

Empowering parents and communities.

November 2025

Contents

1. Addressing training gaps
2. Training best practice principles
3. Online information & digital resources
4. Summary

In this section, we highlight the work that [WellChild](#) has done to empower parents, carers and communities to reduce NHS demand and ensure that children and young people with complex medical needs can thrive at home instead of hospital. In particular, through the provision of training and resources within the NHS itself, the development of training best practice principles and through digital resources and family online information provision.

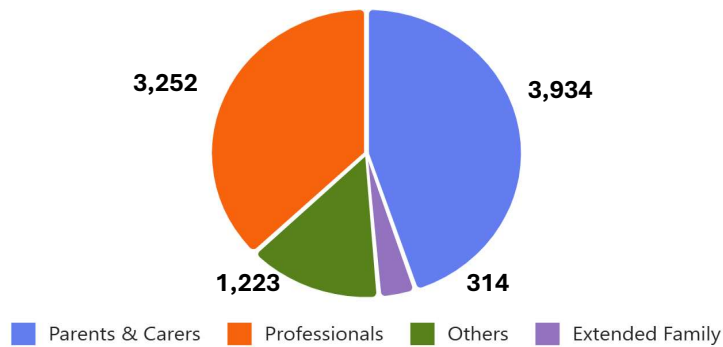
1. Addressing training gaps

For 20 years, WellChild has funded and established **53 specialist Children's Nurses** and **18 Better At Home Training Units and Mobile Resources** across 38 NHS Trusts across the country.

Clinical skills training is one of the primary barriers to hospital discharge for the UK's growing population of children and young people with complex medical needs. Many of these children have multiple and complex conditions and require round the clock care and monitoring. Building clinical skills and confidence amongst parents, carers, family members and local professionals is critical to ensure that these children and young people can be cared for at home, instead of hospital.

On average, 9 different key skills were trained per project. This ranges from tracheostomy care and tube-feeding to basic life support and emergency scenario training.

Last year, through this work we have trained more than 8,723 people in the clinical skills needed to care for these children at home and in their communities. This breaks down as follows:



Case study

Enabling discharge home and back to school

A young girl from Birmingham had previously been fit and well. However, following development of a tumour they required extensive airway surgery and tracheostomy formation.

The girl was extremely fearful of their airway and therefore WellChild Nurses worked closely with the hospital play specialists during routine cares/ changes of tube etc in order to ensure their confidence developed.

Training for all 4 parents started immediately with a structured timetable to ensure when fit of discharge the girl could return to their usual home routine of shared care across 2 homes. Unfortunately, her condition worsened, and further surgery was required, this in turn led to all 4 parents requiring retraining.

This happened rapidly and all 4 parents were signed off prior to the girl being medically fit for discharge. Because of this they were allowed to take the girl out of hospital and on home leave. There was no delay in discharge once medically fit.

The girl is of school age and was keen to get back into school as quickly as possible. Training for the school team could not be accommodated by the community nurses and therefore A WellChild Nurse went out to the schools and trained the teachers on care too.

The girl was discharged from hospital in January, was back in school part time by February half term and in full time, fully by Easter. The WellChild Nurse works alongside the school to ensure no breaks in education occur due to lack of trained staff. Family also requested support for further training of a parent of her friend to further widen her independence allowing her to access socialising without parents present whilst still being safe. This work is ongoing.

2. Training best practice principles

Many children with long term complex health needs require their medical needs to be met at home. Whilst some families are well supported, in some cases with continuing healthcare packages, others get very little, if any support at all.

As such parents and/or other family members are expected to learn and take on a significant proportion of this medical care and these unpaid carers undergo training in these interventions.

There is a paucity of literature on the accepted training content or methodology for these learners and from professional experience it is well understood there is wide variation in provision and practice.

In August 2015 WellChild coordinated a UK training summit to review practice in the training of unpaid carers to support these children and young people. The summit highlighted a lack of guidance for operationalising education, particularly for unpaid carers, and the challenges faced.

The summit also explored the lack of consistency and equity across the country and while it highlighted some excellent practice this was not widespread.

Purpose of this framework

We developed a framework for better training for children and young people with complex medical needs. The purpose of the framework is to provide guiding principles for health and care professionals on the development and delivery of training for unpaid carers. The content of this framework is a consensus of professionals actively delivering healthcare education.

You can read the outcome of this work and the resulting framework here (also attached alongside this evidence): [11 Principles for Better Training](#)

Case study

Upskilling communities to enable life in the community

A 17-year-old young person from London had been an inpatient for a year with complex needs (genetic disorder, epilepsy and global developmental delay).

Part of the staggered discharge process was getting him back to school and then working towards home leave. Training was required for passenger transport assistants (PTAs) to be able to provide O2 therapy, suction and buccal midazolam.

Using the WellChild Better At Home mobile training kit allowed realistic practical training to be commenced in the community, away from the ward.

The two PTAs were able to practice again and again applying O2, administering buccal medication, and providing oral suction without worry of causing distress to the young person.

The use of this resource meant that only one practical session on the ward, with GI was required to complete the competencies for the PTAs, who were then safely able to start taking the young person to school after a year of not attending.

3. Online information & digital resources

Through our work, we have identified three key ways in which online information has been used by parents and carers to help develop their knowledge, skills and confidence as unpaid carers.

3a. Peer-to-peer information

Through our online peer-to-peer family network of more than 3,900 parents of a child with complex medical needs, we see the value in shared lived experience, with parent carers sharing information and advice on themes including condition management. We find that parents who are highly skilled in the care of their children, often place great trust in the advice of others who 'get it' and who have a shared lived experience.

“Support and advice from other families is invaluable. I get very anxious not knowing if I do the right thing but everyone in this group is in similar situations. It gives me the courage to speak out. No one can understand this journey, the prejudices, the changes, the barriers and emotions unless they too are travelling it.”

3b Online information

Through online articles and events, we have witnessed how parents can learn and develop their clinical skills confidence beyond what they have learnt in an NHS setting. Articles via the WellChild Information Hub were accessed 155,000 times last year.

A recent webinar on 'Postural Care' was delivered to members of our parent network. Here was the feedback, demonstrating how these online sessions have addressed skills and knowledge gaps within unpaid carers:

“This has been amazing – I’ve learnt more in this hour than 20 years of consultants. I’d like to share you far and wide. I wish we’d seen you 19 years ago. Thank you so much.”

“I found the webinar very informative and immediately went and looked at her posture in bed!! She had a nurse and carer with her and even though the info given was easy no one has ever explained to me the importance of gravity, lying for supporting sitting and ensuring everything is in line - like a tower. I will always remember this not only for being in bed but also in her stander etc”

“Please do more of these!! My daughter sees a multitude of professionals, has posture clinic, physio and OT but never have I been told/taught the reasons and benefits of 24hr postural care.”

“This event was informative, thought provoking and inspiring- I made changes to my son’s sleep system positioning and support immediately afterwards.”

3c Medicines for Children

In partnership with the Royal College of Paediatrics and Child Health (RCPCH) and the Neonatal Paediatric & Pharmacy Group (NPPG), we have produced a website and accompanying medicine management app called 'Medicines for Children' to help with medicine administration and management with children - [Medicines For Children](#).

Every medicine comes with a patient information leaflet, written by the company that makes the medicine. But, these leaflets are often about the use of the medicine in adults, and not in children. They may include complicated information and may not answer all questions about the medicine how to administer it to a child.

We now have information on over 200 different medicines, and the website was accessed 1.6m times last year. We have developed a rigorous production and review process so that the information is clear, accurate and up to date.

Since March 2011, our leaflets have been certified by NHS England's Information Standard, which is awarded to organisations who produce good quality health and care information. We are now included on NHS Evidence, which gives access evidence-based health information, and in the NHS 111 resource directory used by its call nurses.

"Knowing what each drug does, why it's been prescribed and how to administer it effectively has made a world of difference to my knowledge and confidence around my child's medication."

"I gave another dose of omeprazole because my child was sick immediately after having it. Felt more confident about administering the medication. Medicines for Children gave me that answer. Saved GP time."

Medicines Management App

We are now developing a Medicines Management App to overcome some of the key challenges in communicating and managing medicine routines and minimise medicine errors.

4. Summary

In summary, through our work at WellChild we have addressed key training and skills gaps within unpaid carers, professionals and communities through the provision of specialist WellChild Nurse educators and state-of-the-art training units and equipment, but also through the enablement of information and resources delivered online aimed at supplementing and developing the skills, confidence and knowledge of unpaid carers.

We passionately believe that upskilling parents, carers and those around them with the skills and confidence to meet the clinical needs of this growing population is key to ensuring that these children and young people thrive outside of hospital. Investment in this area consequently will lead to significant cost savings and demand pressures on our health and social care system.

WellChild is working hard to deliver and enable this work. However, without Government-led national complex care workforce and skills development, our growing population of children and young people with complex medical needs will continue to spend unnecessarily long periods of time in hospital, creating significant and unnecessary pressure and cost on local health and social care services.

About WellChild

WellChild is the national charity for children and young people with complex medical needs. Through our national network of children’s nurses, training and family support programmes, our vision is for these children and young people to thrive at home, instead of hospital.

www.wellchild.org.uk

Contact: Matt James, Chief Executive
01242530007 / mattjames@wellchild.org.uk

WellChild, Office 23, Sunningend Business Centre, 22 Lansdown Industrial Estate,
Cheltenham, Gloucestershire, GL51 8PL.
Charity Registered in England and Wales 289600 and Scotland SC045010. Company Number 1815689.