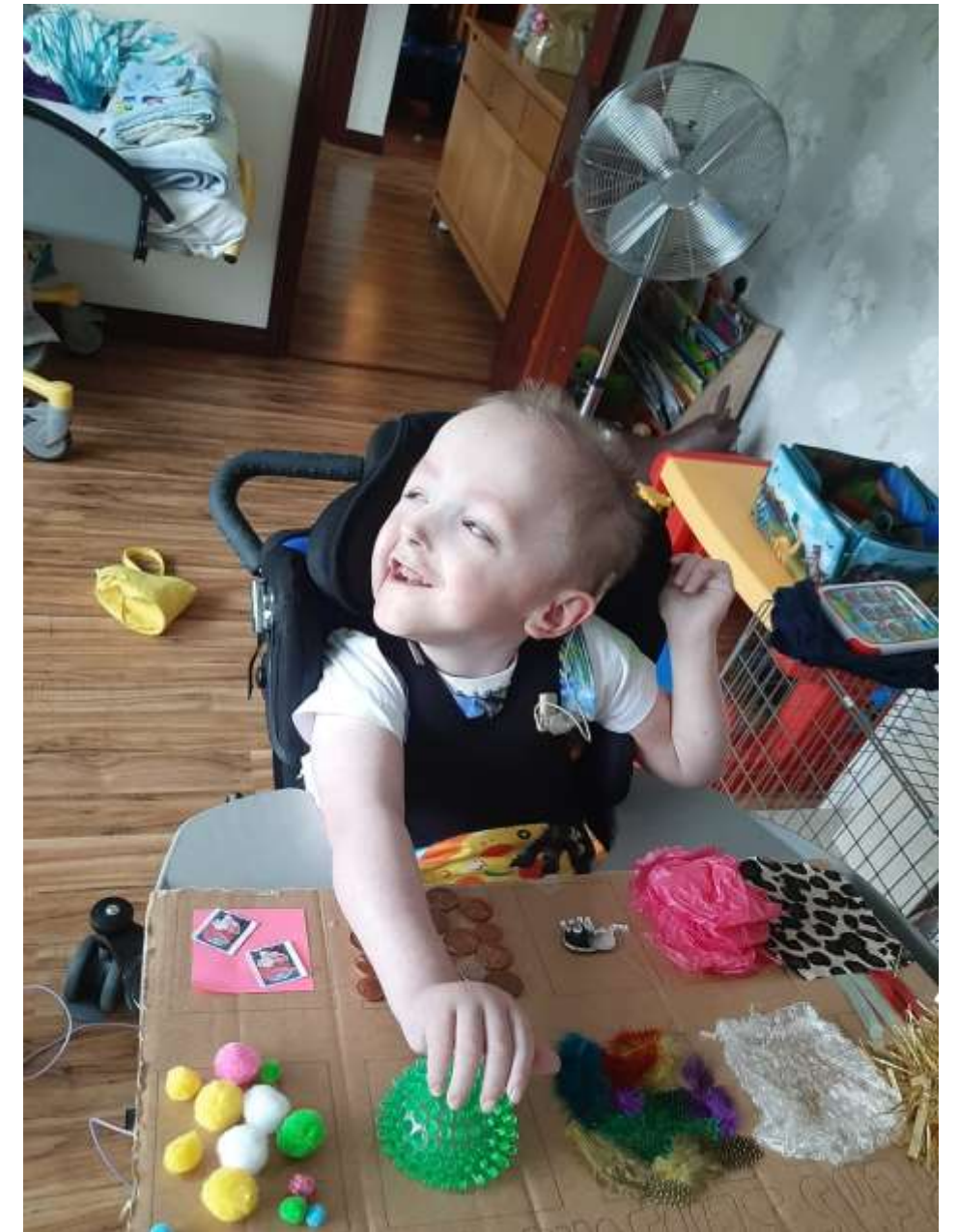
"I just wanted to write a message to you all to say how impressed I've been at the continued support we have received during these last few months. The creativeness that has been shown is amazing, and I'm sure it hasn't been easy for you all to come out of your comfort zone. Having to rethink everything on how you are going to deliver the much needed valuable services and support. I'm not sure on the overall response to the remote sessions, but they have been very much greatly received in our household.

We have thoroughly enjoyed the music sessions, story times, arts and crafts ideas and videos and zoom calls. And I appreciate the links to relevant services and phone calls to check up on us to make sure we are doing ok.

It would be easy to simply wallow in self-pity, or lose motivation to do anything other than the bare minimum during a time that is so frightening and uncertain. The virtual support has created structure into our week, and provided me with motivation into getting up and dressed knowing we are going to do something productive and that we all will enjoy.

I would like to highlight that possibly after all this pandemic is over that there may be a need to continue some services remotely. It's all trial and error now in terms of what works and is successful. But personally, from someone that is generally quite isolated from society due to my son's complex health issues, having some of these activities would greatly help. Especially during the winter time when going out and about isn't an easy option.

You are all doing an amazing job, and I look forward to future ideas and support. The team is making a huge difference in improving the overall health and well-being of my family and other complex needs families in the wider community."



3. Who should deliver care and who should benefit from it?



“Zoom has taken the pressure away from meeting people. In person you might only talk to 2 people either side of you. On zoom you get the chance to talk to many more.”



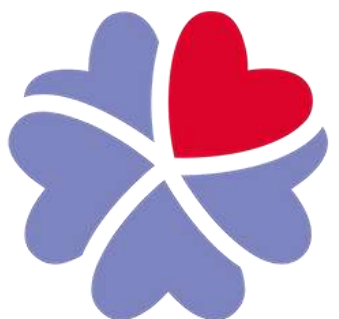
“Online is brilliant for me – don’t have to leave him to attend or the hassle of leaving the house and organising various different things. Works really well – blended approach to delivery.”



Feedback from Families



“The family support service has been amazing, it has given me the opportunity to meet other families like ours. They have provided the opportunity to switch off from our day to day. Even during lockdown they have been fantastic at providing support and resources to help with our routine”



Feedback from Families



“The FSS has been invaluable for our family. My 9-year-old daughter has received 1-1 work from staff re her anxiety about her twin sisters illness/ disability. She looks forward to & really enjoys these sessions and is really benefiting from this work. My daughter & son also really enjoy the siblings days & zoom calls- it has really helped them understand that they are not the only children who have a sibling with special needs. This has helped them 'normalise' their experiences of this & not feel different/ isolated.”



Questions?



References

Lorna K Fraser, Deborah Gibson-Smith, Stuart Jarvis, Paul Norman, Roger Parslow, Martin House Research Centre

Make Every Child Count Fraser et al. 2020

A Core Care Pathway for Children with Life Limiting and Life-Threatening Conditions. 3rd Ed. Together for Short Lives 2013

