



September 8, 2018

IAHPC Written Statement for WHO Regional Committee for Europe, 68th session

**European Child and Adolescent Health Strategy 2015–2020 and European Child Maltreatment Prevention Action Plan 2015–2020, resolution EUR/RC64/R6**

IAHPC, a non-state actor in official relations with WHO, and accredited by ECOSOC, supports the European Child and Adolescent Health Strategy 2015–2020 and the European Child Maltreatment Prevention Action Plan 2015–2020 in relation to resolution EUR/RC64/R6.

We are surprised, however, that the document does not include the right of children and adolescents in the EURO region to access palliative care. IAHPC takes a rights based approach to palliative care, which emphasizes that children and their families needing palliative care are a particularly vulnerable group. Many children born with life-limiting or life-threatening conditions, also have disabilities, and require palliative care. Children with palliative care needs suffer from a broad range of heterogeneous conditions that require interdisciplinary, holistic interventions tailored to meet the needs of the individual child and their family.

The right to palliative care for children, as well as for every human being with serious illness, is an integral part of the right to health. It flows from other core principles enshrined in international human rights law, especially the United Nations Convention on the Rights of the Child, the International Covenant on Economic, Social and Cultural Rights, and the Convention Against Torture.

As children also have the right to access the essential medicines utilised in paediatric palliative care, governments are obliged to ensure access and availability to, easily administrable paediatric formulations of essential medicines for pain and symptom control. This must include that those containing internationally controlled substances, such as morphine, are available, accessible, and affordable to patients in the EURO area. Paediatric palliative care should also be included in all humanitarian health care responses.

In paediatric palliative care the child and their family are considered the unit of care. Parents, siblings and significant family members should be educated and included in the provision of paediatric palliative care. Palliative care for children is holistic and concerns not only clinical needs but has a huge social impact on a large part of the community in which the family lives (school, friends, sports club). It is estimated that for each child receiving palliative care, 300 people are directly and indirectly emotionally involved. Siblings can often experience



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abandonment, loneliness, and suffering including the consequences of not being the focus of their parents' attention. This is often an invisible problem.

IAHPC is committed to acting in the best interest of affected children by focusing on improving the child's and family's quality of life and dignity, and preventing or relieving their physical, psychological, social and spiritual suffering. We strive for the integration of pediatric palliative care into primary care, and its recognition as an essential component of Universal Health Coverage that will support member state's achievement of the Sustainable Development Goals.

We work closely with the International Children's Palliative Care Network, the Worldwide Hospice and Palliative Care Alliance, the European Association for Palliative Care, and the Maruzza Foundation, an independent family run charity. Our aim is to promote excellence and equity in the provision of palliative care and support for persons affected by life-threatening and life-limiting conditions and their families, regardless of age, cultural, social and economic background.

IAHPC and its partners, stand ready to assist member states to integrate palliative care for Children and Adolescents into their public health systems and provide appropriate training for their workforce.