



PNAE
Paediatric Nursing Associations of Europe

Paediatric Nursing Associations of Europe
42nd meeting
27th September 2023 in presence
hosted by Italy- Rome

PNAE document about Health care in the community

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Belgium

POINT 8

**PNAE DOCUMENT ABOUT HEALTH CARE IN
THE COMMUNITY**

POSITION STATEMENT 2015

- *Facilities and resources* - To support equitable care of children and young people in the community:
 - Paediatric home care teams including provision for palliative and end of life care
 - Financial resources to provide the required equipment, as well as support for children depending on assessed needs and support, education and training for parents (caregivers)
- *Qualification and preparation of nurses* - To ensure nurses have the required knowledge, skills and competences:
 - Initial education programmes for paediatric nurses that encompass caring for children in the community and/or post-registration community nursing education programmes
- *Education, training and discharge preparation:* - To ensure that parents and caregivers are appropriately prepared and supported to care for their child in the community:
 - Child and family centred, consistent national and evidence based structured discharge programme including assessment of competencies
- *Support for children and caregivers in the community* - To ensure that parents and caregivers receive adequate support to prevent 'burn out':
 - Provision of respite care, short breaks and financial and social care support packages
- *Research* - To ensure that service planning and the needs of children, young people and families are identified
 - Audit of services and outcomes to assess satisfaction of services provided
 - Participation of children, young people and families in the development and design of service provision, including the transition to adult services

POSTION STATEMENT - ACTION

- Each Paediatric Nursing Association to raise awareness of the needs of children, young people and their families in the home care and community setting
- Each Paediatric Nursing Association to lobby key stakeholders to improve the availability of community nursing services by paediatric nurses
- Governments and Ministries of Health to ensure adequate resources, education and workforce planning to achieve equitable service provision for all children and young people in the community, including palliative and end of life care

REACTIONS & FEEDBACK

- Belgium – Karen & Katrin
- Ireland – Rosemarie Sheham – article by Maria Brenner
- Iceland - Guðrún Kristjánsdóttir
- Turkey – feedback will be given during meeting
- Luxembourg – Marie Friedel – articles in link added
- Italy – Immacolata & Orsola

BELGIUM

- KCE report Transmural care for children in Belgium – recommendations rather on organisation of the care
- With the position statement we search for minimal standards that is necessary and possible for a country to reach.
- We suggest to add recent literature
- We suggest to use principles from the research from Brenner et al (Ireland).

IRELAND

PRINCIPLES FOR PROVISION OF INTEGRATED COMPLEX CARE FOR CHILDREN ACROSS THE ACUTE–COMMUNITY INTERFACE IN EUROPE (BRENNER ET AL, 2018)

- Viewpoint and discussion
- Development of the first core principles and standards for effective, personalised care of children living with complex care needs in Europe.
- The three main principles:
 - access to care,
 - co-creation of care,
 - effective integrated governance.
- It could used
 - as a benchmark
 - or to influence policy in relation to service delivery for these children,
 - to provide a suite of indicators with which to assess future service developments in this area.

IRELAND - ACCESS TO CARE

- Children have access to age-specific and developmentally appropriate care
- A pathway for 24-h access, 7 days a week, to non-urgent specialist care in the community is in place
- Where possible, children are cared for by the same doctor and nurse on each consultation
- Community complex care centres are established where there is a substantial population of children with complex care needs, and where the specialist expertise exists to support the child and their family
- Technical support is available in the community to assist parents caring for a child who is technology-dependent (eg, requiring mechanical ventilation, intravenous nutrition or medication, or respiratory or nutritional support)
- Electronic health records are used to support communication and continuity of care across the acute–community interface
- Children and families have access to community pharmacists
- A child living with complex care needs receives ongoing preventive care screening and developmental checks

IRELAND - ACCES TO CARE

- All screening results are disseminated to all health services caring for the child and are communicated to the child's parent or guardian
- Families have access to a transportation service that can enable the child, and their assistive technology devices, to attend daily activities and health and social care visits
- All information provided to families is linguistically appropriate
- All information provided to families is culturally appropriate
- When a child living with complex care needs has a medical crisis, there is direct access to, and discharge from, a paediatric emergency department or a paediatric intensive care unit
- Children have timely assessment for, and access to, rehabilitation services
- Paediatric palliative care services are available to the child and family when required
- Children have timely access to respite care services.
- Children have access to diagnostic tests in primary care that enable prevention and early detection of health concerns

ICELAND

- Although new studies have been published on the matter, the main statements in this document still hold as far as I see them. Possible. What I miss in the statement is **a more clear focus on situations/reasons when not to provide care at home**. Also, the statement on Key stakeholders seems to be missing out on other important associations and organizations. Professional nursing associations/organizations might need support/co-work from other associations; however, I understand this might be due to the PNAE goals.
- I am not sure we need to change the statement much when renewing it an publish.

TURKEY

- Oral information during meeting

LUXEMBOURG

- child and family centred: could we add a specific focus on evaluation and responding to sibling needs?
- maybe adding some recent references
 - Hyde, R. L., Gallagher, J., Donnelly, K., Thompson, C., & Macfarlane, C. (2023). Community children's nursing: developing a bespoke model of post-registration education. *Nursing children and young people*, 35(3), 16–21. <https://doi.org/10.7748/ncyp.2022.e1449>
 - Nelson, H. J., Pienaar, C., Williams, A. M., Munns, A., McKenzie, K., & Mörelius, E. (2022). Patient experience surveys for children's community health services: A scoping review. *Journal of child health care : for professionals working with children in the hospital and community*, 26(1), 154–166. <https://doi.org/10.1177/13674935211005874>
 - Sobotka, S. A., Lynch, E., & Agrawal, R. (2022). The Role of Care Coordinators for Children with Respiratory Technologies and Home Nursing. *Pediatric allergy, immunology, and pulmonology*, 35(2), 49–57. <https://doi.org/10.1089/ped.2021.0236>

ITALY

1. The literature references are important but too old. Moreover you should search if some new evidence are available
2. In many countries the home care was developed a lot, especially in paediatric setting. We should check also the MOCHA European study to have a deeper vision of this framework
3. We should add the Cohen E. criterias (*Pediatrics, 2011*) to define the children with medical complexities
4. We should declare how the improvement of self-care behaviours are important in such setting
5. We could point on the needs especially for young people of an external family support. This is important also in order to let more free the parents or siblings and facilitate the shift of agency from parents to the young persons, if opportune
6. The "a balance between being a parent and being a caregiver." is a crucial point. In Italy a law permit in such case that the parent could be payed by the State for to taking care of his/her children in chronic complex condition at home.
7. "assessment of competencies" it could be better to change with assessment of abilities (or similar), **the competencies are own of the health professionals and not of the parents**
8. "Each Paediatric Nursing Association to lobby key stakeholders to improve the availability of community nursing services by paediatric nurses" the Master for Family and Community Nurse is oriented towards old persons or adult with chronich or endlife conditions. The perspective of paediatric Nursing in Community is different, it is oriented to mantain and improve the quality of life, nevetherless (when opportune and not in palliative care or similar). Thus is important to improve the compliance at the threathment and include these in the everyday life. It is also very important to support the children and young people in improving social life (school, friends, and so on)
9. Probably we need to add somethigs about the importance with Parent or patients Association, the peer counselling and so on
10. Telemedicine and monitoring at distance (this is the great update of the last ten years, especially after covid 19 pandemia)