

PNAE

**Paediatric Nursing Associations
of Europe**

Community nursing of children and young people

Results of a postal survey
in December 2015 and an update in August 2016

*(presented at the 28th PNAE-meeting
in Paris/France on 8th December 2016)*

Focus on ...

... children and young people (CYP) with long term conditions and complex health care needs

... support and care for these CYP and their families provided out of hospital*

(often referred to as „Hospital at home“ – „home care“ – „Care at home“)*

Postal survey

15 countries responded (*December 2015*)

18 countries responded (*update August 2016*)

Key areas:

- *Facilities of the Health system for care-dependent children and young people (at home)*
- *Qualification of nurses*
- *Role of parents, family members and significant others*
- *Structured discharge programmes*

Responses from ...

- Austria (AT)
- Belgium (BE)
- Croatia (HR)
- Czech Republic (CZ)
- Denmark (DK)
- France (FR)
- Germany (DE)
- Greece (GR)
- Ireland (IE)
- Italy (IT)
- Netherlands (NL)
- Norway (NO)
- Portugal (PT)
- Slovenia (SI)
- Sweden (SE)
- Switzerland (CH)
- Turkey (TR)
- United Kingdom (GB)

No responses from ...

- Armenia (AM)
- Cyprus (CY)
- Estonia (EE)
- Finland (FI)
- Hungary (HU)
- Iceland (IS)
- Lithuania (LT)
- Luxemburg (LU)
- Malta (MT)
- Poland (PL)
- Romania (RO)
- Republic Serbia (RS)
- Slovakia (SK)
- Spain (ES)

Facilities of the Health system for care-dependent children and young people (at home)

- Mostly not only one option in a country, but mix of facilities !
- Often dependent from regional availability !
- **Home care teams** (AT, BE, CH, CZ, DE, DK, FR, GB, HR, NL, PT, SE)
 - "general" (BE, CZ, DE, DK, HR, NL) 6
 - and / or "paediatric" (AT, CH, CZ, DE, HR, NL, PT, SE) 8
 - "Hospital at home" (FR) / outreach team University hospital (BE) 2
- Organizations for **palliative care** (AT) 1
- **Community Health Services** (GR, HR, IE, SI) 4
- **Charities** (CZ) 1
- **Financial support** / insurances (FR, CH, DE, HR, PT, SE, TR) 7
- **Hospice** / Day-care facilities
- **Other support services** (e.g. family assistance ...) (BE, DK) 2

Facilities of the Health system for care-dependent children and young people (at home)

"... home care system ... not often used for children" (DK)

"... there is a strong link between the ward or department where chronically ill children and adolescents attend and their continuity of their care at home. Most of the time physicians provide support by scheduling routine follow up appointments ... in outpatient settings ..." (GR)

"Children ... who are care dependent are supported at home and in community settings bei „Mobile Kinderkrankenpflege" (AT)

"The child home care teams are increasing. If such a team is not available there is the possibility of the ... care done by home care nurses for adults. This is not preferred but sometime necessary" (NL)

"The support can vary between the municipalities" (NO)

"In some regions home care agencies are established" (CZ)

"Access and availability to services varies from location to location ... Ireland is only beginning to develop services for children who have complex health care needs in the community" (IE)

"... Long-term care insurance covers the necessary every-day-care for care-dependent persons. ... This insurance offers services by professionals as well as allowances for people within the family who provide the necessary support. " (DE)

"... various kinds of support ... the options available depend on what the child has been assessed as needing" (GB)

Qualification of nurses

Paediatric Nurses <i>(AT, BE, CH, CZ, DE, HR, IT, NL, NO, GB, PT, SE, TR)</i>	13
General Nurses / Nurses for adults <i>(BE, CZ, DE, DK, FR, GB, HR, IE, IT, NO, SI)</i>	11
Community Nurses <i>(GR, SI)</i>	2

Qualification of nurses

"Care for ill children with complex health is provided by paediatric nurses" (AT)

"... not necessarily paediatric nurses ... The person, who comes into the home to support parents, is not a trained nurse. It can be a student (often a nursing student) or any other person with an interest in the care of sick children" (DK)

"Paediatric nurses work rarely out of hospital, because their specific skills and expertise are not recognised by French Health Insurance, hence not valued financially" (FR)

"... there is a lack of experiences and special knowledge" (SI)

"The paediatric outreach team is responsible for the care planning and educates the general home care nurses" (BE)

"The nurses that provide care for ill children with complex health needs are not usually paediatric nurses, but for the more complex more likely" (NO)

"... not all paediatric nurses. Learning Disability nurses and some adult nurses also provide care. Usually care is provided by trained carers that are trained by paediatric or learning disability nurses and deemed competent in providing a prescribed type of care" (GB)

Role of parents, family members and significant others

"They know the needs of her children best of all" (AT)

"... have a high degree of participation ..." (DK)

„Nursing expiries are discussed with the parents and goals are fixed together“ (AT)

"... have a key role ..." (BE)

"... can receive a salary ..." (SE)

"A survey of "Kindernetzwerk" (Network for CYP) in 2014 found that 80% of the mothers (and 3% of the fathers) of CYP with chronic diseases and disabilities care for their children at home, supported by home care services. This support depends on the care needs and the necessary medical procedures. 60% of the families got money from the Long-term care insurance" (DE)

"It is important paediatric nurses watch for the balance for the parents between being a parent and being a caregiver" (NL)

"... at night time only parents ..." (HR)

"Parents can at times lose the feeling and experience of being the 'parent' and sometimes they are left to undertake all the care in that they become 'mini professionals'. Families take on the role of an advocate because there is no one else that can argue the case for help with care." (GB)

"Parents are the most engaged and they are most of the time isolated with their ill child. Despite parents associations, there is little accompany and support for parents wishing their child to remain at home" (FR)

"... often collide their wishes with the financial means municipalities can make available ..." (DK)

"Often parents ... have more responsibility and workload than they should have" (NO)

Who teaches the parents, family members and significant others ?

(Paediatric) Nurses <i>(AT, BE, CH, CZ, DE, DK, FR, GB, GR, HR, IE, IT, NL, NO, PT, SE, SI, TR)</i>	18
Physicians (doctors) <i>(CZ, IT, NO, PT, SI)</i>	5
Other professions <i>(NO, SI)</i>	2

Who teaches the parents, family members and significant others?

"all caregivers accompanying parents, case specific consultations will be held if necessary with the presence of all." (BE)

"Nurses at the hospital while the children are hospitalized ..." (DK)

"Doctors and nurses of the hospital who care for the child (paediatric ward, PICU) ..." (CZ)

"Who teaches ... depends on the needs of the child. Nurse are almost always included. Doctors gave some education, as do physiotherapists and dietitians." (SI)

"Paediatric nurses who have completed higher education or special training at universities of applied science ..." (CH)

"Time for teaching parents is less recognized by hospitals managers" (FR)

"Generally staff in the acute service are the providers of the training prior to discharge. Once discharged accessing training can sometimes be a challenge" (IE)

"... Paediatric Nurses in the hospitals, in outpatient clinics and at home ..." (DE)

"Who teaches ... differs according to the child's illness. In case of severe brain damage, they often are in close relation with the rehabilitation services that often is connected to the Childrens Department. In case of needing physical support like ventilation, medication – the hospital nurses are the teachers" (NO)

Structured discharge programmes

No	<i>(GR, HR)</i>	2
Yes	<i>(CH, CZ, DE, DK, FR, NL, NO, SE, SI)</i>	9
for certain conditions		4
	<i>(e.g. Diabetes, Cystic fibrosis, Heart diseases, Asthma, Kidney patients ...)</i>	
	<i>(BE, GB, IT, TR)</i>	
„in some hospitals“ / „in some areas“		3
	<i>(AT, IE, PT)</i>	

Structured discharge programmes

"There are programs for diabetes, cystic fibrosis patients, kidney patients" (BE)

"... every paediatric wards has their own program..." (FR)

"... Parents and the child must practice what they need to be at home ..." (SE)

"... overall standards of best practice ... developed by expert panels ... National Expert Standards ... professional levels of nursing care quality, one is the Standard for Discharge management ..." (DE)

"The discharge programme differs per hospital, but they do have a lot in common" (NL)

"There is no structured discharge programme for children and young people with long term conditions. However there is a structured discharge programme for children and young people with complex health care needs" (IT)

"There is a structured discharge programme for children and young people with long term conditions. This includes checklists and special forms for requirements from the community nursing service." (CH)

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Contact details

Fiona Smith

RCN HQ, 20 Cavendish Square, London

W1G 0RN

Tel. +44 (0) 20 7647 3736

fiona.smith@rcn.org.uk