Mapping global access and development in Paediatric Palliative Care

Sue Boucher
ICPCN International Information Officer
A brief history of children’s palliative care

• **Dame Cicely Saunders**, the founder of the Hospice Movement started the first **Modern Hospice**: St Christopher’s Hospice in London in **1967**. (Died 2005)

• 15 years later in **1982** a nun, **Sister Frances Dominica**, and the parents of a young girl called Helen, who had an inoperable brain tumour, founded the very first Children’s Hospice in Oxford.
Helen House opened in 1982
Oxfordshire, United Kingdom
Balfour Mount

• Respected oncologist
• Hospital based care
• 1973 studied at St Christopher’s
• Coined the term ‘palliative care’ based on the word ‘palliate’ – to improve the quality of something.
Elisabeth Kübler Ross

• 1926 - 2004
• Wrote ‘On Death and Dying’ in 1969
• Five stages of grief
• Confronted people’s fear of death
• Wrote about children’s experiences
• Wrote The Dougy letter in 1981
Levels of PPC

- Evidence of broad palliative care provision for children with focused plans for the development of services
- Evidence of localised provision and the availability of training
- Evidence of capacity building activities for the provision of children’s palliative care
- No known provision of children’s palliative care
Children's Hospice International (CHI) was founded in 1983 by Anne Armstrong Dailey to:

- Promote hospice support through paediatric care facilities
- Encourage the inclusion of children in existing and developing hospice, palliative, and home care programs
- Include the hospice perspectives in all areas of paediatric care, education, and the public arena.

In 1983, of the 1,400 hospices in the United States, only four were able to accept children.
1985 - 1999

1985 Hospital based children’s palliative care services opened in St Mary’s Hospital, New York

1986 Hospital based children’s palliative care services opened at Great Ormond Street Hospital in London

1988 ACT was started by Sister Frances Dominica and Prof David Baum as a national resource and information centre in the UK

1992 First palliative care unit started in Argentina
1993 Publication of the textbook: Hospice Care for Children
By Ann Armstrong Dailey and Sarah Zarbock
1985 - 1999

1994 Children`s Hospice was created in Belarus through an initiative of the Republican Centre of children`s oncology and haematology

1995 Canada opened the first free-standing children's hospice in North America

1996 First children’s hospice founded in South Africa

1997 First children’s hospice founded in Australia

1998 First children’s hospice founded in Germany

1999 Specialist children’s palliative care service started in New Zealand
1998 - WHO Definition

Palliative care for children is the **active total care** of the child's body, mind and spirit, and also involves giving support to the family.

It **begins when illness is diagnosed**, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must **evaluate and alleviate** a child's physical, psychological, and social distress.

Effective palliative care requires a **broad multidisciplinary approach** that includes the family and makes use of available community resources.

It can be successfully implemented **even if resources are limited**. It can be provided in tertiary care facilities, in community health centres and even in children's homes.
By 2003 isolated children’s palliative care programmes and services had been started in a number of countries, including:

Uganda, Zimbabwe
Poland, Italy, France, Israel
Romania
Costa Rica
India

THE IDEA FOR THE FORMATION OF THE ICPCN WAS BORN
2006  Oxford Textbook of Palliative Care for Children

   Edited by Dr Richard Hain, Ann Goldman and Stephen Liben

2007  There were still only 6 specialist consultants in children’s palliative medicine in the UK (ACT)

2009  Oxford Textbook on Palliative Care for Children in Africa

   Edited by Dr Justin Amery
Chairs in PPC

2008  Germany – Boris Zernikow
2010  UK – Myra Bluebond-Langner
2011  USA – Sarah Friebert
Children’s Palliative Care in Norway

2009 JA til lindrende enhet og omsorg for barn
The birth of the ICPCN

2005 ICPCN was founded and a group of individuals representing children’s palliative care internationally began to meet as the Steering Group of ICPCN.

2007 With seed funding from The True Colours Trust the ICPCN website was launched and the International Information Officer was employed.
What is the ICPCN all about?

**International Children’s Palliative Care Network**

**Mission of the ICPCN**

Our mission is to achieve the best quality of life and care for children and young people with life-limiting conditions, their families and carers worldwide, by raising awareness of children’s palliative care, lobbying for the global development of children’s palliative care services, and sharing expertise, skills and knowledge.
Aims of the ICPCN

ICPCN focuses on four key aims:

• Networking
• Information sharing
• Advocacy
• Research and education
The present structure of the ICPCN

International Board of Trustees / ICPCN in Africa Board

Chief Executive

Information & Networking
   International Information Officer

Advocacy and Development
   International Advocacy Officer & Advocacy Committee

Education & Research
   Education and Research Consultant & Scientific Committee

Finance & Administration
   Finance and Administration Officer & Finance and Resource Committee

International Membership

National, Regional, Local Organisations & Individuals working or interested in the field of PPC
What does the ICPCN do?

International Board of Trustees representing all the regions of the world
Staff: based in South Africa
With the recent addition of ‘Google Translate’ to the site to make it more accessible
Membership & Directory

254 Organisations

680 Individuals

87 countries
Newsletters and alerts

Welcome to Busi Nkosi - IPCCN Advocacy Officer and newest staff member

ICPCN is a registered charity in England & Wales number 1147241 and a registered company in England & Wales number 7681712.
The Facts

Why should we care about children’s palliative care?

Children’s palliative care is essential to ensure that children with life-limiting illnesses and their families receive the best possible care.

South Africa

About the organisation

The ICPCN Guide to Children’s Hospice & Palliative Care

FACT SHEET

Worldwide – 1.4 million children at home

Our Vision

The International Children’s Palliative Care Network (ICPCN) is a global organisation dedicated to improving the quality of palliative care for children of all ages, in all settings. We work to ensure that children with life-limiting illnesses and their families receive the best possible care.

Our Mission

ICPCN works to improve the quality of palliative care for children worldwide, by providing education and support to professionals and families, and by advocating for better policies and practices.

The ICPCN Guide to Children’s Hospice & Palliative Care

This guide is a resource for professionals working with children with life-limiting illnesses, as well as for families. It provides information on the care that children need, the support that families need, and the policies and practices that need to be in place to ensure that children receive the best possible care.

The guide is available in English, French, Spanish, and Arabic.

For more information, visit the ICPCN website at www.icpcn.org.
Downloads

Children's Palliative Care in Africa
Edited by Justin Amery

Guidelines & Assessment Tools for Children's Palliative Care in South Africa
Hospice Palliative Care Association of South Africa

No Secrets: Incorporating the Needs and Rights of Children into Palliative Care

A Toolkit for Children's Palliative Care Programmes in Africa
Hospice Palliative Care Association of South Africa through the generous funding of the Diana Princess of Wales Memorial Fund Palliative Care Initiative
ADVOCACY & DEVELOPMENT

ICPCN Advocacy Committee – March 2012
Development projects in which ICPCN is involved:

- DPOWMF Beacon centre projects in South Africa, Uganda and Tanzania
- DFID two country project to develop PPC Centres of Excellence in Malawi and Maharashtra District in India
- Intro to PPC Course in Kenya
- Conference & meetings with Govt. officials in Argentina
- Masterclass in Zambia
- Master Class on PPC in Brazil
4X4 donation to Umodzi in Malawi
Donation of equipment to first children's hospice in Guatemala

BOMBA DE INFUSION IN USE IN HOSPICE LIVING ROOM
Working in collaboration with:

• Worldwide Palliative Care Alliance (World Hospice and Palliative Care Day)
• EAPC Children’s Task Team
• United Nations Committee on the Rights of the Child (UNCRC)
• Human Rights Watch
• World Health Organization
• Elizabeth Glaser Paediatric Aids Foundation
• Paediatric AIDS Treatment for Africa - PATA
<table>
<thead>
<tr>
<th>Year</th>
<th>Conference Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>CHI Congress in Cape Town</td>
</tr>
<tr>
<td>2010</td>
<td>5&lt;sup&gt;th&lt;/sup&gt; International PPC Conference in Cardiff</td>
</tr>
<tr>
<td>2012</td>
<td>6&lt;sup&gt;th&lt;/sup&gt; International PPC Conference in Cardiff</td>
</tr>
<tr>
<td>2012</td>
<td>EAPC PPC Conference in Rome</td>
</tr>
</tbody>
</table>
Advocacy publications

ICPCN CHARTER
– an international charter of rights for all children with life limiting or life threatening conditions
– available in 23 languages
– can be downloaded from the ICPCN website

ICPCN ERKLÆRING
Med tilslutning til ACT erklæring, setter ICPCNs sine erklæringer den internasjonale standarden for rettigheter og støtte, for alle familier med barn som har livsbevegende og livstruende tilstander.

1. Et hvert barn skal forvente individualiserte, kulturelle og alderspasset palliativ omsorg, som er definert i Verdens helse organisasjon (WHO). De spesiﬁkke behovene for tenåringer og ungdommer skal adresseres og planlegges.


3. Barnets foreldre eller vørge, skal bli anerkjent som hovedomspningspersoner og som de viktigste omsorgspersonene for barnet. De skal bli gitt og bli anerkjent på lik linje med helsepersonell i all behandling og beslutninger som må tas i forhold til sitt barn.

4. Et hvert barn skal bli oppmuntret til å delta i beslutninger som tas som angår hans eller hennes egen behandling ut i fra alder og forståelse.

5. En sensibel og ærlig tilnærmelse er basen i all kommunikasjon med barnet og barnets familie. De skal bli behandlet med respekt og verdighet og bli gitt private hensyn ut fra psykisk og intellektuell kapasitet.

6. Et hvert barn og ungti menneske, skal ha tilgang til utdannelse og når det er muligheter få tid til å leke, ha friids muligheter, være sammen med sakens, venner og delta i normale barndoms aktiviteter.


9. Barnets hjem skal være benutnet av behandlingen når det er mulig og ønskelig. Behandlingen som skjer utenfor hjemmet, skal være i et barnesentre miljø av helse personell og frivillige, som er trent og besitter kunnskap spesielt på palliativ behandling for barn.

10. Et hvert barn og familiemedlemmer, inklud ert sesken, skal motta passende kulturelle støtte og tilnærminger, kliniske, emos jonelle, psykiske og åndelige, for å møte deres spesialist behov. Ettervern og støtte etter barnets død, skal gis og være tilgjengelig.
Touching Rainbows

Acknowledgements
Child's Voice in Palliative Care

The full image is too complex to read naturally.
Julia Downing - based in the UK & Uganda. (Honorary professor at Makarere University in Uganda)

ICPCN Scientific Committee.
Headed by Prof Susan Fowler-Kerry (Canada)
# Scientific Committee

**Countries**
- Canada, USA
- UK, Ireland, Germany
- South Africa, Uganda
- Argentina
- Australia
- India

**Professions**
- Nurses
- Doctors/ Paediatricians
- Researchers
- Anthropologist
- Educationalists
- Economist
- Social Workers/ Social Scientists
- Psychologists
Education survey

• Evaluation of status of Paed PC training worldwide
• Survey of training needs
• Assessment of existing curricula for CPC
<table>
<thead>
<tr>
<th>Country (16)</th>
<th>Sensitisation</th>
<th>Education</th>
<th>Specialisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belarus</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>England, Scotland and Wales</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>France</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Greece</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Luxemburg</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Norway</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Romania</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Serbia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Switzerland</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
E-learning Pilot programme

- Linked to WHO guidelines
- 4 pilot centers – USA, Romania, South Africa, Argentina
- Open to anyone to complete
- Assessment and evaluation integral
- www.icpcn.org.uk
E-learning Pilot on WHO Guidelines

Participants by profession

- Medical Officers
- Doctors
- Nurses
- Other
Research

- International collaborative research that furthers the aims of the ICPCN

- Delphi study to identify the global priorities for research in children’s palliative care that can then inform the development of a research agenda for the ICPCN and its partners.

- Possible options:
  - Investigating international differences in life-limiting conditions in children
  - International study on the psychological impact of pain in children
  - International study linked to the WHO guidelines
  - International study looking at key ‘conditions’ requiring palliative care in children
Examples of dissemination

**Papers**
- Collaborated in various papers and books
  - CPC in Africa
  - CPC Provision around the world
  - CPC book
  - IJPN focus issue

**Other**
- Conferences e.g. EAPC, APCA
- WPCA
- Newsletter/ website
- Scientific groups e.g. Task Force
The Future

NEXT EXIT
Future plans

• To continue to develop our networking, information provision, advocacy and research
• To train and mentor where required
• To further our reach through providing information in languages other than English
• Further piloting of the web-based curricula
• Identifying placement sites and institutions for accreditation
• First ICPCN PPC Congress in 2013
• A step up in advocacy work since the appointment of an Advocacy Officer in 2012
Present picture of PPC worldwide

2012

Map showing the present picture of palliative care provision worldwide in 2012.
Thank you!