“Do we really need Community Children’s Nurses?”

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***"I COMMENCE BY STATING TWO PROPOSITIONS: FIRST, THAT SICK CHILDREN REQUIRE SPECIAL NURSING; AND SECOND, THAT SICK CHILDREN'S NURSES REQUIRE SPECIAL TRAINING."* (WOOD, 1888)**

WOOD, CATHERINE J (LADY SUPERINTENDENT OF THE HOSPITAL FOR SICK CHILDREN, GREAT ORMOND STREET) 1888 THE TRAINING OF NURSES FOR SICK CHILDREN. THE NURSING RECORD. 6TH DECEMBER. PAGES 507-510.

In the days before Community Children's Nursing

"*A survey in 1843 revealed that:*

- *Of some 2,400 patients in all the London hospitals, only 26 were children under 10 years of age;*
- *Of 51,000 people dying that year in the capital, 21,000 were children under 10.*
- *It was generally assumed that children were "expendable", and better off staying with their mothers even when seriously ill*."

(Archive: Hospital for Children, Great Ormond Street.)

In the days before Community Children's Nursing

- At around this time, Charles West a medical doctor specialising in gynaecology and 'diseases of women and children' was working at the Universal Dispensary in Waterloo Road, London. He tried (and failed) to persuade its management of the need to become a fully-fledged hospital for children with in-patient beds.
- West determined to set up the first children's hospital in Britain and in 1850 he drew together a committee supported by a number of eminent philanthropists and public health reformers (and a helping hand from Charles Dickens!).
- By February 1852, sufficient backing had been obtained to open The Hospital for Sick Children at No. 49 Great Ormond Street.


GREAT ORMOND STREET
HOSPITAL FOR CHILDREN

In the days before Community Children's Nursing

However, as the reputation of the hospital spread, it began to attract a clientele who were prepared to pay for 'expert' medical care of their children in hospital (and subsidise the care of the poor)… but before too very long, questions began to be asked as to the possibility of providing this 'expert' care in the community.

- In 1874, Charles West and Dame Catherine Wood, (Lady Superintendent at the Hospital) proposed the development of a private domiciliary nursing service which was intended to both provide care for children in home settings and enhance the experience of nurses in training.
- However the proposal, which was largely supported by the hospital medical officers, did not go ahead at this time, because the lay members of the hospital committee:
- "*were unanimously opposed to the extension of the work of the hospital beyond the walls*" (THFSC, 1874).

And the rest is history…..

- By 1888, a ‘Private Domiciliary Nursing Service’ was established, based at the Great Ormond Street Hospital and staffed by nurses who:
  - Had completed **at least three years of training in the medical and surgical care of children in a hospital of not less than sixty beds.**
  - Training in tracheostomy nursing was considered to be particularly important at this time in respect of the care of children who were recovering from diphtheria.
  - Other conditions which were supported by the nurses in the community included:
    - Orthopaedic problems such as cervical curvature and hip disease,
    - Post-operative care following surgical treatment for phimosis, abdominal abscess, and peritonitis, and
    - Acute paediatric conditions including whooping cough, scarlet fever, scarlatina, malnutrition and marasmus.

"Staff meeting of the Private Domiciliary Nursing Service, Great Ormond Street Hospital – October 1888"……

NOT!

- At its peak, in 1938, 30 nurses were employed within the Private Domiciliary Nursing Service, providing full time care for 30 children, often on a 'living-in' basis.
- This was a 'paid-for' community outreach service, from the hospital. One which allowed the hospital to provide subsidized or free care to families who could not afford to pay.
- And the work of the nurses was not restricted to caring only for children who lived in central London!
- Several of the Children's Hospitals that were established across the UK in the years leading up to the formation of the NHS also developed their own community outreach nursing services, though not all were successful and several operated for only a few short years.

(Hunt and Whiting, 1999).

And as we all know, a register for Children's Nurses was established in 1919 at the same time as the Register for General Nurses

The Early Years of the NHS - Rotherham 1949

- Appointment of a single Queen's Nursing Sister who had undertaken a **postgraduate course covering 'children's diseases**'
- Prompted by concerns relating to a high rate of infant mortality in the Rotherham area during the course of the preceding winter, including hospital deaths arising from cross infection within the local children's ward.
- A particular focus upon the care of children with acute infectious diseases, notably pneumonia, bronchitis, measles and gastro-enteritis.
- Avoidance of unnecessary hospital admission was highlighted as a major benefit of this initiative. (Gillet, 1954)

The Early Years of the NHS - Birmingham 1954

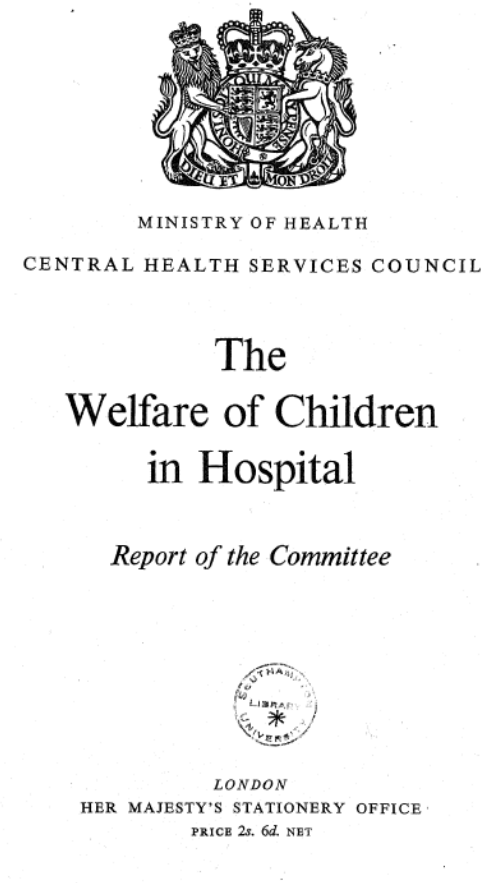
- Birmingham Health Committee, Local Medial Committee and Local Executive Council agreed to appoint:
- **Two District Nursing Sisters** who had undertaken an **orientation programme in the care of children at Birmingham Children's Hospital**
- Focus upon children with acute infectious disease
- Avoidance of hospital admission and facilitation of early discharge
- Evening visits "*most important in allaying the worries and anxieties of the mothers so that there have been very few calls during the night.*"
- 1960 - 92% of referrals from GPs, 1973 – 43% of referrals from GPs. (Smellie, 1956;Howells, 1974)

The Early Years of the NHS - Paddington 1954

- Paddington 'Home Care' Team established including **three nurses 'with paediatric training'** and trained paediatricians.
- Unique collaboration between GPs, paediatricians and Community Children's Nurses.
- In first 10 years of operation:
- Received 2923 referrals, 1882 (64%) from GPs, 2497 children nursed at home and only 165 admitted to hospital.
- Focus on acute respiratory and gastro-intestinal problems, predominantly infections/contagious diseases.

(Bergman et al, 1965)

The Welfare of Children in Hospital (Ministry of Health, 1959)



MINISTRY OF HEALTH

CENTRAL HEALTH SERVICES COUNCIL

The
Welfare of Children
in Hospital

Report of the Committee

LONDON
HER MAJESTY'S STATIONERY OFFICE
PRICE 2s. 6d. NET

- *'Children should not be admitted to hospital if it can possibly be avoided.'* (para. 17)
- *'Special nursing facilities for looking after sick children at home should be extended.'* (paras. 18-19)

Edinburgh 1969

Two separate schemes established.

- Outreach service based upon the children's out-patient department for children with long term conditions, specifically coeliac disease and diabetes mellitus and congenital abnormalities such as cleft lip.
- Attachment to the hospital of a **District Nursing Sister (previously trained as a children's nurse).** Focus of work was upon children referred to the hospital for acute care.
  - **In the year prior to the establishment of this service, only four children were seen in the community by the local District Nursing teams. Within two years, 5,700 home visits were made to children by the same teams.**

Hunter (1974)

Southampton 1969

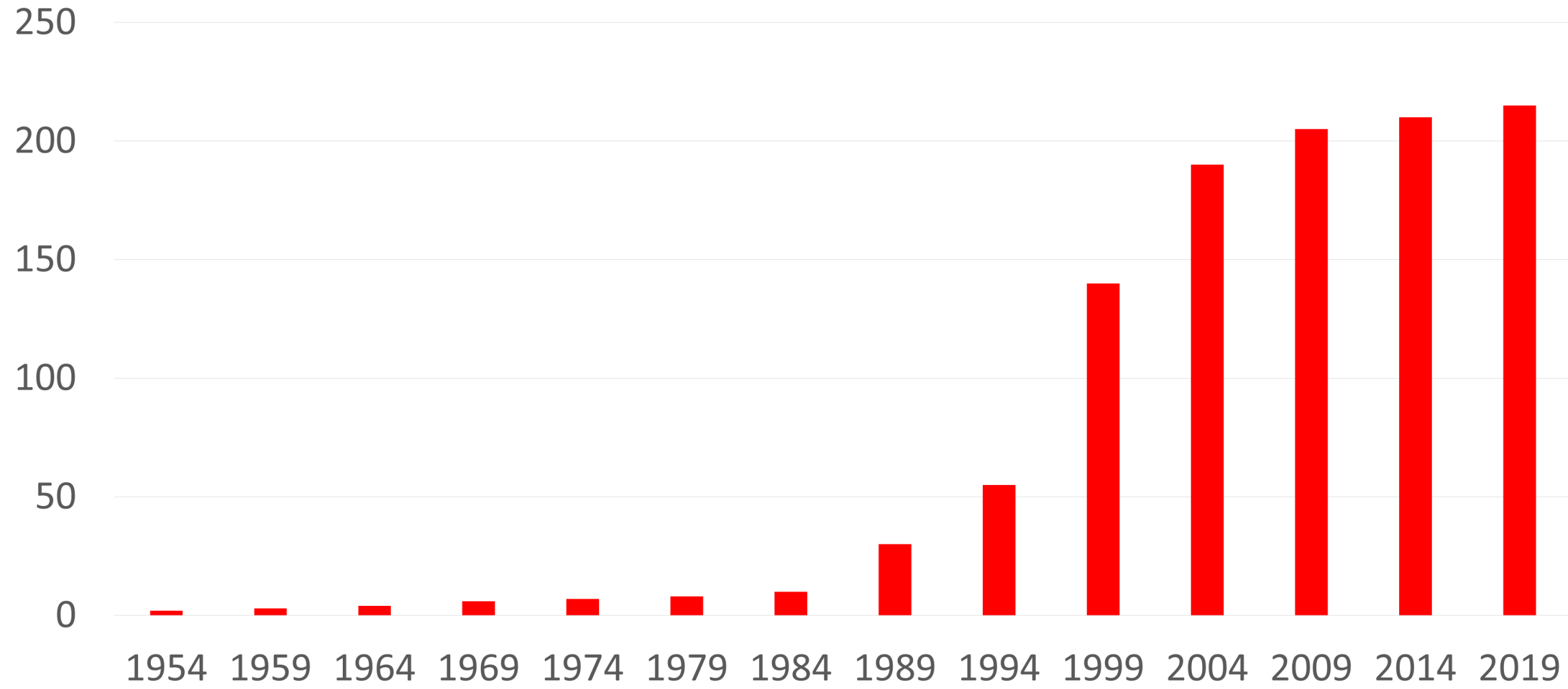
- Appointment of two **Registered Children's Nurses who were also Queen's District Nurses** to support the establishment of a newly opened Regional Centre for Paediatric Surgery.
- Supported children having day surgery for conditions which often required an in-patient stay of between 1 and 3 nights in other centres.
- Service expanded and by 1980 team was supporting 10 day surgery lists per week in general surgery, orthopaedics, ENT, plastics, ophthalmics, and genito-urinary surgery.
- Service developed further and nursing team also supported children having planned or emergency surgery and those with a range of acute and long-term medical problems.

(Gow and Atwell, 1980)

1988: Survey of CCN Provision - England

- 23 CCN services in England employing a total of 45 nurses – 11 services were made up of only one nurse.
- 44 staff were **Registered as Sick Children's Nurses**, all but one of whom were also RGN/SRN.
- There was one enrolled nurse.
- 22 staff were qualified as **District Nurses**, 2 as **Health Visitors** and one held both DN and HV certificates.
- Only two of the nurses held degrees!
- Many of the nurses who became CCNs had worked at "Sister" grade in the local hospital prior to moving into the community.

Growth in Provision of CCN Services in the UK 1954-2019



CCN Education

- In 1991, the United Kingdom Central Council for Nursing, Midwifery and Health visiting published draft proposals for the future of community education and practice – but failed to identify the need for a specific pathway to address the needs of ‘sick’ children in the community.
- Representation from RCN, ABPN, Action for Sick Children, and British Association for Community Child Health and others resulted in the establishment of a pathway for CCN education which was included in the 1994 UKCC Standards for Education and Practice, though the standards were largely a ‘cut and paste’ of the standards developed for District Nursing and Health Visiting! These formed the basis for the development of Specialist Practice Qualification programmes which were hosted by a number of UK Universities.

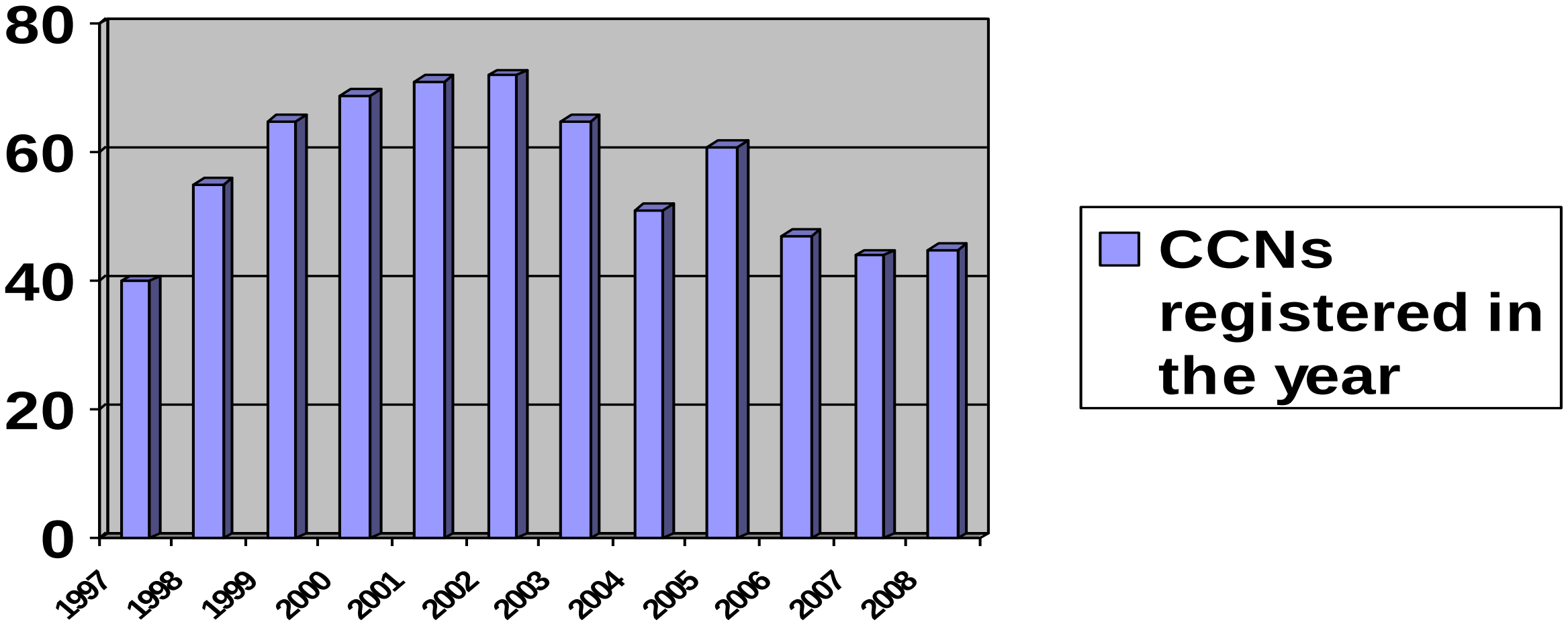
CCN Education

- These standards were subsequently formally adopted by the Nursing and Midwifery Council
- However, the standards were seen by many CCNs as being obsolete (almost from the point of publication).
- In spite of multiple overtures to update the CCN and other specialist practice standards, they were not actually updated by the NMC, until 2022, with the publication of the **‘generic’** standards of proficiency for community nursing specialist practice.
- In the meantime, the Queen’s Nursing Institute had developed a set of ‘Voluntary Standards for Community Children’s Nursing’ published in 2018.
- These significantly informed the development of the Field Specific Standards for Community Children’s Nursing Education and Practice published by the QNI in 2023 with a clear endorsement from the NMC.

CCN Education – However……..

- Uptake of the Specialist Practitioner Qualification programmes has been inconsistent.
- Somewhat haphazard geographical distribution of programmes, making them inaccessible to potential students in many parts of the UK (though post-COVID, a number of HEIs have developed programmes whose delivery does not require major attendance at the University site).
- Lack of support for the programmes by NHS commissioners at local, regional and national levels. Some areas of the UK are virtual deserts in terms of CCNs who hold the Specialist Practice Programmes, whereas some Trusts have supported students to access the programme for many, many years.
- Some teams (and their managers) have a strong belief in the value of the Specialist Qualification, others do not. However……

New Registrations of CCNs per year 1997-2008(Data supplied by NMC)



So what do CCNs actually do?

- The English National Board undertook a number of Project 2000 evaluations, including two that focussed specifically on elements of the CCN role in the context of pre-Registration student experience.

Cash et al 1994 and Proctor et al 1998 (both English National Board) based upon conversations with CCNs, parents and pre-registration students

- Technical skills and formal knowledge (**Advanced practice skills, - examination, diagnosis and prescribing skills**)
- Practical help, including skills for managing their own workload
- Networking, coordinating and advocacy skills
- Interpersonal and psychological support skills
- Teaching skills
- Thinking skills

So who do CCNs actually do this for?

- Children with acute and short-term conditions.
- Children with long-term conditions.
- Children with disabilities and complex conditions, including those requiring continuing care and neonates.
- Children with life limiting and life threatening illness, including those requiring palliative and end-of-life care.

But not….

- Children with learning disabilities
- Children with autism spectrum disorder
- Children with mental ill-health

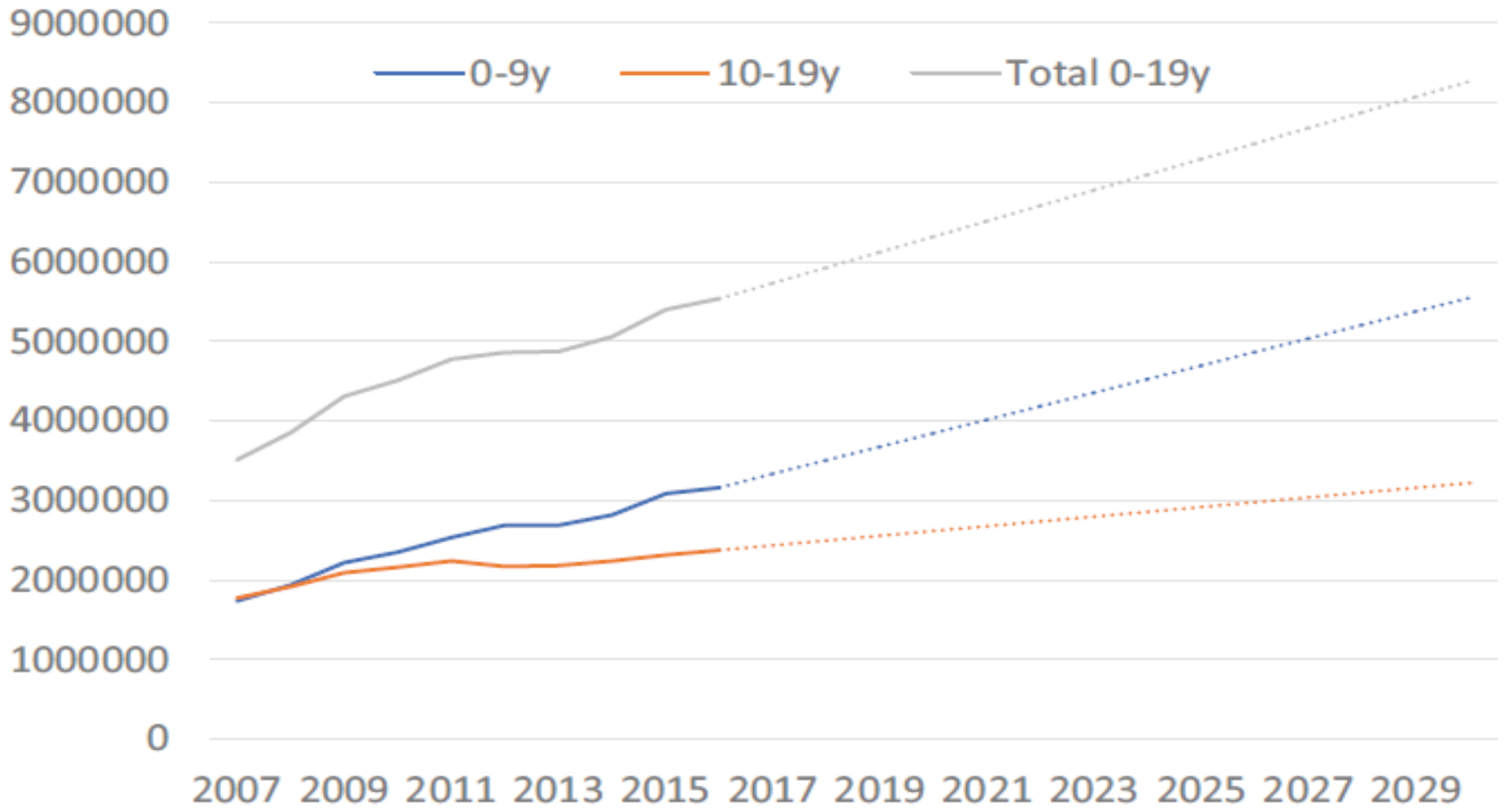
Children with acute and short-term conditions.

- In 2010 there were 20.6 million emergency department attendances in England, a quarter of these were of infants, children and young people.
- In 2008-9, six conditions (abdominal pain, asthma/wheeze, bronchiolitis, febrile illness, gastro-enteritis and accidental head injury) accounted for over 420,000 hospital admission for children in England under the age of 19 years, over 50% of all acute admissions, with an associated cost of £327million per year….
- But the significant majority of CCN teams actually see very few children with acute/short term care needs.

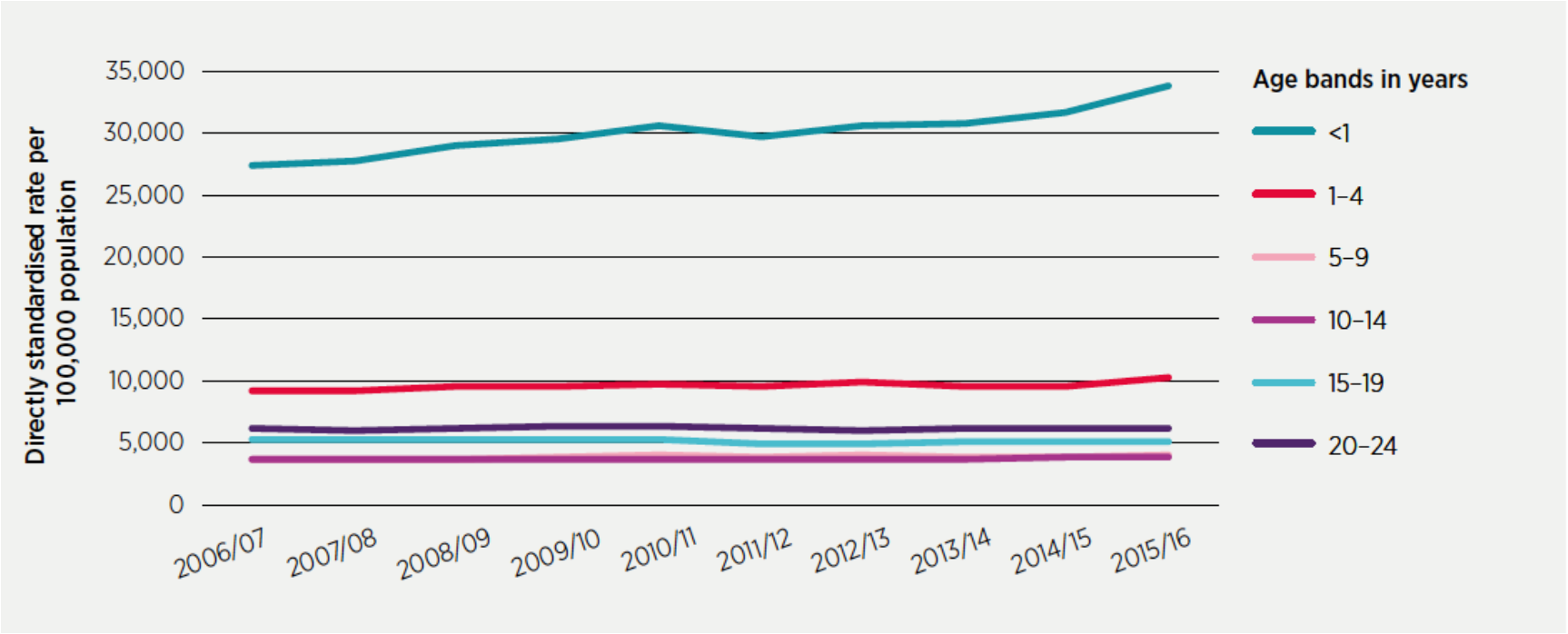
Children with acute and short-term conditions.

- More and more children attend A&E departments every year (COVID notwithstanding). The recently published Darzi Report noted:
  - "More children are attending A&E, but the emergency admission rate has not increased, suggesting that they could be cared for elsewhere." and …
  - In 2023, "More than 100,000 infants waited more than 6 hours." to be seen in an A&E department.
- In the 65 years since the Platt Report, we have seen more and more children attending A&E each year and more and more children admitted to hospital for stays of less than 36 hours.
- In spite of a massive and continuing growth in CCN provision, children born in 2024 are more than three times as likely to attend A&E in the first year of their life and almost three times as likely to be admitted to hospital, than were their contemporaries born in 1959.

ED attendances for England 2007-2016 by 0-19 year olds projected to 2030 (RCPCH, 2018)



Emergency admission for children and young people in England from 2006/7 to 2015/16 (RCPCH, 2018)



Children with long-term conditions.

DoH (2011): key elements of CCN role in supporting children with LTCs, including:

- Improved management of LTCs, supporting a reduction in hospital admissions/in-patient care.
- Education of children and families in order to enable them to better manage their illness and its treatment.
- Teaching families how to recognise early signs of exacerbation or deterioration of a long standing illness.
- Providing specialist knowledge and skills for children with specific conditions, including **epilepsy, asthma, diabetes, eczema or cancer**.
- Provision of nurse-led clinics in community settings as a viable alternative to hospital-based, consultant-led out-patient services.

Children with long-term conditions.

If CCNs are to achieve these they will need to be able to clearly demonstrate:

- The expert care that they are providing to these children.
- The knowledge and skills that underpin that expert care.
- The impact of this care for children and their families, in particular in preventing admission/re-admission to hospital and in facilitating early hospital discharge.
- The improvement in both short and long term outcomes for children and families arising as a direct result of the care which CCNs are providing.

Children with disabilities and complex conditions, including those requiring continuing care and neonates.

- **The DoH (2011) highlights several key areas of work related to this element of CCN work:**
- Enabling care at home – reducing length of stay and costs.
- Safe governance arrangements/supervision of carers/support workers providing complex packages of care including training and ensuring on-going competence of parents/carers/non-registered staff.
- Co-ordination of a multi-agency package of care – acting as the lead professional.
- Neonatal care.

Children with disabilities and complex conditions, including those requiring continuing care and neonates.

- Data on this group of children is not robust. Most recent detailed work was undertaken 25 years ago at which time there were:
- 2500 children receiving artificial feeding
- 1000 children with tracheostomies
- 1000 children on intravenous infusions
- 150 on peritoneal dialysis
- Over 1000 receiving oxygen at home
- 93 on long-term ventilation at home

(Glendinning et al, 1999)

- These figures are now way, way out of date. For example, Wallis et al reported in 2010 that there were 844 children on long term home ventilation. Received wisdom is that numbers have increased significantly, but data is sadly lacking.

Children with life limiting and life threatening illness, including those requiring palliative and end-of-life care.

- Around four thousand children (0-19 years) die each year in the UK of whom approximately half are neonates).
- 50% of child deaths are as a result of conditions that are likely to have required palliative care.
- Only 19% of child deaths (for children who might have required palliative care) take place at home.
- 74% of palliative care deaths are in hospital.
- For every child who dies, approximately 10 others are living with a life-limiting/life-threatening condition at any one time.

What do CCNs do? (summary)

- Provide expert clinical care to children in the context of a physical health care need.
- Offer practical advice to children and their families including problem-solving/trouble-shooting issues related to clinical care.
- Coordinate care (sometimes as a formally designated key worker or lead professional), including advocating for and networking on behalf of families.
- Empower children and families to promote independence and self-sufficiency in taking responsibility for their own care.

What do CCNs do? (summary)

- Provide teaching/training for children, their parents and other carers.
- Provide equipment, including electrical equipment, disposable supplies, continence products and items not available on GP prescription.
- Offer emotional and psychological support to children and their families.
- Promote health and prevent ill-health both in the context of the child's existing long-term condition, complex health need or disability and more generally.

What do CCNs do? (summary)

Additional roles in the context of palliative/end-of-life care

- Symptom care, including the management of complex medication regimes, working alongside General Practitioners, Paediatricians and specialist Palliative Care doctors (ACT, 2011).
- Out-of-hours care, including 24 hour care, particularly when supporting children and families at the end-of-life.
- Emotional and psychological support including bereavement care to the family
- Counselling and support of siblings.

But here is the …….

Questions …

- Is the ‘skill set’ that is required by children and families exclusively one that can only be delivered by a Registered Children’s Nurse who has undertaken a Post-Registration Programme in Community Nursing? Or could somebody else do the job? A Nursing Associate, A District Nurse, A Practice Nurse, A hospital Nurse, A Social Worker? A parent? Grandma?
- What does current CCN provision offer to some specific groups of children who seem to be missing from this conversation entirely?
  - Children with learning disabilities?
  - Children with autism spectrum disorder?
  - Children who are experiencing mental ill health?
- And (just to return to a personal bug-bear) why on earth aren’t CCNs making major inroads into reducing the number of children attending A&E or being admitted to hospital for conditions that their predecessors seemed perfectly happy to care for at home….

Do we really need CCNs at all?