

Exclusive: Charity nurses warn of 'postcode lottery' in specialist children's care

23 MAY, 2016



BY **JO STEPHENSON** Reporter



Expert children's nurses have highlighted wide variations in services and standards for children with complex health needs as the ground-breaking charity nursing scheme celebrates its 10th anniversary.

The WellChild Children's Nurse Programme, which has been in existence for a decade as of last month, was set up to address gaps in care for children with multiple health needs.

"I don't think we make their journey from hospital to home and beyond as easy as it should be" Linda Partridge

Services provided by its nurses have made a dramatic difference to families including reducing distressing emergency hospital admissions and cutting lengthy stays in hospital.

However, nurses and managers involved in the scheme warn that many children with complex health conditions still face a “postcode lottery” when it comes to getting all-round support. Problems include reductions in children’s community nursing teams, huge variation in the types of services available and a lack of emotional support and training for parents caring for seriously ill children.

The WellChild charity works with healthcare providers to establish specialist nursing roles, funding the posts for the first three years. There are currently about 30 WellChild nurses in a variety of hospital and community-based roles across the UK.

“It may be a challenge to get the same package for a different child in another area” Tracy Brooks

However, a group of them told *Nursing Times* that changes in the way services were commissioned and lack of funding had hit families and put “obstacles” in the way of seamless care.

“When things are reconfigured it’s always said ‘this will make things better for families’ but often it simply creates new challenges and obstacles,” said Linda Partridge, director of programmes for WellChild.

“These children and young people are not suddenly going to get better and I don’t think we make their journey from hospital to home and beyond as easy as it should be,” she said.

Issues highlighted by the WellChild nurses included significant reductions in children’s community nursing services – especially in big cities.

“Across London, one of the biggest challenges is fewer and fewer teams providing out-of-hours support for children with end-of-life care needs,” said Tara Kerr-Elliott, a WellChild nurse working at Great Ormond Street Hospital.

“People are looking at 24-7 care and previously that’s what all teams around London were driving towards, but now we have teams that don’t work Tuesdays and Thursdays, don’t work weekends, let alone providing out-of-hours care,” she said.



SOURCE: WELLCHILD
Wellchild nurse and young patient

“So when we are talking to families about their choices when leaving hospital in terms of end of life care, that is very difficult, and very variable depending on where they live,” she added

Ms Kerr-Elliott said care available to children and families living within just yards of one another could vary dramatically.

“There are boroughs in the east of London that provide 24-hour care and one borough in the west doesn’t have a children’s community nurse team anymore,” she said. “A family on one side of the road where a borough splits may have exactly the same needs as a family on the other side, but one will get something and the other won’t.”

Tracy Brooks, WellChild nurse and trainee advanced paediatric nurse practitioner in long-term ventilation, highlighted similar problems for families in Manchester where she works.

“Throughout Manchester you will have different types of teams, private and NHS, and different commissioners understanding things in different ways,” she said.

“You may get one child with long-term ventilation needs getting an excellent package of care with lots of hours but it may be a challenge to get the same package for a different child in another area,” she told *Nursing Times*.

WellChild nurses also flagged up a lack of psychological and emotional support as well as practical training for parents who undertake complex care tasks – as highlighted by the charity’s #notanurse_but awareness campaign.

“We know the incidence of post-traumatic stress disorder among parents whose children have been in intensive care for a long time is very high,” said Ms Partridge.

“We’re asking them to cope with so many things, it is bound to have an impact on their emotional wellbeing but we have not really addressed this,” she said.

Currently there are no national standards for training parents caring for children with complex health needs and coping with tasks like suctioning a tracheotomy tube, gastric feeding and administering medication.

“One of the challenges for parents going home is being able to manage their children’s needs and there is no standard way of training these parents,” said Ms Partridge.

“There are some really good models where training is excellent and starts well before they go home but in other areas it’s a bit of a hotch-potch with different people in a team trying to teach the same parent different ways of doing things,” she told *Nursing Times*.

“There are some really good models where training is excellent... but in other areas it’s a bit of a hotch-potch”

Linda Partridge

WellChild nurses and others are currently working together to devise a set of UK-wide principles for training based on examples of best practice and what works.

The project is being overseen by a steering group with input from carers, commissioners, representatives from higher education and nurses. A literature review is under way with the aim of creating a first draft by the end of the year.

The guidance will initially focus on nurses providing training and education to parents but the aim is to expand this to encompass training for paid carers, nursing teams and training for trainers.