**Integration of Primary and Community Care Committee – call for evidence**

**Response from the Royal Collage of Paediatrics and Child Health (RCPCH) and the British Association for Community Child Health (BACCH)**

**Background**

The **Royal College of Paediatrics and Child Health (RCPCH)** is responsible for training and examining paediatricians, setting professional standards and informing research and policy. RCPCH has over 22,000 members in the UK and internationally. We work to transform child health through knowledge, research and expertise, to improve the health and wellbeing of infants, children and young people across the world.

The **British Association for Community Child Health (BACCH)** is the professional membership organisation for doctors and other professionals working in paediatrics & child health in the community.

Our response relates to children and young people, a group whose needs are often overlooked despite the fact they make up over 25% of the population using primary and community services.

**1. What are the main challenges facing primary and community health services?**

**1.1.** There are significant challenges with capacity and ensuring an adequately resourced and trained workforce across the whole NHS, but these are particularly pronounced in primary care and children's community services.

1.2. In January this year waiting lists for community child health services reached their highest ever levels. It is also notable that community paediatrics has a greater proportion of patients waiting over 52 weeks than any adult specialism. The number of children waiting for 78 week waits for care has also risen, while falling for the adult population during the same time period,[1] and waits of 1-2 years are sadly becoming commonplace for Autism Spectrum Disorder and ADHD assessments. Underinvestment in and long waits for children and young people's mental health services have also been a longstanding concern.

1.3. Such long waits have a significant impact on children's healthy development into adults, as well as on their education, socialisation and wellbeing.

1.4. Children's health service recovery is also lagging behind adult service recovery, with children's community services sometimes forgotten altogether in some Integrated Care System's recovery planning. There is a need for urgent investment in children's services in order to provide safe, high-quality care to children.

1.5. Prioritisation of community child health recovery is further hampered by poor quality data on children's waiting times as they are not included in the Referral to Treatment (RTT) metrics used by the NHS to monitor recovery, and the number of different providers mean data is captured inconsistently.[2]

1.6. Additionally, the underinvestment in children and young people's mental health and difficulties in accessing specialist Child and Adolescent mental Health services (CAMHS) for children and young people have been a longstanding concern.

1.7. Continued advances in medical care mean that the number of children and young people with complex health needs is increasing. This had led to the need for more complex medical and technological support and care to be managed in community settings, however, investment in primary and community health services for this growing population have not kept pace.

1.8. Furthermore, the lack of sufficient training for many GPs and primary care practitioners in paediatrics can mean they do not feel as confident managing and treating children, with RCPCH members reporting that even common paediatric presentations are increasingly referred on for specialist input.

1.9. The impact of this can also be seen by the increasing numbers of children seen in emergency departments, which reached its highest ever levels this Winter. Many children fell into one of two camps: children who were not particularly unwell but whose parents had been unable to access advice and reassurance from primary care[3], and young people presenting in mental health crisis, often while they remained on waiting lists for child and adolescent mental health services (CAMHS) or other mental health support.

[1] NHS England, Community Health Services Waiting list. https://www.england.nhs.uk/statistics/statistical-work-areas/community-health-services-waiting-lists/

[2] NHS England, Consultant-led Referral to Treatment Waiting Times https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/

[3] https://rcem.ac.uk/aes-see-dramatic-rise-in-number-of-young-children-but-its-not-covid/

1.10. An additional challenge for children's community and primary services is a shortage and difficulty recruiting community paediatricians, children's community nurses, health visitors, school nurses, speech and language therapists and other Allied Health Professionals. The location of health visitors and school nurses in local authorities also presents a challenge to integration. Previous links between HVs and school nurses with GP practices and with general and community paediatric services have been fractured leading to more isolated working. These important links need to be considered and re-established in order to see a fully integrated service and meet the needs of children and families.

**2. What are the solutions within the current framework?**

**2.1.** Developing a sustainable, multi-disciplinary child health workforce that supports a whole system approach, embraces new models of care and protects staff wellbeing is key to addressing the challenges faced by primary and community services. Planning should be based on robust data, future trend modelling and consultation with frontline workers and children and young people. This should happen at a local, regional and national level and be led by a fully funded national workforce plan.[4]

**2.2.** It is important that the approach to finding solutions to the current challenges doesn't just focus on individual components or primary and community services alone but involves the wider system including secondary care, education, the VCSE sector and social care.

**2.3.** Some health, care and education systems continue to use diagnostic labels as a threshold for children being able to access support. Moving to a needs-led model of care, including for education, EHCP and SEND support, would allow for earlier and more responsive interventions and ensure children have appropriate support while waiting for a possible diagnosis. This may also reduce some of the pressure on community paediatric services which deliver large numbers of diagnostic assessments, for example for autism.

**2.4.** Urgent investment in and prioritisation of community child health services is required to address the growing waiting lists that are having an irreversible impact on vulnerable children's long term health.

**2.5.** It is reported that less than half of GPs are given the opportunity to undertake a paediatric placement during their training.[5] It is crucial that all primary care practitioners receive the necessary training so they have the confidence to manage and treat common conditions in children, where appropriate, closer to home.

**3. What steps should be taken to improve support for the long-term management of complex conditions in the community, and respond to the needs of patients and communities?**

**3.1.** The Kennedy report (*Getting it right for children and young people; Overcoming cultural barriers in the NHS*) was published in 2010 and many of the recommendations are still relevant today.

**3.2.** Children's palliative care has a model of home-based nursing, psychology and social support for children with life-threatening conditions. The service provides support for the whole child, their parents and carers, siblings and school-based and respite care services. Better investment in this model would improve support and respond to the needs of children with life-threatening conditions and complex severe life limiting disabilities and respond to the needs of their families.

**3.3.** The impact of caring for a child with a significant disability (e.g. non verbal autism, quadriplegic cerebral palsy) is considerable and often underestimated. More comprehensive, joined up assessments and services specifically designed to meet their needs could dramatically improve the quality of life of these children and their families. An example is the Lifetime service based in Bristol, North Somerset and South Gloucestershire.

**3.4.** Integrated services need to cover home, respite and schools to ensure that the whole workforce and all carers have the necessary competencies to support the needs of children, young people with complex conditions and their families.

**4. What are the key barriers preventing improved integration, and how might these be overcome?**

**4.1.** The essential element of integrated care is adopting a patient centred approach (as opposed to structural reform). Integrated care must have direct benefits for patients in order to achieve better equity and outcomes.

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[4] RCPCH. Workforce Census 2022 - Overview of our key findings and recommendations. October 2022. https://www.rcpch.ac.uk/resources/workforce-census-2022-overview#recommendations

[5] RCPCH. Facing the Future: Together for Child Health 2015. https://www.rcpch.ac.uk/sites/default/files/Facing_the_Future_Together_for_Child_Health.pdf

**4.2.** In order to implement effective integrated care the planning and commissioning process should be able to cover complete pathways, that may span different parts of the system, with the aim of distributing resources to best achieve outcomes.

**4.3.** Additionally, regulators at present usually inspect one component part of the pathway rather than looking at overall network outcomes. Safeguarding inspections have moved towards a more "whole system" approach to regulation.

**4.4.** The NHS is at a very early stage of integration particularly with other agencies for example housing, social care, education, and voluntary and private sectors. Often differences in organizational culture and a lack of trust between potential partners can be a barrier to partnership working.

**5. Could you provide examples of successful or innovative models of integration between primary and community care, either in the UK or internationally?**

**5.1.** The Nuffield Trust reviewed new models of child health services in 2016. This includes Connecting Care 4 Children and the Children and Young People's Health Partnership that provide models of integrated care for children that bring together primary, secondary and community services in a primary care setting providing more comprehensive care closer to home for families. The key outcomes of these models are children are seen closer to home, GPs gain confidence managing more common conditions, children and parents regain confidence in their GP practice, a reduction of children attending EDs inappropriately and reduced referrals to hospital clinics.

**5.2.** The Fuller Stocktake report provides a framework for integrating primary care and includes examples of integrated services for children and young people.

**5.3.** In the Netherlands the healthcare organisation Buurtzorg has pioneered a successful model integrated of nurse-led holistic care for all ages including children and young people.

**5.4.** Singapore has also developed a model of integrated care. An evaluation of the process concluded that functional integration alone is insufficient for a successful right-site care program implementation. Improvement in relationships between providers, organisations, and patients are also needed for further development of the program.

**6. Could you give an indication of where integration has not worked well, and the reasons for this?**

**6.1.** NHS England has funded pilots looking at integrated models of care for children and young people across 14 ICS. These pilots are ongoing at present but evaluation will take place and learning shared over the next year.

**7. Pressures on primary care have been well documented. How would you assess the current state of community care, in particular the integration between both areas?**

**7.1.** Children's community services are under intense pressure. Recent data from NHS England shows that waiting lists for community paediatric services rose by almost 8% from October to January, leaving 64,597 waiting. The number of children waiting for speech and language therapy also rose by 6%, with 67,774 children waiting, and waits for occupational therapy rose by a staggering 20%. At the same time, waits for adult services *fell* by 8%.[1]

**7.2.** We also know that children's community services have a greater proportion of patients waiting for over 52 weeks than any other services across the health system – while 1.8% of adults have been waiting for more than a year, 5.9% of children have been, more than 14,000 children. Such long waits are unacceptable for any patient but missing opportunities to intervene at the right age or developmental stage can have a significant and life long impact on children.

**7.3.** The experience of our members is that children's community services are often deprioritised in the recovery agenda, and sometimes within ICS priorities. These are services often working with the most vulnerable children in the country: conducting child in need assessments, supporting unaccompanied asylum seeking children, and providing care for children with special educational needs and disabilities. It is unacceptable these services are lagging so far behind the rest of the health system, and there is a need for urgent investment and a clear message to Integrated Care Systems to prioritise community child health services.

**7.4.** As children are often supported by a wider range of services, including local authority SEND teams, school nursing, education staff, and children's social care, we need significantly improved information sharing within the health service and between the health service and these vital partners. A key part of this is implementing a consistent child identifier across services, to support effective information sharing between primary and community care, education, health visiting and social care. Using the NHS number

as a consistent identifier between adult social care and health services was implemented in 2015 and allowed services to work together effectively to meet the needs of vulnerable adults, we would like to see children benefit from the same approach.

**7.5.** Safeguarding is example of an area where a move towards integration and multi-professional working has enhanced the service. However, further integration with services providing support for parental mental health, substance misuse, learning difficulties and poverty are required to enable the development of more long-term solutions for children's wellbeing.

**8. What are the implications of the Government's long-term workforce plan for the NHS on primary and community care staffing?**

**8.1.** It is essential that the government publishes an adequately funded, long term workforce plan to enable the sustainable development of new integrated models of care to meet the needs of children and young people across primary and community services. Initiatives that would be particularly beneficial for community child health services are

**8.1.1.** Creating career pathways for work in community child health, starting in undergraduate training.

**8.1.2.** The development of Advanced Clinical Practice and Physician Associate roles to support community paediatricians. These exist in other parts of paediatric practice but much less so in the community

**8.1.3.** Many trainee paediatricians are now working less than full time. There is therefore scope to maximise training opportunities through the use of shared training posts for paediatric trainees including those in community child health sub-specialty training.

**9. What is the impact of recent structural changes to the NHS in England (enacted through the Health and Care Act 2022) on integration between primary and community care services?**

**9.1.** Integrated Care Systems are at very different stages of maturity, with some that have well developed for several years, and others continuing to develop their priorities and governance structure since the statutory transition from CCGs last summer. We are aware of pockets of excellent practice with some ICS prioritising CYP needs and working in innovative ways with new partners such as housing and local authorities to deliver change for children.

**9.2.** However, we are also aware that children and the services which support them are simply not a priority for many Integrated Care Systems as they develop their initial plans.

**9.3.** While it is important that each system is able to set their own plans and agenda to respond to local population need, it is vital that children's services are protected and not further deprioritised during the transition to ICSs. Robust national oversight is needed to ensure there is not an increase in unwarranted regional variation, and that specialised and low volume children's services are not decommissioned.

**10. Is the current primary care model fit for purpose and servicing the needs of patients?**

**10.1.** It can be challenging to identify which children are acutely unwell, when the vast majority of children's illnesses seen in primary care are minor and require little or no medical intervention, while some serious illnesses may have non-specific presentations and clinical features mimicking those of non-serious illness. The challenge is compounded by lower rates of paediatric training across primary care which may have decreased the confidence of some primary care professionals to respond to childhood illness, and by the pressure and underfunding of primary care services which can make it make it hard for families to access timely advice.

**10.2.** The experience this winter demonstrated this, when footfall in paediatric emergency departments doubled across the country, with many families having been advised to attend emergency settings by primary care or NHS 111, while others attended because they could not get advice from primary settings. Despite the high level of A&E attendance, there was no equivalent rise in admissions. This suggests that many children and families who end up in emergency care may have benefited from other interventions and support, including primary care and supported self-management.

**10.3.** The primary care model needs to be better equipped to support children and their families. This means ensuring common paediatric presentations can be well managed in primary care settings and families can access high quality support and reassurance, any risks are appropriately identified, and ensuring that all children receive the right care at the right time.

**10.4.** Specifically, the College recommends greater investment and training across the health system to reinstate and improve the confidence of the primary care workforce in managing common paediatric presentations and to ensure they have the capacity and resource to do this well. We also want to see paediatric clinical input embedded across NHS111 to ensure messages are clinically appropriate and tailored to children's needs, and that any urgent concerns are appropriately identified at the earliest point. Additionally, we need clearer and accessible information aimed at families to be available through NHS

online, NHS 111 and Healthier Together to ensure parents and carers have greater confidence managing childhood illnesses where appropriate and know when to seek help.

**10.5.** There are pockets of excellent practice around integration between paediatrics and primary care settings which should be encouraged.

**10.6.** Elsewhere in our submission we speak of the need to improve information sharing in order to enable better partnership working with other services.

**10.7.** In Facing the Future: Together for Child Health, the College sets out standards across the unscheduled pathway to improve healthcare for children, focused on the acutely mild to moderately unwell child.

**11. How successful have Primary Care Networks been in facilitating joined up working between primary and community care provision, and other parts of the system?**

**11.1.** There has been little evaluation of primary care networks, however the ability of the network to provide a wider range of services than a single general practice is welcomed, as are services like social prescribing and care navigation.

**12. To what extent have Integrated Care Systems (ICSs) been able to deliver the aims they were set up to achieve?**

**12.1.** As Integrated Care Systems (ICS) are only recently established and there has been no formal evaluation it is difficult to say if they have as yet been able to deliver the aims they were set up to achieve.

**12.2.** The recently published Hewitt review that looked at the oversight and accountability of ICS made a number of recommendations including a shift in focus from primary illness to prevention and better data interoperability and more effective use of high-quality data. We were concerned, however, by the call to significantly reduce the number of national priorities and targets. While we understand the need for flexibility to allow individual systems to prioritise based on their local need, clear national standards are still needed to ensure every ICS provides safe and high-quality care to children across the country.[6]

**13. In what way could the existing infrastructure be enhanced to improve the use of health technologies, and what are the possible benefits for patients?**

**13.1.** Children are often in contact with a range of services within and outside of the health system who face challenges sharing information within and across service boundaries, due to the lack of interoperability of systems, and the lack of a consistent child identifier as there are many different identifiers used for the same child across services.[7] These challenges are compounded by the lack of clear guidance on exactly when, how and what information about children's health and care should be collected and shared, with the relevant sections in the Health and Social Care Act 2012 only referring to information sharing between health and *adult* social care.[8]

**13.2.** A key part of developing high quality data on children's health is to use a set of harmonised terminologies which describe children's needs consistently and allow for data to be captured in an accurate way, and therefore for trends over time to be meaningfully understood and analysed. We therefore recommend the national adoption of the SNOMED CT paediatric terminology set, and support for providers to embed this coding in their services.

**13.3.** There are a number on online resources including the Healthier Together Programme and the Alder Hey symptom checker that provide access to high quality advice and information promoting self-care for families.

**14. Could you please outline one key change or recommendation you would like to see to enable effective and efficient integration in the delivery of primary and community care services?**

**14.1.** Urgent investment in and prioritisation of community child health services to address the growing waiting lists that are having an irreversible impact on vulnerable children's long term health.

**14.2.** The development of a sustainable, multi-disciplinary child health workforce that supports a whole system approach with planning at local, regional and national levels led by a fully funded national workforce plan.[9]

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[6] https://www.rcpch.ac.uk/news-events/news/rcpch-responds-hewitt-review

[7] RCPCH. NHS number as a unique identifier for children – position statement https://www.rcpch.ac.uk/resources/nhs-number-unique-identifier-children-position-statement

[8] Health and Social Care Act 2012, section 251B https://www.legislation.gov.uk/ukpga/2012/7/section/251B#:~:text=(b)a%20common%20law%20duty,and%20not%20under%20this%20section)

[9] RCPCH. Workforce Census 2022 - Overview of our key findings and recommendations. October 2022. https://www.rcpch.ac.uk/resources/workforce-census-2022-overview#recommendations

**14.3.** The implementation of an integrated approach to service delivery for children and young people spanning all the partner organisations, including better data interoperability and information sharing. An enabler for this would be the adoption of a consistent child identifier.[7] The British Association for Community Child Health (BACCH) have developed a position statement that looks to describe "the meaning of integrated care for children and families" and have described a "family friendly framework" for the commissioning, delivery and improvement of services for children and families.