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The Tony Hudgell Rehabilition Programme: Project 1 Findings

Understanding the Therapy Needs of Children and Young People with Complex Needs Across South East England

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Programme Partners: TH Foundation, Evelina Charity, STPN, ELCH, KCL

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This programme was hosted by the South Thames Paediatric Network.

It has been a pleasure to host the Tony Hudgell Rehabilitation Programme. This has been a unique opportunity for us, as one of the national paediatric networks, to have dedicated time to support a team to focus on the work of Allied Health Professionals, and to understand how their services are commissioned and delivered across South East England. We were able to use our knowledge and comprehensive links with multiple stakeholders - from leaders within NHS England to commissioners and service providers, to help deliver the key aims of the programme. The programme findings have in turn informed our work, as Allied Health Professionals are a significant part of the workforce providing care for children within the setting of our other programmes of work (Critical care, Surgery, Epilepsy and Long-Term Ventilation www.stpn.uk). We have learnt how to gather the views of the children and young people and their families, as service users, and have developed stronger academic links.

We look forward to supporting the second phase of the programme and are grateful to the Charity, Tony and his family for trusting us with this work.

Project Team:

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Sammy is a Highly Specialist Occupational Therapist by professional background. She holds an extensive clinical portfolio, with 13 years of experience working with children and young people with a range of conditions and health needs. She has experience working in the NHS, education and voluntary sectors, and across both community and in-patient settings. Sammy is currently employed with Guys and St Thomas NHS Trust, as Clinical Lead Allied Health Professional (AHP) for the Tony Hudgell Rehabilitation Programme, hosted by the South Thames Paediatric Network.

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After a long career in nursing and as a genetic counsellor, Sally moved from clinical work to pursue her growing interest in service transformation and development. She is currently the Joint Manager of the STPN.

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Abbreviations

AAC	Augmentative and Alternative Communication
AHP	Allied Health Professional
BCYP	Babies, Children and Young People
CSP	The Chartered Society of Physiotherapy
DCO	Designated Clinical Officer
DNA	Did not attend
DfE	Department for Education
EHCP	Education, Health and Care Plan
ESR	Electronic Staff Records
FTE	Full time equivalent
HCPC	The Health and Care Professions Council
ICB	Integrated Care Board

ICF	International Classification of Functioning, Disability and Health
ICS	Integrated Care System
IDACI	Income Deprivation Affecting Children Index
MDT	Multidisciplinary Team
MP	Member of Parliament
NHSE	National Health Service England
OT	Occupational Therapy
PMLD	Profound and Multiple Learning Difficulties
PT	Physiotherapy
RCOT	Royal College of Occupational Therapy
RCSLT	Royal College of Speech and Language Therapy
SE	South East
SENCO	Special Educational Needs Coordinator
SEND	Special Educational Needs and Disabilities
SLT	Speech and Language Therapy
SLCN	Speech, Language and Communication Needs
STPN	South Thames Paediatric Network
WTE	Whole Time Equivalent

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Executive Summary

The Evelina London Charity commissioned this programme on behalf of the Tony Hudgell Fund, to better understand what therapy services are being accessed and received by children and young people in the South Thames region, and to what extent it is meeting their needs.

This report outlines the findings from the first phase of a four-year programme, with a particular focus on children's community therapy services, which are often less understood than other parts of the NHS. It brings together the perspectives of children and young people, their parents/carers, service providers and commissioners, in order to identify the barriers and enablers to accessing effective and timely therapy services and therapeutic interventions.

Community services are integral to deliver on the NHS Long Term Plan and the strategic ambitions of the health and social care system. The community sector covers a wide range of services which are delivered in a variety of settings. Community services are designed to support children to live well at home and in the community, for as long as possible. Allied Health Professional services are essential in children's community settings to facilitate the delivery of care closer to home.

The COVID-19 pandemic has significantly affected access to community health services for children and young people, with data from 2024 NHS England statistics revealing that over 272,625 children and young people in England are currently waiting for community services. The largest proportion are waiting for Community Paediatric services, followed by Speech and Language Therapy, Occupational Therapy and Physiotherapy. Not only is it having a profoundly negative impact on a child's developmental outcomes, including educational skills, social development and mental health and wellbeing, but delays to accessing treatment is also adding pressure to other parts of the system.

Children with complex needs will typically access a range of services and have more than one domain of need. Their needs may develop over the course of their lifespan and fluctuate. For the purposes of this report, "complex needs" refers to a child with needs in one or more of the following domains: physical health, mental health, special educational needs and/or speech, language and communication needs. These needs may overlap and co-exist, and are exacerbated by other factors, including social, societal, environmental and personal factors, referred to as 'situation complexity'. This definition has been informed by the lived experience of children and young people, and their parents and carers.

As children are developmentally distinct from adults, and present with a diverse range of needs, they require dedicated paediatric services to deliver rehabilitation interventions which are needs led, and tailored to individual need. Every professional can play a role in rehabilitation, but those who are commonly primary providers of rehabilitation are Physiotherapists, Occupational Therapists and Speech and Language Therapists, amongst other Allied Health Professionals.

For the purpose of this report, “Rehabilitation” has been defined according to the perspectives of Allied Health Professionals working in children’s community settings, where rehabilitation is developmentally focused. The term “Rehabilitation” refers to a much more diverse population of children that require therapeutic intervention to enable them to adapt and adjust to disability, in order to live the best life possible. It includes, but is not limited to, children who are recovering from an injury or illness. These definitions align with national policy drivers relating to personalised care and family centred services, which are designed to account for individual differences.

This report brings together the views of four essential stakeholder groups, together with a range of publicly available population-based data, to better understand what is available at a regional and local level. To address this nationally important issue, primary data has been generated through a regional survey, interviews and focus groups. Secondary data sources have also been reviewed, including recent research studies and policy documents. Quantitative data has been extrapolated from published datasets. Key sources of data include:

- SEN data
- Official National Statistics
- NHS England statistics
- Community services dataset
- Index of Multiple Deprivation

Two distinctly different geographical areas within the region were chosen to gain in depth information about the community therapy service provision. These areas were two of the most deprived boroughs in the region, referred to as site A and site B. From the two sites, rich qualitative data was gathered from children and young people, parents, providers and commissioners, who took part in semi-structured interviews and focus groups.

In summary, a total of 109 stakeholders have been consulted and the findings indicate that there are a range of issues which are impacting on children and young people’s access to therapy services and the provision that they receive. The challenges that exist are complex and interconnected, and arise from a number of variables, including systematic and structural barriers. The overall findings indicate:

- Statutory provision for EHCPs is adding significant pressure to the system
- The demand for therapy provision is outstripping the capacity that is available to deliver it
- Recruitment and retention is a challenge nationwide, but there are also specific local challenges in certain geographical locations
- Some areas are commissioning a lot of independent provision to manage the unmet need and shortfall in the NHS workforce, with more parents paying for private therapy
- There is a lack of investment in early intervention and children and families are often reaching crisis point before being able to access support
- Diagnostically driven pathways and policy drivers create early intervention opportunities for some and not others, impacting on equity of outcomes
- Waiting lists are increasing, with children experiencing long delays before they are able to access treatment at the right time. This includes delays to the provision of home adaptations and specialist equipment

- Certain subgroups of children are more likely to have unmet need, including babies and children under the age of 5, children of school age, children without a diagnosis, children living in deprivation and children who are attending a school or GP outside of their local area.

The findings are relevant to local, network and national teams and for the planning and delivery of service provision. This report is timely, given the challenge to meet clinical need, alongside economic and workforce constraints that are being experienced currently.

This report has identified what children's therapy services require in order to sustain and deliver effective and timely, needs-led rehabilitation for children and young people. The top 7 priorities for change according to children and young people, their parents and carers, service providers and commissioners are:

- Increasing time for direct patient care
- Delivering well-co-ordinated early interventions to reduce waiting lists
- Demonstrating outcomes and impact of therapeutic interventions
- Increasing funding of AHP services and equipment provision
- Achieving equitable access and provision to assessment and treatment
- Recruiting, maintaining and training a skilled workforce
- Increased system working between health, education and social care

Recommendations are presented below, which have been developed to improve care at all levels of the system. These include:

1. A national service specification and/or quality indicator for children's therapy-delivered services
2. The opportunity and visibility of Allied Health Professionals, children and young people and their parents/carers in system evolution and design
3. Promotion of therapy services at local, regional and national level
4. There are examples of opportunities for parents/carers and young people to be supported by each other and statutory services – these could be rolled out more widely with a focus on reaching families who may not yet engage with the established forums.

1. Rationale

Babies, children and young people (BCYP) represent a third of the population of England [1] and account for almost 17 million BCYP, according to national statistics [2]. It is estimated that in England, around 1.7 million children, age 0-19 years have a long-term condition or disability [3], approximately 73,000 children aged 5-16 years have complex health needs [4], and around 86,625 children under 19 years have a life-limiting condition [5].

Children's community-based therapy services aim to support those living with healthcare conditions that include those with complex needs, requiring the provision of a range of professional services to meet learning, physical, mental health needs and beyond. These services include physiotherapy, occupational therapy, speech and language therapy and dietetics (amongst others) and are delivered in homes, children's centres and education settings to support and enable BCYP to grow, develop and live their most independent and health lives possible. Relative to medically delivered care, or that provided in hospitals, little attention has been paid to what is understood to be a highly complex landscape of increasing demand for children's therapy services, growing waiting lists, challenges in retaining and training workforce, and pressures across the board in delivery of community-based healthcare including in educational settings.

This project described in this report focussed on intervention provided by Allied Health Professionals, with a focus on the largest sections of the workforce – Physiotherapy, Occupational Therapy and Speech and Language Therapy. Further, the focus of attention was on the provision of intervention i.e. beyond initial diagnosis or assessment. Anecdotally, our experience as clinicians and in network roles is that this is where families, providers and commissioners have told us there are particular challenges. The South Thames Paediatric Network and Evelina London Children's Hospital reach across a large population of South East England, providing the opportunity to consider a range of experiences, services, and systems.

As experienced by Tony Hudgell and his family, who inspired this project, many children seen by therapy services in the community have complex needs i.e. require a range of services to meet needs across more that one of the domains of physical health, mental health, special educational needs and learning. Babies, children and young people's life chances can directly be impacted by high quality, timely and robust therapy intervention delivered to meet their individual needs. It is widely understood in healthcare that this is a complicated picture, and this project aimed to systematically describe in one region of England the perspective of service users, providers and commissioners of healthcare services. The ambition is that this could inform a tangible next step to improve access to high quality services, along with work being undertaken elsewhere looking at population needs, workforce configuration, and the lived experience of young people and their parents/carers.

2. Definitions of Terms

This work adopts a broad definition of the scope of 'rehabilitation' and 'complex needs', to reflect contemporary schools of thought. Historical perspectives of childhood rehabilitation which still prevail today are commonly associated with recovery from illness, injury or disability, with an emphasis on returning to a previous state of health and functioning [6]. Contemporary theories go beyond this to encompass a developmental perspective of rehabilitation, that is concerned with individual need, rather than diagnosis, prognosis or disease origin [7]. For the purpose of this programme of work, *'Complex needs'* refers to children and young people, aged 0-19 who have one or more of the following: a physical health, mental health, special education need and/or speech, language and communication need. These needs often overlap and co-exist [8].

Figure 1: Conceptual model of complex needs

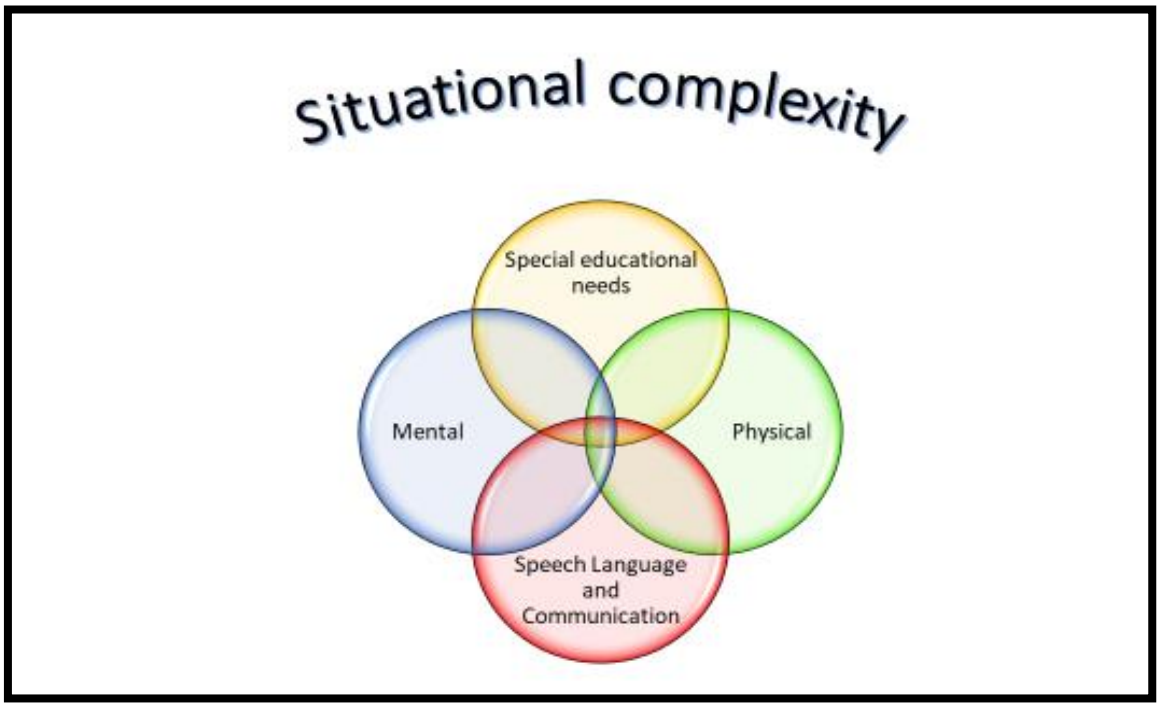


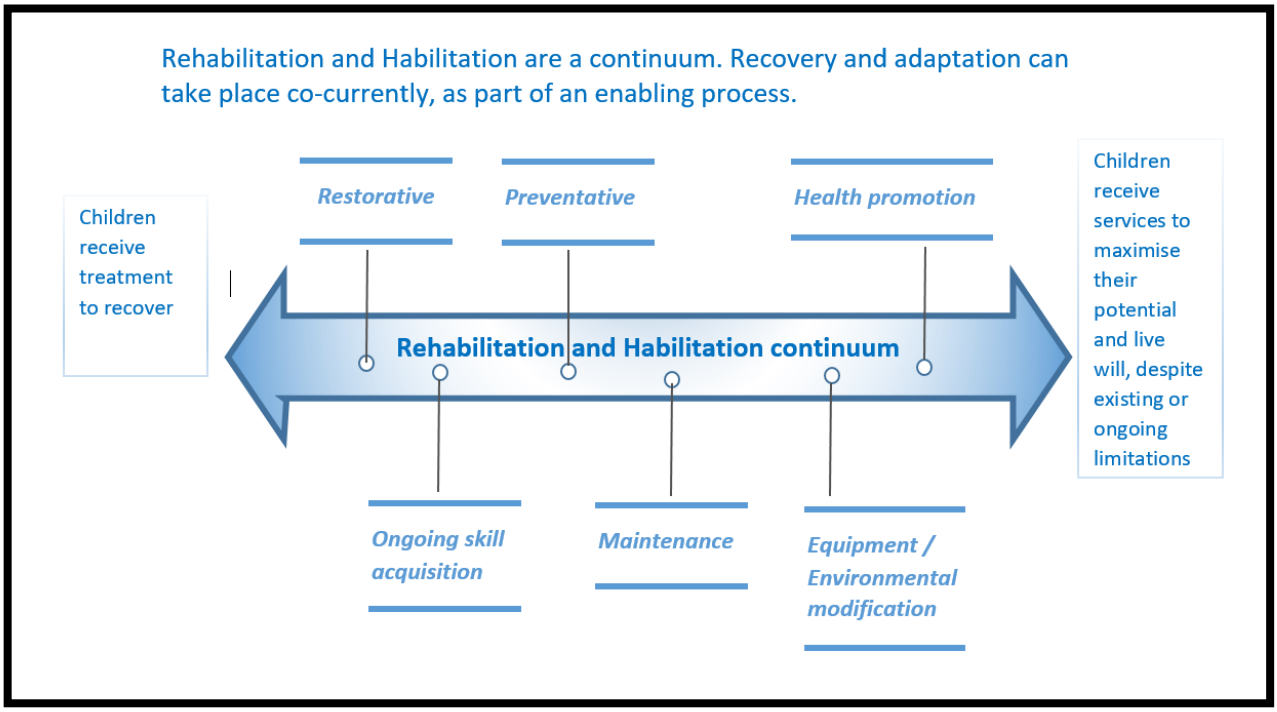
Figure 1 illustrates how complex needs has been conceptualised for the purpose of this work.

The ICF acknowledges that wider determinants of health (such as personal and environmental factors), also influence complexity of need, and can serve as barriers or enablers of health and wellbeing [9].

Children with complex needs often experience difficulties in their daily lives, because of illness, disability, broader life circumstances and/or a combination of these. These needs may develop over the course of their lifespan and fluctuate [10].

Figure 2 illustrates how rehabilitation and habilitation have been conceptualised for the purpose of this work.

Figure 2: Conceptualisation of Rehabilitation and Habilitation



"Rehabilitation can take place at any time across a life course or in a continuum and may include habilitation, reablement and recovery" [11]. It has been argued that 'rehabilitation' in the context of childhood disability is an ableist premise, which can be valuable when restoration and recovery is possible, but can be harmful when it is not achievable, or when nothing has been lost [12].

Habilitation is a relatively new concept and whilst it has not been cited in much of the existing literature and policy, the gradual shift in language reflects current societal and political trends [13]. In recent years, there has been greater emphasis on 'habilitation', which aims to enable children to adapt and adjust to disability, in order to live the best life possible [12]. This paradigm shift encompasses a much more diverse population of children that require rehabilitation services, but also aligns with national policy drivers relating to personalised care and family centred service provision, that is designed to account for individual differences [14]; [3].

'Rehabilitation' is therefore the term used in this report, to refer to both habilitation and rehabilitation concepts. Every professional can play a role in rehabilitation, but those who are commonly primary providers of rehabilitation are Physiotherapists, Occupational Therapists and Speech and Language Therapists, amongst other Allied Health Professionals [11]. As a result, for the purpose of this programme of work, only Allied Health Professional Services have been considered.

3. Methodology

This programme of work is a registered service evaluation which seeks to assess the current access and provision of children's rehabilitation and multi-professional therapy services, across the South Thames region (Kent and Medway, Surrey Heartlands, Sussex and South East and South West London). Service evaluations generate information that can be used to inform local decision making [15].

3.1 Data collection

Between July 2023 and December 2023, we collected the views of 109 stakeholders in total. A mixed method approach was used to consult with stakeholders, including semi-structured interviews, focus groups and surveys. We spoke to children and young people (n=6) & their parents (n=42), Therapists and Heads of Therapy (n=48) and commissioners across the 5 ICBs within the region (n=9). These formulated the four essential stakeholder groups.

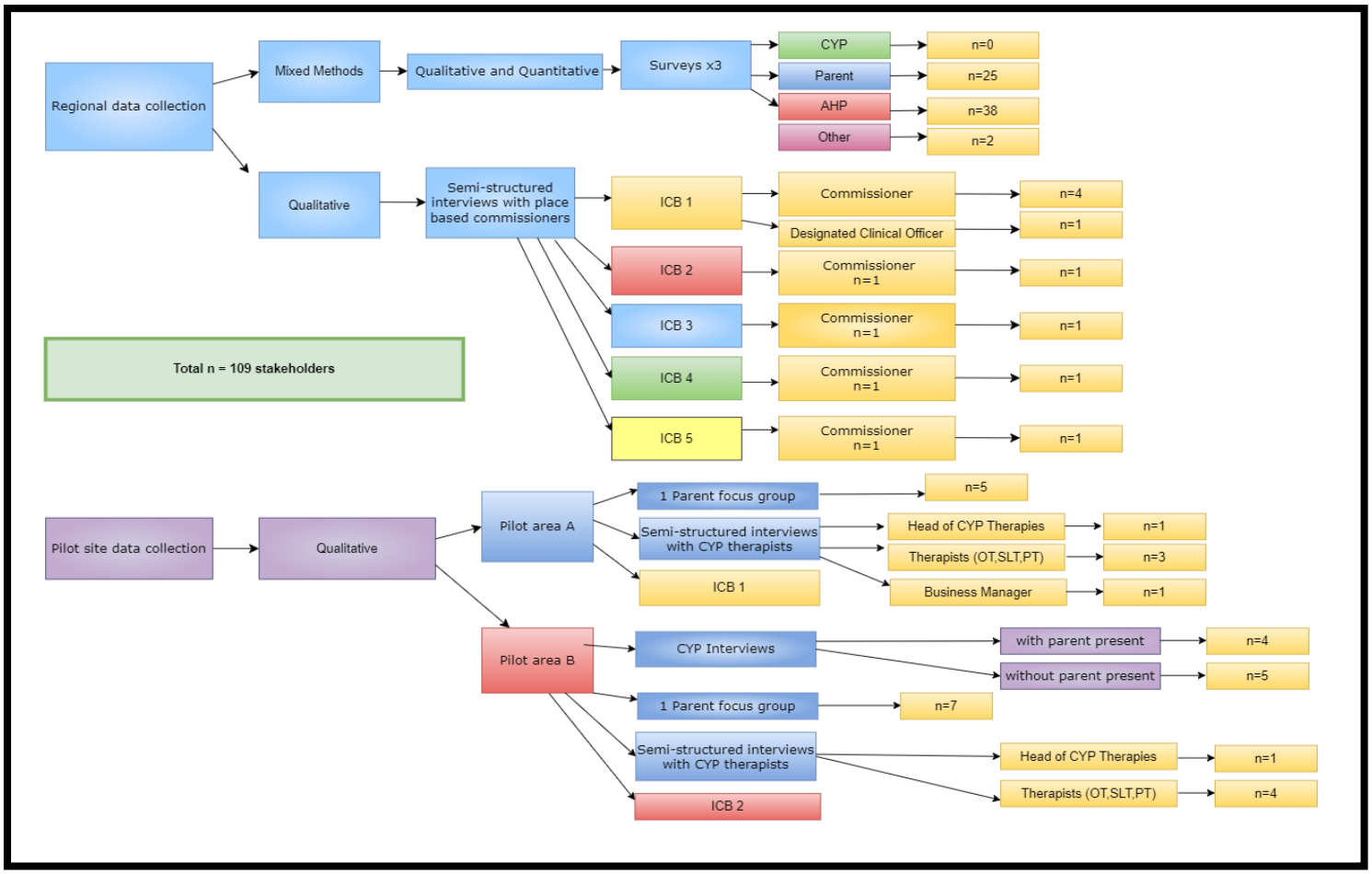
Appendix 1 presents the demographic characteristics of the participants across the four stakeholder groups.

We also collected the views of some other professional groups, including an educational professional (n=1), Dietician (n=1), Business Manager (n=1), and Designated Clinical Officer (n=1). We consulted informally with additional stakeholders at various stages throughout the programme.

The extent of engagement varied between organisations. A list of the key stakeholders that were consulted has been outlined in Appendix 2.

Data has been collected using mixed methods, including semi-structured interviews, focus groups and surveys. Figure 3 outlines the methodological approach taken.

Figure 3: Methodology



3.2 Recruitment and sampling

Children and young people, parents, therapists and commissioners formed the four essential stakeholder groups. They met the inclusion criteria for participating in the study if they received or provided services in the South Thames region (including Kent, Surrey, Sussex, South East and South West London).

Regional data capture

Children and young people: A recruitment strategy was employed with the aim of reaching children and young people (aged 0-24) with a range of needs. In order to provide equal engagement opportunities across the region, social media and word-of-mouth were used, as well as contacting existing children's advisory groups and youth forums. When this approach was not successful, a more targeted approach was developed through existing NHS provider contacts in the two areas. A proactive approach was taken, including attending a child development centre on a chosen day, to speak with children and families before and after their appointments, and attending a local specialist school placement. The child development centre and specialist school were both based in a location within the site B area. A small sample of children and young people were subsequently recruited using this approach and took part in interviews. Participants under 16 years of age required consent from a caregiver to take part and have their parents present during the interviews.

Parents and carers: Regional data was collected from parents via an online survey. This was advertised on social media and in clinic waiting rooms and also via the parent carer forum. Each of the surveys included a mixture of open and closed questions.

Service providers: Regional data was collected from therapists via an online survey. The survey was advertised on social media and in staff areas. The survey asked a mixture of open and closed questions to increase understanding about the multi-professional therapy that is being accessed and provided to children and young people within the region. Children's therapists were mapped across the region and a contact database was developed. All of the therapy contacts for the region were emailed a copy of the survey and asked to complete it and share it with their AHP colleagues.

Commissioners: Commissioners from each of the five Integrated Care Systems (ICS) across the STPN footprint were interviewed, in relation to the commissioning of community therapies.

'Deep dive' data capture with two sites

Two distinctly different geographical areas within the region were chosen to gain in depth information about the community therapy service provision. These areas will be referred to as 'Site A' and 'Site B'. There was consensus amongst the steering group committee that further detailed information should be collected from these two areas because they were identified as being the most deprived areas within the region, according to data extrapolated from Official National Statistics. Each area is geographically located in a different ICB footprint. Site A is a rural setting. Site B is an urban setting. From the two areas, four essential stakeholder groups (children and young people, their parents, therapists and commissioners) took part in semi-structured interviews and focus groups.

Parents and therapists were also recruited from the two areas and participated in semi-structured interviews and focus groups. An interview guide with open ended questions was used to collect the data. Interviews were conducted in person or online, depending on the availability and time of the participants. All of the interviews and focus groups were recorded and transcribed verbatim into Microsoft Word. Informed consent for video recording was provided by the participants.

All participants were given a participant information sheet and a written consent form to sign and return, before their data was collected. This included information about their right to withdraw, and how their data would be managed and stored confidentially. The participants were advised that their data may be used for future research purposes, and that the findings may be written up for publication. They were advised that their views would be kept anonymous, with no person identifiable information included in the final report and dissemination.

3.3 Data analysis

All of the interviews and focus groups were recorded and transcribed, and the data analysed by an external researcher.

Thematic analysis is widely used to analyse qualitative data from interviews and focus groups [16] and thus, it is an appropriate method of data analysis for the purpose of this programme of work.

Braun and Clarke (2006) developed six phases of thematic analysis. Data from the interviews and focus groups have been analysed according to this framework. The six phases can be seen in Figure 4.

Figure 4: A six-phase analytical process by Braun and Clarke (2006)

Phase one	Familiarisation with the data
Phase two	Generating initial codes
Phase three	Generating themes
Phase four	Reviewing potential themes
Phase five	Defining and naming theme
Phase six	Producing the report

4. Results

The results of this project were obtained from publicly available population-based data, in addition to that from the children, young people, their parents / carers, therapy providers and commissioners.

4.1 South Thames Region Population

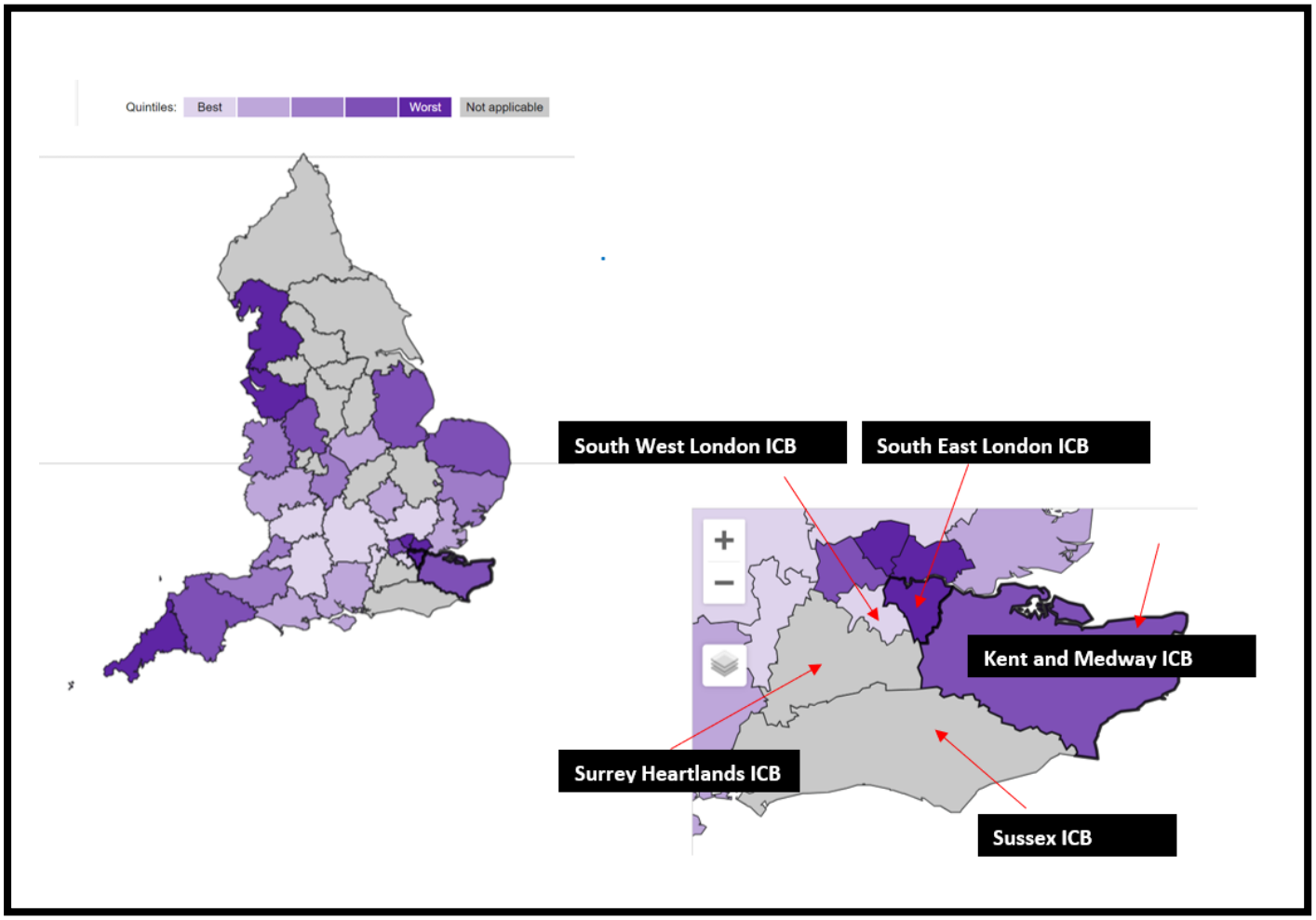
Population demographics were obtained from publicly available records. There are approximately 1.4 million (1,461,377) BCYP in the South Thames region [17]. The population density in inner London is much higher than the rest of England, with Lambeth being the most densely populated local authority area in the region, followed by Southwark and then Lewisham. Inner London includes the South East and the South West of London, which are part of the South Thames region.

There is an increasing prevalence of disability in younger age groups nationally [18]. In 2021, the percentage of children and young people aged 0-24 with disabilities was significantly higher than the percentage in the previous two decades. Meanwhile, disability trends in adults and older age groups is decreasing. Whilst London's age profile remains relatively unchanged since 2011, it continues to have the highest percentage of children and young people than any other part of England [18]. There is a much higher incidence of disability in boys (aged between 5-14 years of age) compared to girls.

Poverty and deprivation are key determinants in child health outcomes. Disability onset starts at a younger age for children and young people living in the most deprived areas of England. 4 out of the 6 boroughs in South East London (Lambeth, Southwark, Lewisham and Greenwich) rank among the 15% most deprived local authority areas in the country.

Figure 5 illustrates the patterns of deprivation across the region at an ICS level, according to the Index of Multiple Deprivation (IMD).

Figure 5: Patterns of deprivation across the region



The darker areas on the map indicate the most deprived areas and lighter areas represent the least deprived areas. According to the existing data from the IMD 2019 [19], Kent and Medway and South East London have higher levels of deprivation within the ICB footprint, compared to other areas in

the region. Nevertheless, it is evident that there are pockets of deprivation across the region, and varying levels of deprivation within each ICS, at a local authority and place-based level.

4.2 Data extrapolation

There are significant gaps in national data reported by education, health and social services, including a lack of evidence on some of the most important trends for children and young people [4]. These include:

- The numbers of children with long term conditions and complex health needs [20]
- Data gaps relating to children in the early years of life [4]
- Incomplete data relating to young people at critical points of transition, including those aged over 16, and those who will be moving over to adult services post 19 (AYPH) [21]
- No data submitted from private schools despite the rising number of children with EHC plans being placed in independent sector provision [22]

Data representing childhood disability is not routinely published and data from community children's services lacks visibility and appropriate digital infrastructure [4].

Children and young people are not as visible in official statistics as they should be [20] and as a result, there is still a limited understanding of the prevalence of disability in children, and their associated support needs.

Furthermore, the data that exists is typically one dimensional. Data systems for education, health and care are not linked together to provide an integrated representation of need, which makes it difficult to accurately interpret.

4.2.1 Children with Special Educational Needs (SEN)

Extrapolated SEN data for the region, and at ICS and place-based level can be seen in Appendix 3.

In the South Thames region, ASD is by far the most common primary need in pupils who have EHC plans, and this coincides with national trends. The majority of children with Speech, Language and Communication Needs (SLCN) – who constitute in total approximately 8% of children – will not have, or meet the threshold for, an EHC plan [23]. In the South Thames region, SLCN is the most common primary need amongst pupils with special educational needs (SEN) who *do not have* an EHC plan. The second most common primary need is SEMH & then ASD. This is also the trend nationally [24].

4.2.2 Children without an EHC Plan

In 2022/23, the pupils who were least likely to have EHC had one of the following needs: a multi-sensory impairment, visual impairment, PMLD, hearing impairment, specific learning difficulty, or physical disability. It is these needs that are significantly less accounted for through an EHC plan. Nationally, there is a stark difference in numbers. Children with the least common needs represent between 14,020 and 1,104 pupils, whereas those with the most common needs (ASD, SLCN and SEMH) account for much higher numbers, ranging between 103,429 and 49,525 pupils [24].

4.2.3 Children with an EHC Plan

The three most common primary needs named above are also featuring most commonly for pupils who *have* an EHC plan. However, in contrast, the data shows that it is significantly more likely that pupils will have an EHC plan if they have a diagnostically driven need (in this case, a diagnosis of ASD) [25].

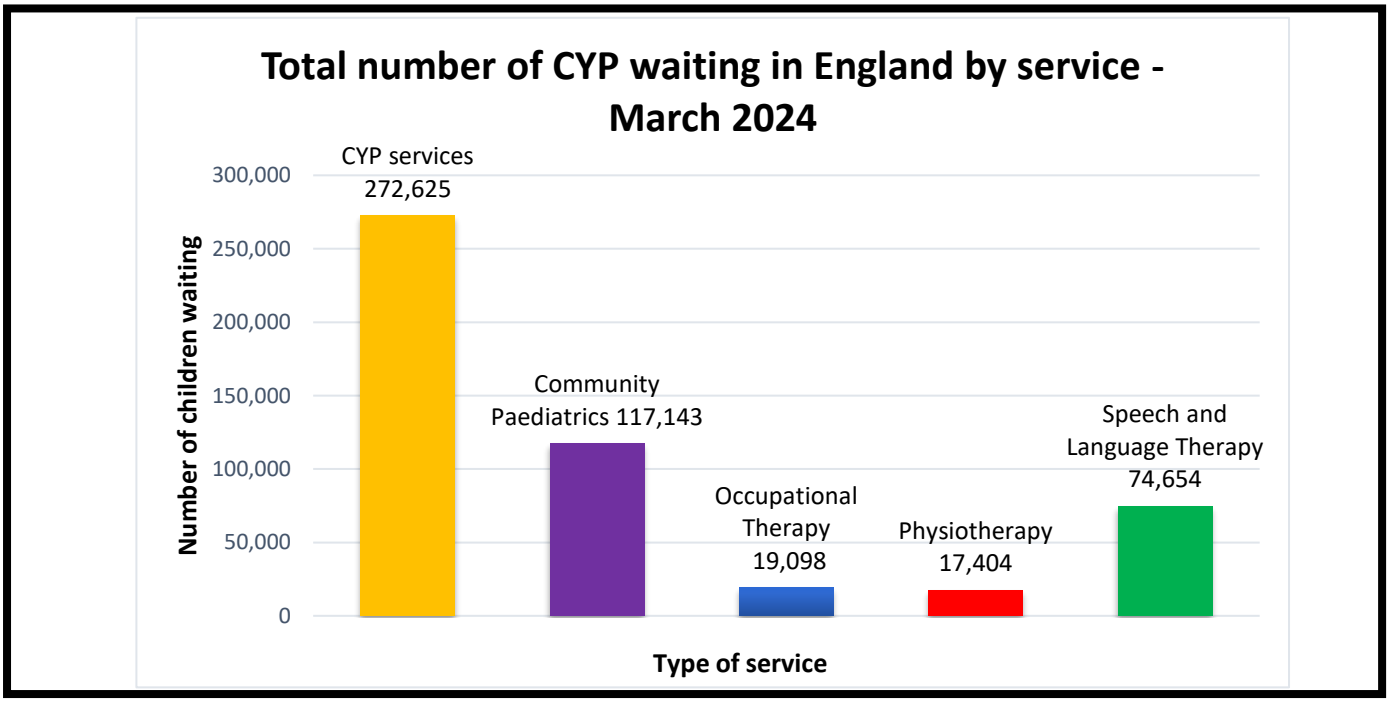
4.2.4 Children on waiting lists

Access to timely, effective therapeutic intervention is essential to improve children's outcomes. Failing to provide treatment at the right time can result in deterioration of a child's condition, functional independence and a greater use of primary care and emergency services. This incurs costs to the system in the longer term.

Waiting lists are considered to be an indicator of demand for a service, however, the existing data should be interpreted with caution. Children and young people experiencing 'hidden waits' are not currently represented in published data. These children are typically those who have been taken off a waiting list once they have had an assessment of their needs, but are still waiting to receive an intervention [26].
The number of children waiting for follow up appointments is not routinely recorded and providers are currently not obliged to publish this, and hence, the waiting times for referral to treatment remain 'hidden' [27].

According to NHS England statistics [28], there are a total of 272,625 children and young people in England currently waiting for community services. The largest proportion of these children (51%) are waiting for Community Paediatric services, followed by 33% of children waiting for Speech and Language Therapy. The remaining children (16%) are waiting for Occupational Therapy and Physiotherapy. This has been illustrated in figure 6.

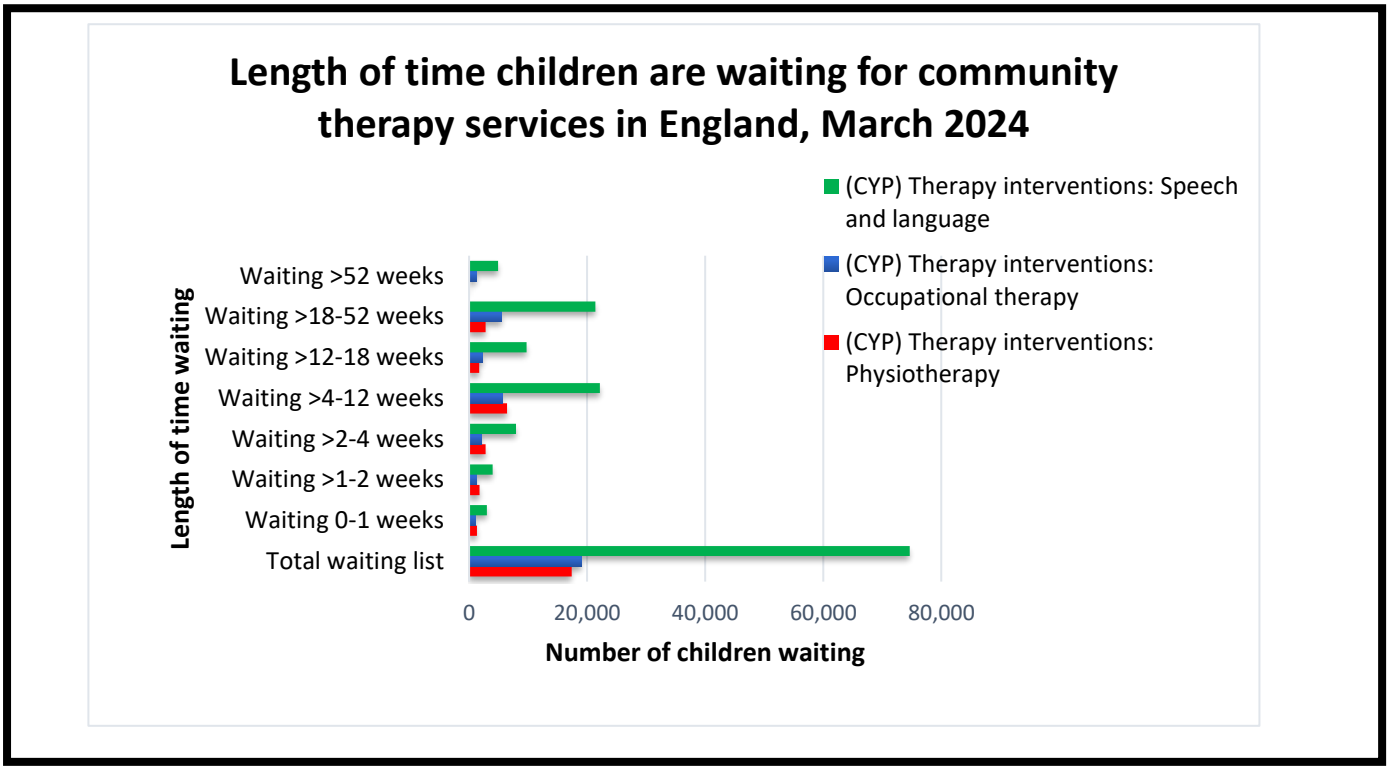
Figure 6: Number of CYP waiting in England by service – March 2024



The proportion of children waiting longer than the NHS standard of 18 weeks from referral is increasing, with 2 in 5 children waiting in excess of that target [29]. 20% of the children in England waiting for a community paediatrician (diagnostic) appointment have been waiting for over a year, and an additional 40%, which accounts for the majority of the waiting list, have been waiting over 18 – 52 weeks.

The length of time that children are waiting for community therapy services can be seen in figure 7. Whilst the waiting list is longest for Speech and Language Therapy, there are similar proportions of children waiting for a year or more across all three therapy disciplines.

Figure 7: Length of time children are waiting for community therapy services in England, March 2024



Speech and Language Therapy

7% of children in England have been waiting for a Speech and Language Therapy appointment for over a year, and 29% have been waiting between 18- 52 weeks.

Occupational Therapy

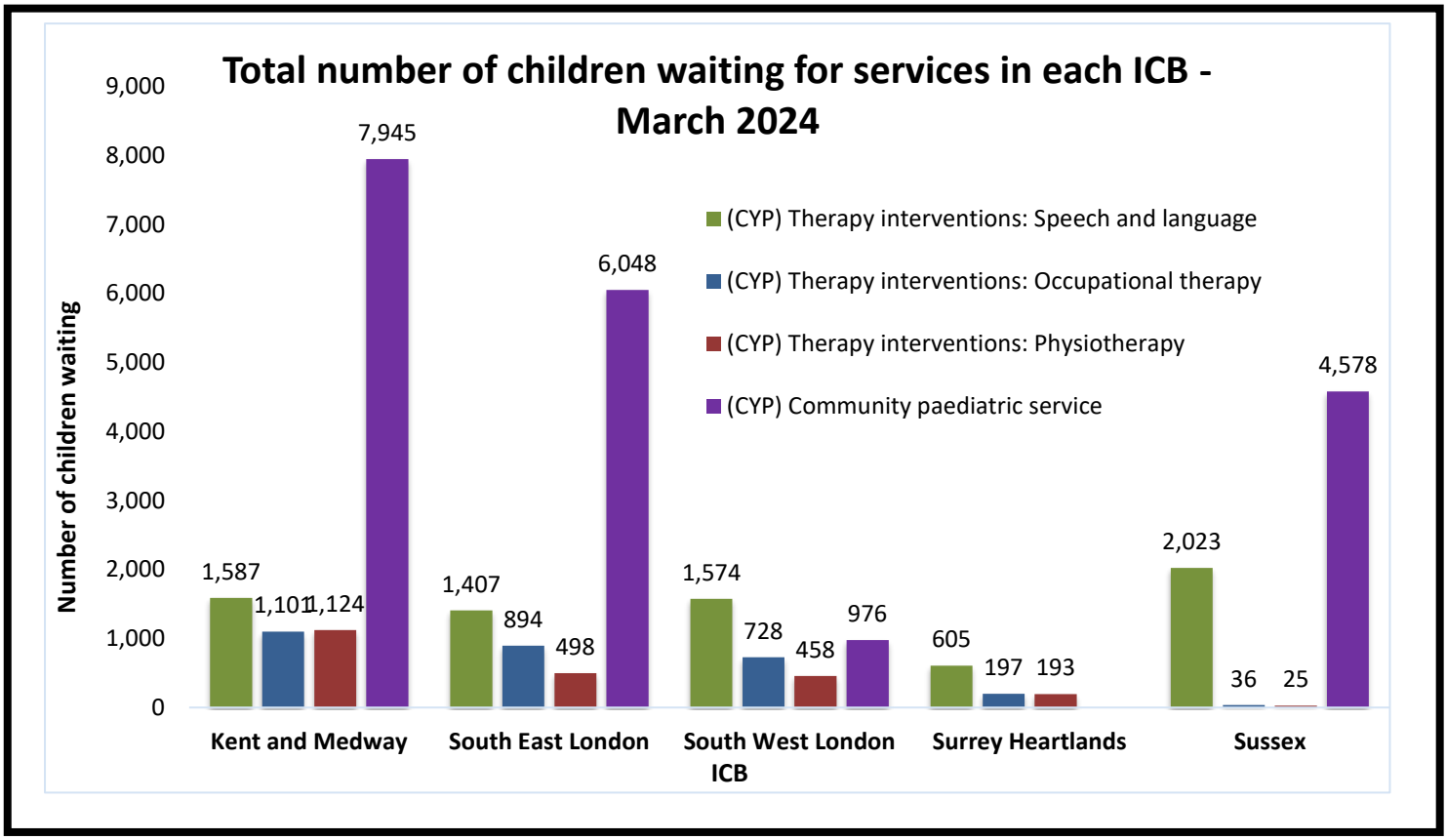
Amongst the children waiting for Occupational Therapy, 6% have been waiting for over a year and 29% between 18-52 weeks.

Physiotherapy

In comparison, Physiotherapy has the least number of children in England waiting for an appointment out of the three therapy disciplines. A smaller proportion of children on the waiting list for Physiotherapy have been waiting for over a year (1%), and 17% between 18-52 weeks.

There is regional variation in the size of waiting lists. Figure 8 shows the variation in waiting lists within the South Thames region, at an ICB level.

Figure 8: Total number of children waiting for services in each ICB – March 2024



Little is known at a more granular level, about the number of children and young people waiting for therapeutic interventions according to local trust provider.

A recent survey [30] found that the most important national enablers to help providers address wait lists and reduce waiting times for children and young people's services were:

- Increased investment in prevention and early intervention (66 per cent)
- Access to additional national funding (58 per cent)
- Support to increase numbers of staff with the right skills mix (54 per cent)
- Simplified commissioning and contracting structures for children and young people (39 per cent).

The above findings closely correlate with the top priorities that have been reported in the South Thames region by parents, providers and commissioners. These are considered to be identified levers for change.

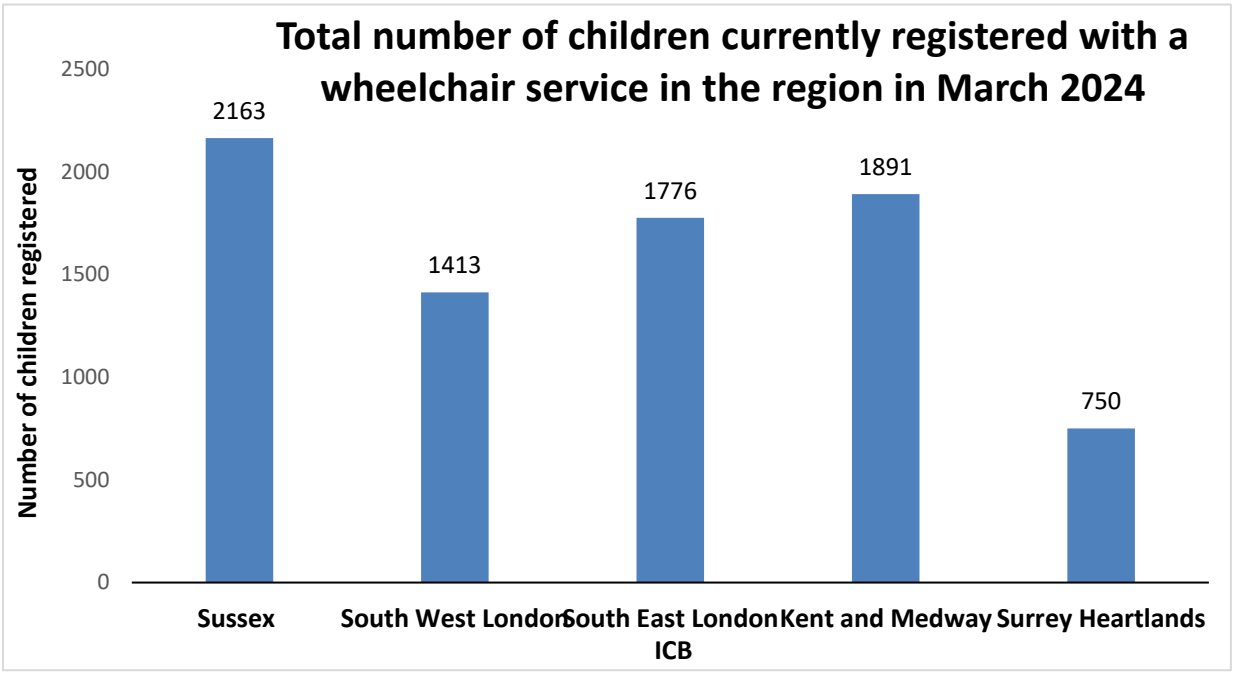
4.2.5 Wheelchair services waiting lists

For children with complex needs, being able to access the right wheelchair, quickly, and with appropriate support, is of paramount importance. Wheelchairs provide a significant gateway to independence, wellbeing and quality of life for children.

According to most recent statistics [31], there are currently 70,792 children who are registered with a wheelchair service in England.

In the South Thames region, 7,993 children (11%) are registered with a wheelchair service. Figure 9 illustrates the number of children currently registered in each ICB.

Figure 9: Total number of children currently registered with a wheelchair service in the region in March 2024



All 5 ICBs in the South Thames region now have personal wheelchair budgets, which aim to offer increased choice and control for children and young people.

There is a national NHS standard for providing wheelchairs to disabled children with mobility needs. According to NHS England targets, children should receive a wheelchair within 18 weeks of referral or re-referral, and 92% of cases should be completed in that time.

For the year 2023/24, approximately 8% of children in England were waiting longer than 18 weeks for their wheelchair to be delivered. Whilst this is in line with the national NHS standard, this data is likely to under represent the number of young people waiting for a wheelchair in England, because it does not account for those aged 19-25. The actual figure is therefore likely to be higher than this.

National data for wheelchair services reveals that disabled children with high or specialist needs wait longer than their peers with lower or moderate need. This is not just the case for new referrals, but also for disabled children already known to services, who require updated equipment as they grow and develop and their needs change.

4.2.6 The unmet needs of children

Much of what is known about the unmet needs of children in the region has been gathered from speaking with young people and their parents, service providers and commissioners.

In order to further understand the needs of children and young people in the region, data was extrapolated from existing data systems, including national statistics and childhood disability datasets.

- Babies and children under 5

  Babies in the early years of life and children under 5, typically do not have EHC or SEND support. They are more likely to have unmet need because the provision that they receive is not mandated, and yet, there is evidence that supports intervention in the early years of life. There is a mismatch between what the evidence base says and what is being provided in therapy services in the region.

  Many babies and children under 5 are presenting with significant delay to their developmental milestones, but are on a long waiting list for diagnosis and therapeutic intervention.

- Children of school age

  At school age, children have more established need, but they can be lost to follow up, resulting in children not receiving the provision they need at key points in time (such as prior to transitioning to a new school or moving onto adult services). Some parents feel that the type of school placement that their child attends (and whether this is a mainstream or special school), has an influence on the level of intervention they receive.

- Children without an Education, Health and Care Plan (EHCP)

  In the South Thames region, children without an EHCP most commonly have a Speech, Language and Communication need (SLCN). This is closely followed by children with Social, Emotional and Mental Health needs (SEMH).

  The children who were least likely to have EHC had one of the following needs: a multi-sensory impairment, visual impairment, PMLD, hearing impairment, specific learning difficulty, or physical disability. It is these needs that are significantly less prevalent than other types of need, and are less accounted for through an EHCP.

- Children with an EHCP
  In the South Thames region, Autistic Spectrum Disorder is by far the most common primary need in pupils who have an EHCP, and this coincides with national trends.

  It is perhaps a misconception that a child's needs will be met once they have an EHCP. Many parents of children who have an EHCP told us that this did not make any difference to frequency or delivery of therapy for their child.

Parents most commonly spoke of the school placement as being the most positive outcome from obtaining an EHCP, due to the in-house support of the school, rather than the therapy provision that followed.

- Children without a diagnosis

  There are long waiting lists for diagnostic assessments, and as a result, diagnosis is being made later on in the child's life. There is a belief held by parents, and also by some schools that you must have a diagnosis in order to be able to access therapy support. This impacts on the therapeutic opportunities available for children and young people.

- Children who are attending a school or GP outside of their local area

  Neighbouring boroughs within an ICB footprint have different commissioning arrangements for children's therapies, which contributes to unmet need. Children are slipping through the net when they have their school, home and their GP in different catchment areas. The risk is that the child is not being seen by therapies in either area. This is particularly true of certain areas in the region, who do not have reciprocal arrangements in place to decide which provider delivers the child's therapy.

- Children living in deprivation

  Four of the six boroughs in South East London alone (Lambeth, Southwark, Lewisham and Greenwich) rank among the 15% most deprived local authority areas in the country. We spoke to parents and therapists who gave us examples of how this influences children's health outcomes, including families not being able to afford private therapy, children from low income families who are not brought to appointments because their families cannot afford to travel to get there, and families who do not have access to technology in order to attend online appointments. This means the opportunities to access therapeutic support are reduced for children living in poverty and deprivation.

4.3 South Thames Therapy Workforce

4.3.1 Workforce composition

Several attempts were made to extrapolate paediatric Allied Health Professional (AHP) workforce data from existing systems and stakeholders, including the Health Care Professions Council (HCPC), NHS Digital, Electronic staff Records (ESR) and consultation with Professional Bodies.
Despite extensive scoping, it was not possible to separate out the numbers of AHPs working with children, compared to adults. Existing systems do not currently collect national or regional data on the paediatric AHP workforce.
As a result, this information was sought via the regional survey that children's AHPs were asked to complete. The respondents who submitted data about their workforce composition were from children's therapy professional disciplines, and therefore the data is specifically relevant to the workforce composition of Occupational Therapy, Physical Therapy and Speech and Language Therapy services, rather than the wider AHP workforce. Examples of workforce composition for paediatric therapies can be seen in Appendix 4.

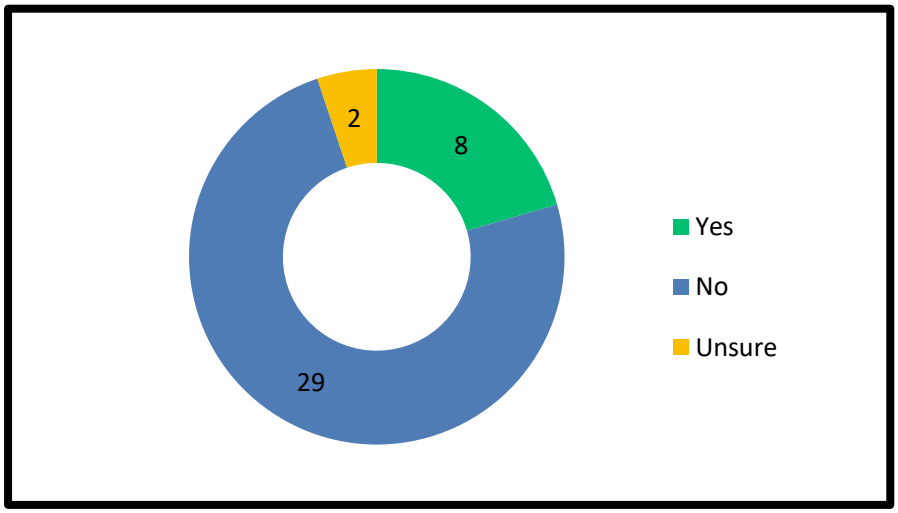
Due to the small sample of respondents who submitted data, the findings should be treated as indicative, rather than representative of the Paediatric Children's Therapies workforce as a whole. Nevertheless, the findings illustrate that there is significant variation in team composition within and between services, and also between professional disciplines, with regards to banding and number of whole-time equivalent hours. In most cases, services employed discipline specific therapy assistants, rather than multidisciplinary assistants. There were usually between 1-3 in a team. There were however individual cases where the number of full time equivalent (FTE) hours provided by therapy assistants was greater than the FTE hours of the therapists working in the service. Due to the quantitative nature of this data, it is not possible to understand if this is intentional or not, although the vacancy rates that were submitted `by each site were not particularly high, with some sites stating that they were fully staffed. Nonetheless, the data that has been collected from staff interviews would suggest that the therapy workforce is still not equipped for meeting the demand. Illustrative quotes that demonstrate this can be found below.

4.3.2 Demand and capacity in the workforce

76% (29 respondents) reported having insufficient Allied Health Professionals in their area/setting, to meet the therapeutic needs of children and young people (Figure 10).

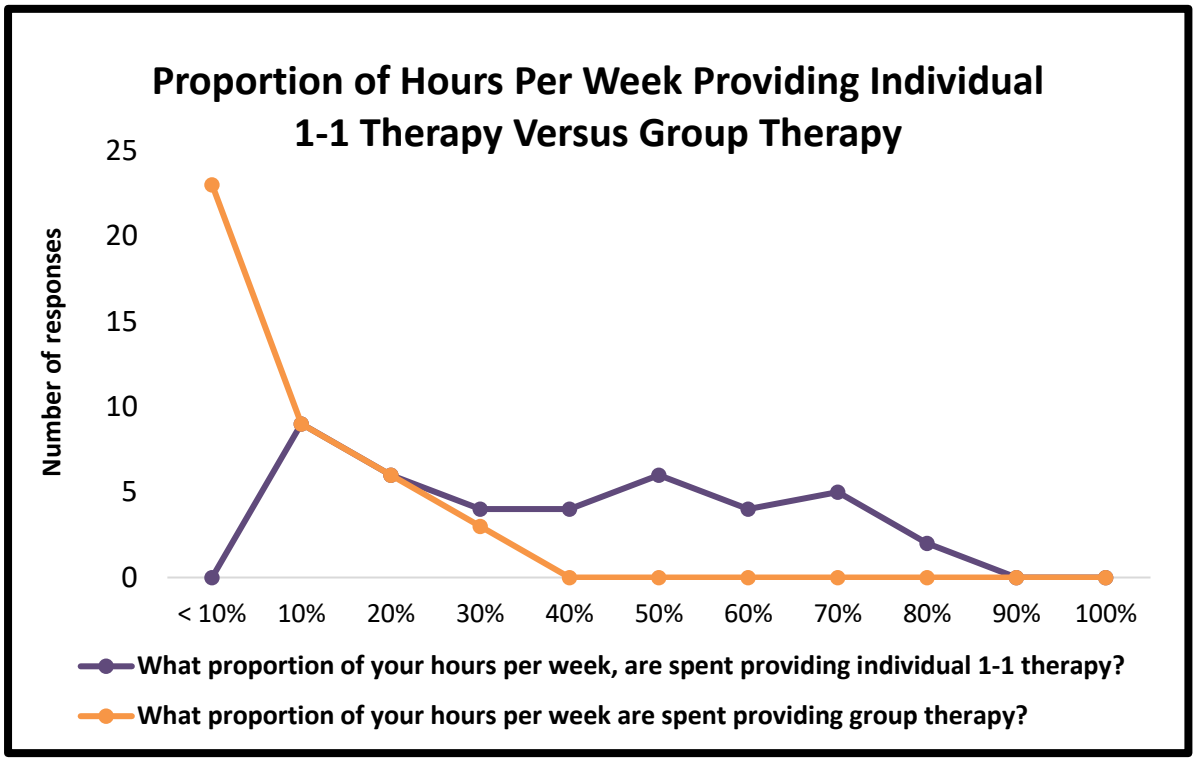
Only 21% (8 respondents) reported that they had an appropriately staffed workforce to meet the needs of the children and young people accessing their service. The minority of respondents (5%) said they were unsure.

Figure 10: Do you think there are sufficient AHPs to meet the needs of children and young people requiring rehabilitation and therapeutic support?



We asked about the number of hours that children's therapists are delivering direct clinical care to children and young people. Figure 11 illustrates the percentage of hours being given to direct clinical care, as a mean average, across services that took part in the survey.

Figure 11: Proportion of hours per week providing direct 1-1 therapy and group therapy



Amongst the therapists that took part in the survey, the results show that on average, only 10% of their time is being spent on delivering direct (1-1) therapy intervention to children and young people.

Therapists were also asked what proportion of time they spent providing group therapy. The responses followed a similar trend to the time being given for direct 1-1 therapy, with 10-20% of working hours being spent on clinical work delivered in a group. The majority of respondents (60% of them) told us that they do not deliver group therapy at all in their service.

This information needs to be analysed in conjunction with the number of whole-time equivalent hours in each service, to determine the workforce capacity that is available.

Irrespective of this, the data demonstrates that regardless of individual staff schedules and working hours, on average, a very small proportion of time is being spent delivering direct therapy to children and young people.

4.3.3 Workforce optimisation

NHS England have published best practice guidance on job planning for Allied Health Professionals, with the intention to ensure that there is enough clinical capacity to meet the expected demand on the service [32].

Early benchmarking work has been completed to understand the proportion of hours being assigned for direct clinical care within job plans. Whilst some of the therapists that were consulted had individual job plans, there was variance in the way that these were used and reported on to inform service needs.

4.4 Young person perspective

4.4.1 Involvement of children and young people

The lived experiences of children and young people are often excluded in research. In official statistics, children's views are often represented by their parents and carers, who submit data on their behalf [20].

Stakeholders with specialist expertise were consulted and an engagement plan was subsequently developed, which was intended to be inclusive and accessible to children and young people with a range of needs. Key relationships were formed with professional gatekeepers of services, including schools, parent carer forums and charities, in order to obtain the views of children and young people who are often underrepresented in public and patient involvement (PPI) and research.

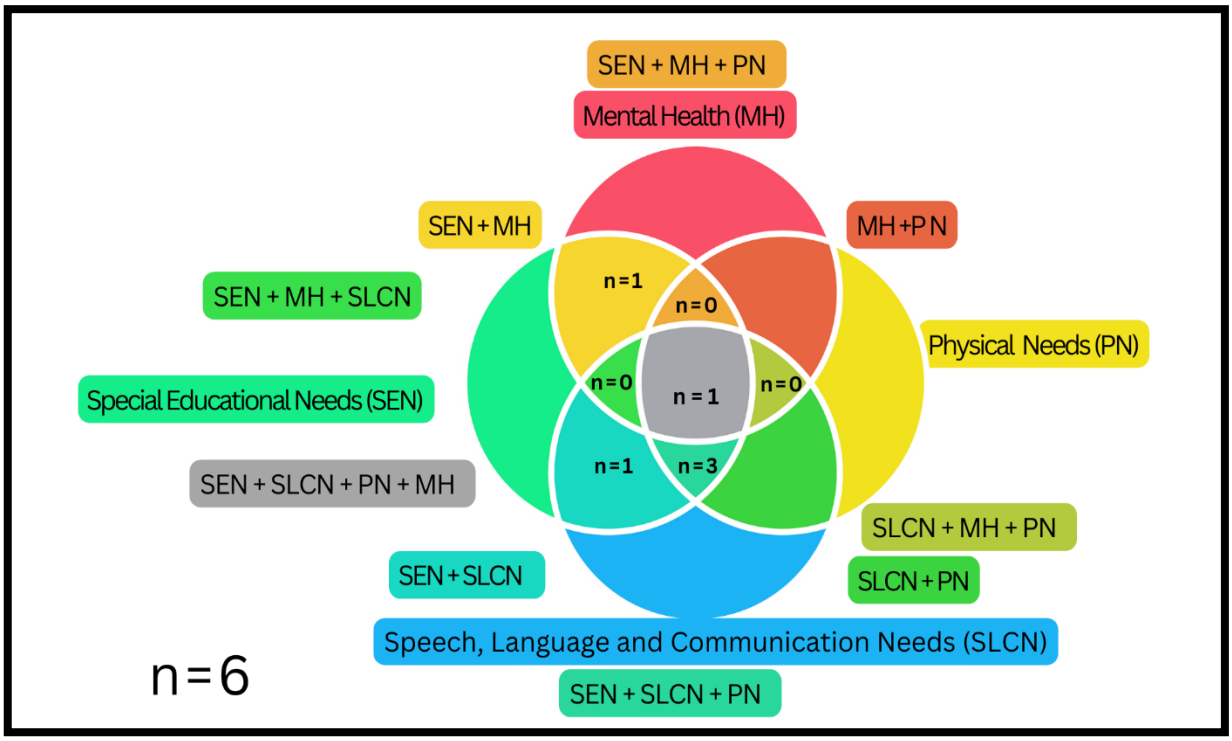
A range of communication methods were used, to enable children with complex communication difficulties, and Profound and Multiple Learning needs (PMLD), to express their views. 'Talking Mats' [33] , a visual communication tool, was used with some children to support their comprehension and express their views on given topics. This was used as part of a Total Communication approach, alongside other communication methods, including the use of objects, symbols and eye pointing, tactile prompts, communication books, switches and pre-recorded speech devices, Makaton (sign language with speech) and Electronic Alternative and Augmentative Communication (AAC) devices.

4.4.2 The needs of children and young people

This Programme of work has included the views of a small sample of children and young people with complex needs, as defined by the conceptual model. Figure 12 illustrates the self-reported needs of children who were included.

These children were visited at the specialist school they attended (for children with PMLD). Case examples of the views of these children can be seen in Appendix 5.

Figure 12: The self-reported needs of children and young people



Children most commonly had a combination of the following three domains of need: a special educational need (SEN), speech, language and communication need (SLCN) and physical need (PN).

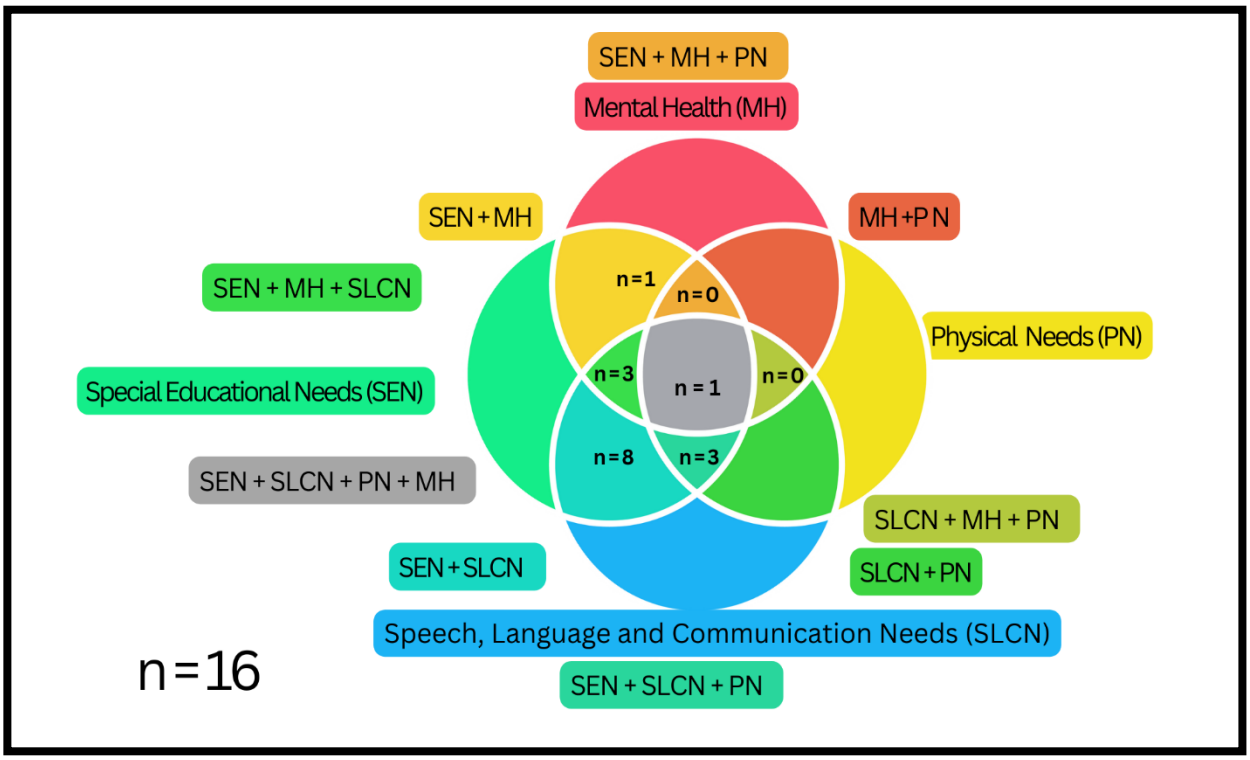
The Talking Mats framework provides a clear visual structure and pictorial support. This enables children to communicate their views more readily than in ordinary or structured conversation.

Talking mats has showed to be a very helpful tool to find out what therapy activities children and young people like at school. All of the children were able to utilise the Talking Mats framework, (with additional communication supports as required), in order to express their views, wishes and feelings on the different aspects of therapeutic support that they receive.

Overall, children and young people generally enjoyed therapy interventions, particularly if they were delivered and relevant to the educational context, such as swimming, hydrotherapy, movement, changes of position and music. Some children expressed a dislike to receiving personal care, and this was one finding that could be explored further by trusted adults that know these children well.

For children who had more difficulty expressing their views, parents, carers and school staff who knew the young people well, provided essential knowledge and support to obtain their views. Figure 13 illustrates the needs of children, as reported by their parents and teachers.

Figure 13: The needs of children as reported by parents and teachers



In the majority of cases, proxy responses were given by parents and teachers. This was due to the challenges associated with recruiting children and young people to share their views. In these cases, where it was possible, we interviewed children and young people together with their parents. Some parents had more than one child with complex needs.

4.3.3 Barriers and enablers to accessing and receiving therapeutic support

In order to understand what therapeutic support is available and the nature of the provision that is being accessed by young people, we asked them the following questions:

1. In order to be able to live your best life possible at home and at school. What are the things that help you?
2. What help would you like from therapy?
3. If you could teach the therapists anything, what would it be?
4. What are your hopes for the future?
5. How can therapists help you to achieve them?

Their responses highlight things that help and hinder their participation in daily life, and what they need from therapeutic intervention in order to address this.

Their responses have been categorised into the following key areas:

- **School**

  One young person said:

  "My teachers at school taught me about the zones of regulation. Then I taught my mum"

Speaking about a mental health crisis before taking her GCSE's, another young person said:

"My school were really helpful. All of my teachers were great at helping me to do stuff. There were some exams I didn't take, but I still got my grades. They were just very adaptable… helping me to do as much as I could from home".

- **Independence**

  One young person said:
  "I was trying to convince my mum and dad the other day…. It was this morning, in fact – to ask if I could get the bus to [….]. That did not go down well with my dad. I like getting the bus on my own. It's just a bit nerve wracking when it's dark".

- **Having the right equipment and environment**

  One young person said:
  "I love how my mum helps me, but I want to be able to have a shower on my own. I can wash myself, but it's just getting inside the shower [that is the problem]"

- **Self-management**

  Young people would like to receive self-management strategies from therapists. One young person said:
  "The therapists have suggested stuff like joining a gym and that seem OK.. yeah, that's a great idea. But what would I do in the gym"?

  The same young person also wanted to have her therapy programme updated. She said:

  "I still want to work on my balance. The Physiotherapy programmes are too easy now. They are painfully easy"

- **Relationship with therapist**

  Young people said that being accepted and included is important to them. They want to be supported to participate in the things that matter to them. This influences their experience. Young people gave mixed reviews about their relationships with therapists.

  One young person said:
  "She is open and she lets you talk and the questions she asks are thoughtful and insightful and they actually help you think"
  "Therapists can still try and fix problems, instead of listening. If I know anyone who has had problems with CAMHS, it is because they have been seeing therapists like that. The whole point of therapies is that you want people to listen to you first, and then you come up with a solution. And if the therapist comes up with a solution, you don't end up feeling heard".

Another young person said:
"Let the person be… don't force them to do something"

Another said:
"I had some therapists that were not as good and were trying to rush. It didn't feel much like therapy. It just felt like talking to someone who didn't really care that much"

- **Support of friends, family and teachers**

Young people identified support from others as a factor which contributed to their day to day participation experiences.

One young person said:
"My family are supportive"

Another said:

"I am the kind of person that doesn't really like change. I like things to stay the same. So sixth form, at the beginning, on my first day, I was sitting outside at lunch and I was thinking, maybe sixth form isn't for me. But now honestly, it is not going too bad because I have got nice friends and I like my teachers"

- **Waiting times**

The impact of waiting for home adaptations was illustrated in this dialogue between a parent and young person:

Young person:

"One thing I want to do is fix the bathroom"

Parent:

"We're actually waiting for the people who come out and look at the house [Social Care Occupational Therapy]. We are going to do it, even if we don't get input from them. We can put in a railing for you".

Another young person said:
"It took a really long time" [to be seen by a CAMHS therapist].

Another said:
"my friend… his whole family is Autistic, and he has been waiting for an autism diagnosis (an assessment), for years. He still hasn't got one. It is just long waiting lists really".

- **Early intervention**

One young person shared her personal story of reaching crisis point before being able to access support. She said:

"The only problem I ever really had is the fact that they didn't really talk to me the first time, to say the least. When you try to kill yourself, you have people from a mental health team obviously wanting to talk to you. So they came to talk to me but the thing that was weird though, is that I didn't get put with CAMHS and they didn't do a safety plan. They didn't check… I was supposed to have a 7 day follow up, but I didn't see them… for years. My mum kept chasing it and they were just busy. When it happened the second time, I had some meetings with the response team once I got out of hospital. They would come to my house".

- **EHCP**

  The dialogue between a parent and young person revealed:
  Parent:

  "The EHCP was good from an educational point of view because she, had access to the inclusion unit. She had Learning Support Assistants to help her at school and that kind of thing. But from a therapy point of view, I don't know. I don't think it helped"

  Young person:
  "No. It didn't, no"

- **Future aspirations**

  For most of the young people, talking about the future was a concept which was too abstract, but one young person said:
  "I hope to get a bit of support with keeping myself exercised".
  "To get some sort of job, and to be able to find work to do".
  "I get bit anxious meeting new staff and new people. I would probably need help with learning how to deal with that without getting so worried about it".

4.5 Parent/carer perspective – needs, what good rehab looks like

4.5.1 Barriers and enablers to accessing and receiving therapeutic support

In order to understand the experiences of parents and carers who have accessed Allied Health Professional and/or children's therapy services for their child, we asked parents:

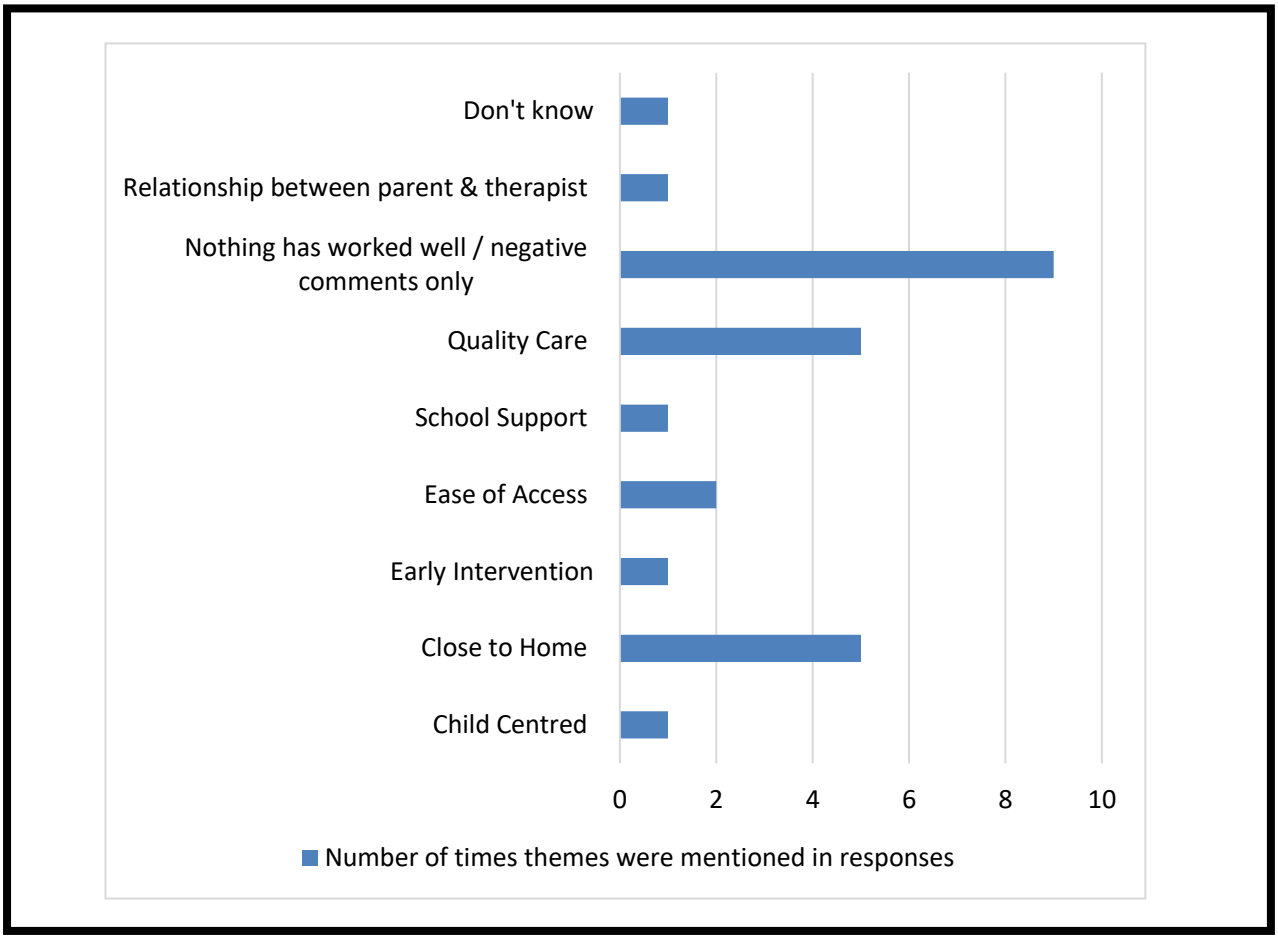
- What has worked well?
- What are the challenges?
- If you had a magic wand, what would you change about the services?

Positive responses from parents are outlined in figure 14. The top two positive themes most commonly mentioned by parents in the survey included having services that are local to home and the quality of the therapy.

One parent commented:

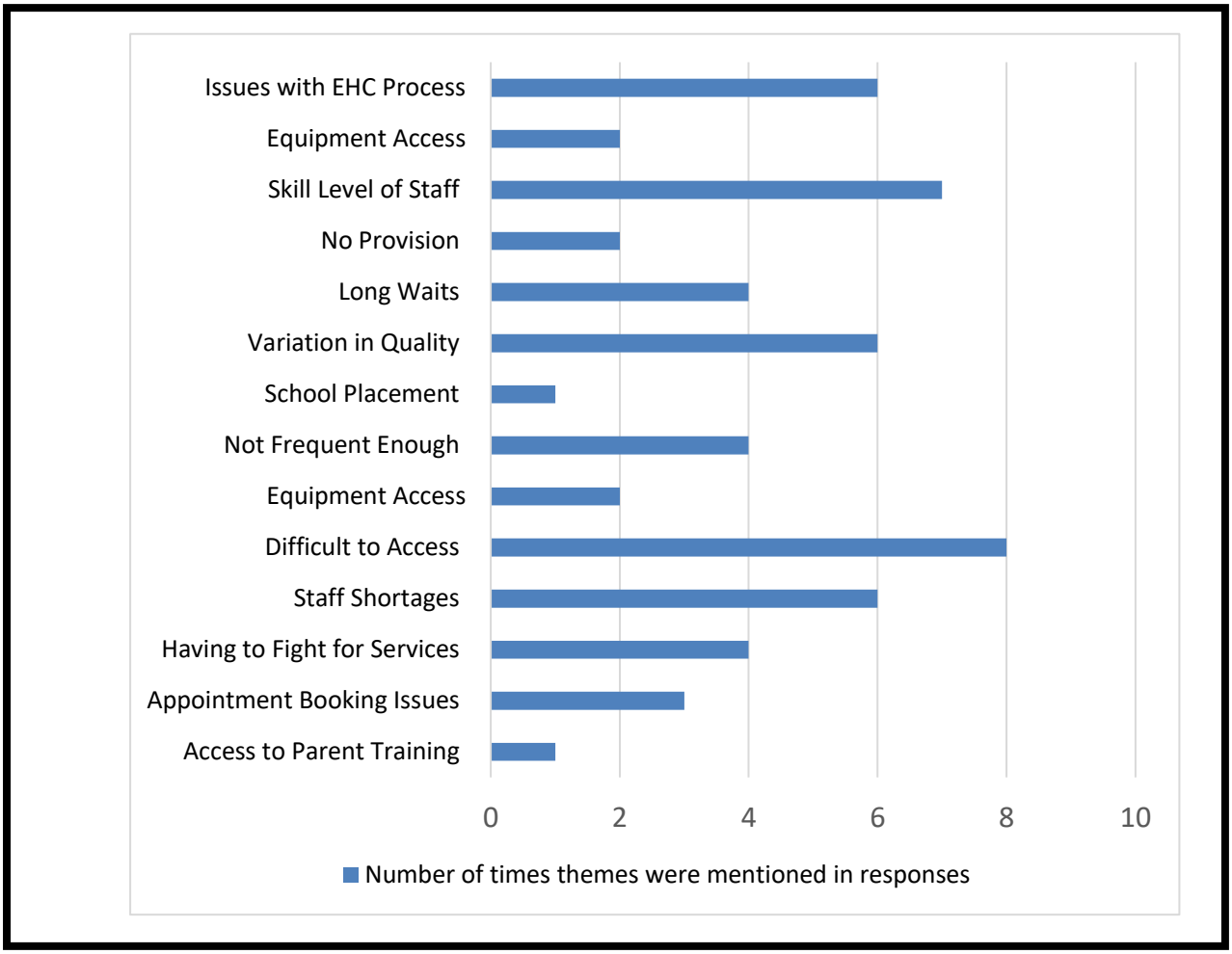
> ***"The relationship we have built with our OT, physiotherapist, and speech and language has been wonderful. We can contact them directly and their knowledge has been outstanding. They've been with us since the beginning of our journey and they understand my daughter and her changing needs. They come to see her especially so they can check in, even if we haven't booked an official appointment".***

Figure 14: Positive responses from parents



Negative responses from parents are outlined in figure 15. The majority identified difficulties accessing the services as the most common challenge, closely followed by concerns about the skill level of staff. The third most common themes that were each mentioned an equal amount of times were Issues with the EHC process, variations in quality of services and staff shortages.

Figure 15: Negative responses from parents



The narrative findings from parent surveys, interviews and focus groups have been combined, and categorised into the following key areas:

- **School**
  School was often seen as a source of support for both parents and children. In particular, parents of children in special school placements felt that their child's developmental progress could be directly attributed to the school's input, (rather than as a result of therapeutic intervention):

  "We are very lucky. Without the school, I think we would have been lost. Because so many things that we get …. Occupational therapy, speech therapy…. It is all from the school. The school provides all this. So if the school was not providing this, I think our children would be something else"

  Another said:
  "I have seen so much improvement, but I wouldn't say it is [because of] therapy. I have seen all this improvement because of home and probably school as well. I don't think it has to do with speech therapy or anything like that. He only had

speech therapy like three years ago, and from there we have not really had any speech therapy. Occupational Therapy is the same. We have not had anyone for a while. For my son, I think the improvement came from home and from school. I would recommend the school. He used to go to mainstream before. Since I had the sponsorship for the special needs school, he is really coping well"

- **Support for parents and carers**

"Some of us… we are unable to sleep in the night. We need our children to sleep, so we can sleep."

"We never have any [respite care]"

"It feels like parents have to fight the system to be considered for any therapies for their child/children. This shouldn't be how you get help"

- **Waiting times**

Similarly, to children and young people, parents have also highlighted that there are long waits for community paediatrician appointments, and for therapy services. In some cases, children and young people are not receiving the interventions that they need in a timely manner.

"The therapies are a brilliant service, they really are. But the waiting is a joke"

Another said:

"My son is 3 ½ years old. He has been on the waiting list for OT and SLT for 2 years. We went to the GP and they referred him to the Paediatrician [for ASD assessment]. We are still waiting for that. It is a worry for me, still being on the waiting list, not having an assessment. It worries me a lot, honestly it stresses me, because I don't want to see him lagging behind"

The negative impact on children due to long waiting times to access services was confirmed by therapists and service managers too. It is arguably a key metric to monitor as a marker of access to therapeutic support.

- **Transferability of therapy advice to the home context**

Parents also reported that they would like choice in how and where their child receives therapy intervention. Parents from both sites said that it was not possible to transfer therapy advice to the home context:

"The advice in the clinic setting doesn't work at home"

Similarly, another said:

"I've had so much annoying advice from professionals over the years, where they will say, 'do this' and at the time, you think ... okay right, and then you get home… I've got another child, a few dogs and you just think, I can't do that, there is just no way that is going to happen! Whereas they are thinking about it in a one to one session, with a few adults involved and the child is not in the home environment".

"Once there were two therapists and me, trying to get my son into some sort of sitting position and the therapists would say: 'do you do this at home'? and I'd say: well I've got a baby. It is just me and the baby at home. How is that going to work? In the end, it turns out that three therapists could not seat him. And they expect you to just deal with these things on your own"

Yet another parent said:
"Everything is going from better to worse, because I am not able to apply the therapies. Why? My home is not conducive for him. It is enclosed. It is not safe"

- **Parental involvement**

  "I have been to therapy sessions, group therapy sessions, where parents are just sitting on the side and just leaving the therapist to do the work. But, this is something that we, as parents, need to learn. We need to be watching, we need to be interacting. If I am going to make a mistake, I want to make it once the therapist is around. So they can say, let's try it this way instead. So I think it is quite important that parental involvement is there right from the beginning"

- **Early intervention**

  Speaking of an injury her child sustained, one mother said:
  "I applied for a Blue Badge three times. The school did every effort to help. It was rejected! But now that my son has had an accident, it is approved! So when the worst crisis happens, then they come!"

- **Challenges with accessing therapy services**
  Parents reported that they would like more opportunities to meet with their child's therapist:
  "At my children's special school if we have a question or query for a therapist we have to get the teacher to ask on our behalf, and are not allowed to contact the therapist directly. It just creates more barriers, a lack of understanding and in some cases, mixed messages"

  Another said:
  "In school, there is progress, but the problem is out of the school"

A mother reported:

" I can't get past the GP to access services. When I finally get the GP to do the referral, it can take months or years for the therapy service to give out an appointment.. or they refuse to see my child, claiming that she does not meet the criteria"

Some of the parents that were interviewed had more than one child with additional needs. Parents remarked on the variation in therapy access and provision, depending on the type of school placement that their child attends:

"now that he's in a special school, it's much easier for him to access the physiotherapist, the occupational therapist and the nursing team, because they're all visiting as part of the school. But my other children, who are in mainstream schools, I still have to go through the wait process. They don't have that instant access. We get invited to drop-ins, where they do a half an hour appointment and they will give you a little bit of advice d. And then it's… we'll put you on the waiting list"

Some parents said they needed more education about their child's condition, and had a lack of awareness about what therapeutic support is available for their child:

"In this country we have lots of parents, and English is the second language. When my son was diagnosed, even the name 'autism', I didn't know it. It is very important for example, you are the specialist, you know he has autism,. It is good to inform more parents. Because not all parents know the information. You know? It is very helpful honestly. Because it says for example, go to occupational therapy, physiotherapy, speech and language therapy. But how to do that? Most of the parents, they don't know that. They [parents] step back because they can't express themselves properly"

They gave examples of the difficulties they face with navigating their local therapy services, which created health inequalities with booking and attending appointments:

"After lockdown, it is to book online everything. One who doesn't know English, how to book. Even basic thing. Doesn't know how to submit. You know what I mean. It is very difficult, honestly to book online"

"I know some people who live in [place] and had their child's paediatrician appointment changed to another location. That's fine for us…. we have a car! Other people just have to cancel… and the thing is, it's not taking into account: do these parents have access to a vehicle? …. not even can they put fuel in vehicle, but do they even have access to a car?"

4.6 Service Provider perspective – needs, what good rehab looks like

A total of 48 providers were consulted. 38 responded to the survey, whilst the remainder participated in interviews and focus groups. The majority of participants that took part were therapists and therapy managers, and therefore the responses are not reflective of other professional disciplines within the Allied Health Professional workforce.

In order to understand the experiences of Allied Health Professionals, we asked:

- What does 'good' rehabilitation mean to you?
- What do you need to help you develop, deliver and sustain your service to meet the local (re)habilitation needs of children and young people?
- What is working well in your service?
- What are the biggest challenges?
- What do you spend a disproportionate amount of time on?
- What do you think are the most important priorities for children and young people at the moment?

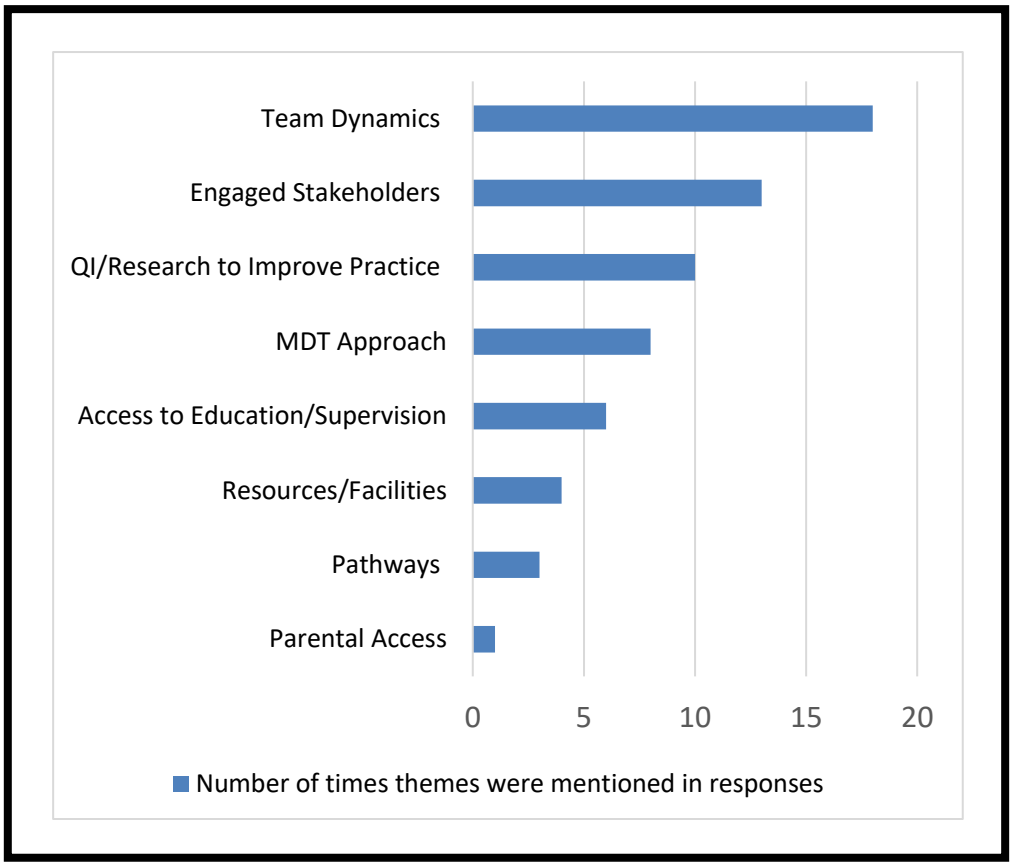
Positive responses from the AHP survey are outlined in figure 16. The top two positive responses from the survey that were most commonly mentioned were:

- Team dynamics (Working with supportive and knowledgeable teams and with caring and compassionate colleagues)
- Working with engaged stakeholders (having good relationships with other services along the patient journey i.e. between community & hospital teams, opportunities for joint working with other professions and building relationships across health, education & social care systems).

Other factors that therapists identified as working well included:

- Time given for service development, research and CPD
- Freedom to innovate & influence quality improvement
- Good communication and MDT working which is supported by infrastructures including facilities, resources and IT systems
- Time for learning with and through others - including supervision
- Working in a service with a strong vision for integrated working

Figure 16: Positive responses from AHPs



The challenges with delivering therapy services to children, from the perspective of AHPs, are outlined in figure 17.

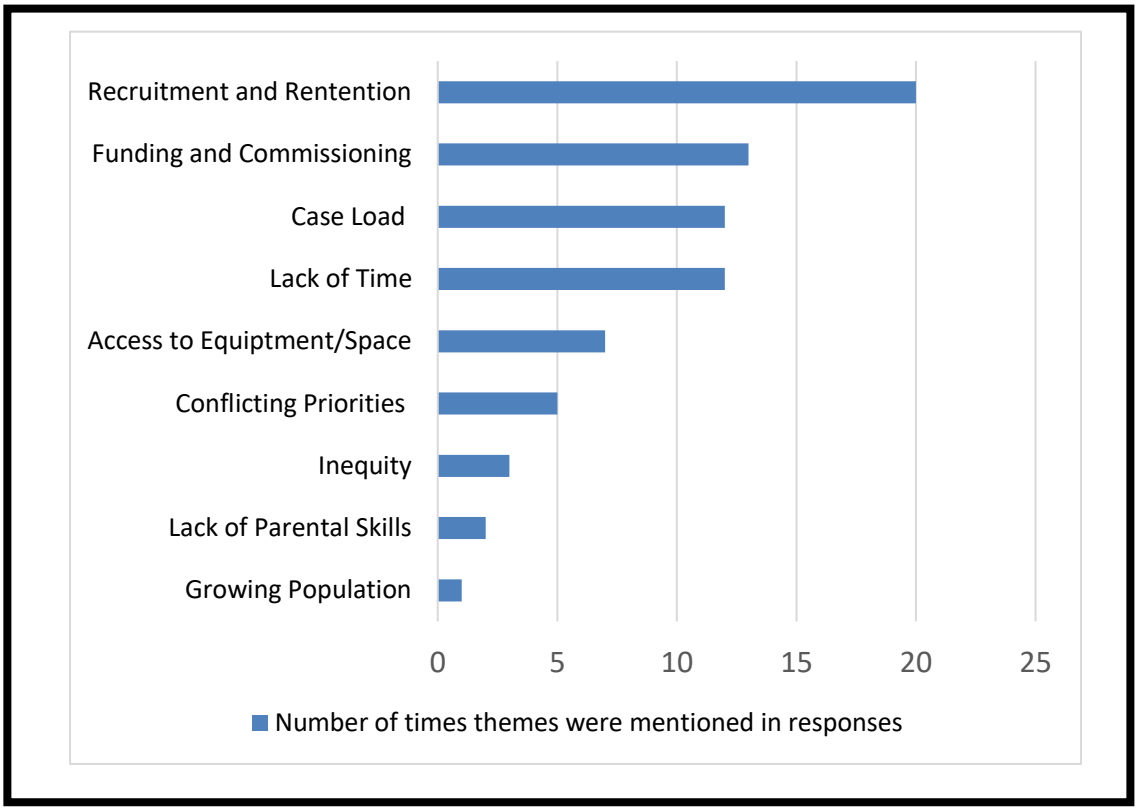
The top two themes that were most commonly mentioned as challenges included:

- Recruitment and retention (A quarter of the responses related to this issue)
- Funding and commissioning (This was mentioned 16% of the time). In particular, lack of investment into children's community services was frequently mentioned, as well as gaps in provision due to inequity of commissioning and differences in commissioning across boundaries.

  One respondent said:

  "For many of those children to be able to live, learn, play and thrive within their local community they need robust services provided by a range of specialist professionals from all agencies, who are working in a strengths focused, transdisciplinary way, putting the child and the family at the heart of the services and interventions. There needs to be a recognition that all professions are essential to this and that provision needs to be effectively costed"

Figure 17: Challenges reported by AHPs



The narrative findings from the AHP survey, interviews and focus groups have been combined, and categorised into the following key areas:

4.6.1 'Good' rehabilitation

Therapists and service managers feel that they are providing 'good' rehabilitation when:

- Assessments and Interventions are evidence based
- Children's therapy is clinically indicated
- Goals for treatment are child centred
- Outcomes are measured
- Therapeutic intervention is goal directed, supporting children to achieve their aspirations and fulfil their full potential
- Timely access to services that are coordinated by a multidisciplinary team
- Proactive service provision which is holistic, co-produced and empowering

4.6.2 Key findings from AHPs

The challenges reported below are closely interrelated, and the quotes illustrate how one challenge is a cause and/or consequence of another:

- **Recruitment and retention**
  Recruitment and retention were mentioned most commonly as challenges, exacerbated by statutory duties (which many said was a catalyst for increasing waiting lists).

"We have a waiting list which can grow rather exponentially, staff are working at capacity and often cry when feeling overloaded. The referral rate has not dropped despite year on year cuts to the budget. We are now in "affordable budgets" due to some huge over spending, and so no vacancies are being filled. SEND inspections, tribunals and EHCP reports take up staff time and the work generated by them is large"

- **Early intervention**
  There is a clear desire from therapists to release more of their time for delivering early intervention, and yet this is not being achieved currently:
  "Despite research to prove how important early intervention is, we don't have the time to complete this"

- **Time for direct patient care**
  "The therapists do not regularly provide therapeutic intervention, let alone assessment. OTs and PTs are in limited supply, around 1 FTE to every 100-150 children. When able, we are able to cope by using well trained therapy assistants to provide treatment"

- **Statutory responsibilities**
  A disproportionate amount of time is being spent on statutory duties, including (whether this is an EHC assessment, providing what is mandated in an EHC Plan, EHC report writing, and attending tribunals and annual reviews). Therapists frequently reported that in many cases, this can be at the expense of releasing time to deliver therapy intervention to the children who are most in need and/or likely to benefit from it.
  "A large portion of referrals are linked to EHCPs. They become a priority as a result of statutory time frames. These however, are not always referrals that clinically, we would deem to be a priority"

- **Equipment**
  Similarly, a lot of time is being spent on various equipment processes including ordering equipment, addressing issues with delivery of equipment, obtaining funding for the best possible equipment, as well as setting up and maintaining equipment.
  This inevitably means a large proportion of therapy time is being spent on non-clinical activity, and in some cases, this was also related to unnecessary bureaucracy in administrative processes:
  "It is more and more difficult to obtain funding for specialist equipment. Often the initial equipment requests are declined and require re-submission"

4.6.3 Top priorities for change according to AHP service providers:

1. Time for direct patient care. Large caseloads with increasing numbers, without an increase in workforce, means clinical face to face contact time is diluted.

"As the complexity of the children increase, we are often only able to support them with one off visits or information a few times a year, rather than regular intervention and support. Our visits are ensuring the children are safe, but it doesn't ensure that they have all the support needed to excel"

"The population has increased, but the number of physios and OTs has reduced. It has become a see and advise service, not a hands-on service. The children with complex needs have very little hands on therapy time with a therapist once they have gone to school. Those with less complex needs hardly get to see a therapist at all"

2. Appropriate staffing

"The gradual erosion of staffing levels without any reduction in referrals is debilitating. I will leave sooner than I had planned, due to stress of trying to spread ourselves ever more thinly"

"If we had more staff within the MDT we could reduce our waitlist and provided a prompter service"

"I feel there has been a big dilution to skills and expertise within our organisation".

"We constantly have vacancies and over two thirds of my therapy staff are locums, as we cannot recruit into permanent positions. This is a huge problem nationwide. British trained therapists are not given enough training in paediatric practice, so therapists rarely come with the skills we need"

"We seem to have significantly less staff than when I started 10 years ago; unfortunately, it seems that when a therapist leaves, they are not always directly replaced. This goes for PT, OT and SLT within our service"

3. Early Intervention

"I need to be able to focus on children's goals within an early intervention framework"

4. Research and evidence-based practice embedded into clinical service delivery

There was also a recognition of the need for outcomes which are transdisciplinary (across disciplines), and for more staff and more training to meet the growing demand for children's service. There was also reference to greater equity in commissioning and an increased investment in funding of community therapy services:

"I would like to start hearing a mantra of not how we can do more for less but a recognition that if we really provide the right services at the right time and that this might be costly, savings will be made in adulthood"

Therapists also reported a mismatch between service offer and need, with variation in provision according to postcode, which contributes to health inequalities.

4.7 Commissioner perspective – needs, what good rehab looks like

A total of 9 commissioners from across all 5 ICBs in the region were each interviewed individually to understand their challenges and needs in relation to commissioning children's therapy services. Each of the ICBs varied in size of population, location and levels of deprivation.

Questions that commissioners were asked included:

- Who has overall responsibility for commissioning therapies for children in your area/ICS?
- Since the establishment of Integrated Care Systems, what is (or will be) the impact on local provisions in your area for children and young people with complex needs?
- How well do you think the therapy needs of children and young people are being addressed?
- If you could rank the top 3 challenges to commissioning therapy services, what would they be?
- What are your top three priorities for change?

4.7.1 Key findings from commissioners

The perspectives of commissioners have been categorised into the following key areas:

- Models of joint commissioning are variable across the nation:
  "... I think nationally the models of joint commissioning are variable and there is such a massive spectrum. If there was clear guidance around how joint commissioning should occur, it would be so much easier. … it doesn't necessarily mean that the pots of money are together, but in some areas it's much better, and in other areas it is much more challenging. In [ICB 1] we are under what's called the safety valve program, which means being scrutinised about our financial investment." **ICB 1**

- Different ICBs have different commissioning arrangements:
  "There are two community health providers in [ICB]… but because they're commissioned under the same contract, they deliver to the same service specification" **ICB 4**

- There is inequity in access and provision across each ICB footprint. This variation in service access and provision according to place, creates health inequalities across the ICS, and means that children are slipping through the net when they have their school, home and their GP in different catchment areas:

"Some would say, well… our contract only states we see children within borough. So… we need to review those to understand what's best for the young people, because basing it on GP doesn't work, basing it on where you live and where you go to school would probably be a better model…. But there's no consistency of how that's applied within the different places, so that's the piece of work we need to look at" ICB 2

- There was some debate over different commissioning models, with tensions between services delivered or commissioned over a larger geographical area (for example across London or a sub-region of London) versus 'close to the ground' commissioning and delivery at the borough or neighbourhood level. We heard concerns that services commissioned or delivered across multiple local authorities could be less responsive to local needs and voices:

***"One of the interesting things is obviously with the creation of ICS's…. Where does that leave responsible commissioning guidance? Because it used to be around GP, but now we've got a place-based approach"* ICB 2**

- Commissioners would like national joint commissioning guidance which includes good practice principles for the nation, regardless of place:

***"There should be national service specification, so we can't pick and choose, so everyone has to deliver to the same level. So it's not a post code lottery"* ICB 3**

- Some areas are commissioning a lot of independent provision (to manage the unmet need and shortfall in the NHS workforce):

***"So what you've got, is a whole private practice boosting up. And that's really been fed by our SEN system"* ICB 5**

***"We have quite an affluent set of parents in some of our areas, which means that they pay for a lot of private therapy and private provision. And so a lot of our NHS therapists are going over to private and perpetuating that"* ICB 1**

- Strengthening investment in community therapy services is challenging, despite the knowledge that exists across the system about the benefits for children and young people's outcome, as well as the economic benefits to the system.

***"I recently went to a one day urgent and emergency care session. My feedback was: that's great, but where's the data for children? So I think it is about recognising the value of children's services. For the ICS that kind of recognition will significantly help."* ICB 2**

Another commissioner said:

"I think Community services absolutely need that boost. They need to be able to say [to their staff]: you've got a really good career structure, you've got loads of opportunity to get into very senior clinical positions, and all that other stuff that people need to feel good. But you also need the investment in the actual resource to deliver community therapy services" **ICB 5**

- Service specifications do not reflect children and young people as 0-25 year olds. Ultimately, the cut off age for services is typically up to the age of 18, which leaves gaps in provision for young people who are 19-25 years old:

  "At the moment it's 18, however, we are fully aware that there is a requirement up to the age of 25 for send. Honestly we're, we're not there across our services, so we are still working to historic arrangements which is up to the age of 18" **ICB 1**

  "We are not really doing them a service, because we haven't commissioned in a way that really thinks about that whole age process. There are no speech and language therapy services for children from the age of 16 in [Place]. So if you move to a nice higher education college, but you've still got some speech disfluency, you can't get any speech therapy, even though it's written in your EHCP. So, then I have to pay for private providers to deliver it and I can't govern that private provider, so I'm really worried about that" **ICB 5**

  "It was my wish this time round, when recommissioning community health services, that we could have taken a bit of budget from adults and made the service up to 25 … But no, we're not quite in that position yet, so it is up to 19" **ICB 4**

- Similarly, service specifications dictated different service offers, for example:
  "In [place], why is there a service specification which states that children and young people aged from 0-11 years of age have provision from the feeding clinic? ….Why did they think that 12-18 year olds wouldn't need anything?" **ICB 3**

- Service specifications have not been reviewed for some time and are therefore outdated and no longer fit for purpose to meet local population need:
  "They haven't been reviewed since 2016. But we're doing a full review of the service specifications across all of the Community services now" **ICB 2**

- There is also a lack of integrated commissioning, which is heavily influenced by past commissioning practices:
  "So, you know, you have a child in front of you. Why would the local authority be responsible for meeting the needs for that child versus that child sitting in front of

***the NHS? Why is it ours? Because if I'm absolutely honest, because of that lack of clarity, it's really difficult to almost go into that joint commissioning pathway discussion*" ICB1**

***"There is an absolute conflict between what's priority for health and what is education. So, you're seeing those absolute strains on the system there. We've got a statutory function and we can't not do it, but we've got things that are health related. It plays with your morals and it plays with your mind, because we've got to spread thinner or we've got to make some very, very, very tough, horrible decisions and it's dreadful" ICB 5**

- The majority of community services are commissioned under block contracts that provide a fixed annual payment for a service. The implications of this are threefold.

Firstly, as payments are made in advance of a service being delivered, unexpected pressures such as increased demand or cost of care are not considered:

***"All of our providers are blocked contract. If I say yes to Peter one day, what happens if Paul comes and I haven't got no money left within our contract?" ICB 5**

Secondly, there is a lack of oversight and accountability associated with block contract payments:

***"We don't have contract monitoring meetings for individual elements of that block contract, so there's no oversight of the therapies and getting reports on KP because it's a block contract and it's very difficult to get that level of contract oversight with it" ICB 3**

Lastly, this means that the contracts and service specifications are broadly framed, lacking specificity:

***"A service specification should be used to understand exactly what it is we are providing" ICB 2**

From another ICB, a commissioner said:

***"If you haven't got it written in your service contract, you are never going to have people delivering it" ICB 3**

Another commissioner said:

***"some providers will go through a service spec and say 'I can't see that listed, therefore, we're not doing it', so there is a…. there's a balance between I, I think… between detail and, and enough information that obviously asks a provider to deliver what you want them to deliver. Just because it's in the spec doesn't mean it's going to happen for lots of reasons. And if it's not in the spec, doesn't mean you don't want it to happen. So it's … it's a relationship" ICB 4**

- The Council for Disabled children has published guidance on the various functions of a DCO role, with the acknowledgement that each role will be different according to local circumstances and priorities [34].
  The majority of commissioners felt that the role of the Designated Clinical officers (DCO) was a valuable resource for coordinating children's therapy support:
  "we have utilised them where we think… especially where we think there is something… kind of… at an ICS level that needs some kind of navigation or support. So the big one being cross boundary provision of care and who does what. So we felt they were well placed to actually take them on and they all felt the same" **ICB 2**

  "I have asked them to do a bit more with us on EHCP tribunals, because the rate of tribunals has gone through the roof. And it would be good to get the themes back from a health perspective, about any themes that we need to be aware of" **ICB 4**

  Another commissioner said:
  "We're investing in some DCOs and we've got some money from our local authorities to do that. That's going to be really helpful for me, so that we're making these decisions about what is reasonable, informed by clinical decision making. And that for me is really important" **ICB 5**

  In contrast, some commissioners told us that the roles of DCO's were less defined:
  "My DCOs want nothing to do with commissioning or budget" ICB 3

4.7.2 Top priorities for change according to commissioners

1. Developing and delivering an equitable therapy service for the whole of an ICS footprint
   "It should be equal across all areas. I want to see the same commissioning levels of service across all of the boroughs" **ICB 3**

2. To measure outcomes and have key performance indicators that demonstrate impact and return on investment for therapy services, with the digital infrastructure to enable providers to achieve it
   "I think number one for me would be what interventions are clinically evidenced? Number two is get your data right. It's got to be for me that I think our therapists need to understand the power of what they can produce to evidence…." ICB 5

   "It doesn't matter that you see five people. If those five interventions aren't having some kind of meaningful outcome that we can measure" **ICB 2**

3. To have paediatrics and community therapy services as a higher priority on the commissioning agenda
   "what you don't have in community services is that push from the government or that desire from really high up. You need the investment in the actual resource of

***those community therapy services"* ICB 5**

4. To have national commissioning guidance, with clarity around joint commissioning responsibilities and integrated pathways for NHS and Local Authority
   ***"There should be national service specification, so we can't pick and choose, so everyone has to deliver to the same level. So it's not a post code lottery"* ICB 3**

   ***"it's almost like we need a commissioning toolkit. It is that clarity around NHS responsibilities versus local authority. If I'm absolutely honest, because of that lack of clarity, it's really difficult to go into that joint commissioning pathway discussion".* ICB 1**

4.8. Deep Dive sites

Each of the two sites were based in a different Integrated Care System. One was based in Inner London, whereas the other was based in outside of London.

ICSs tend to cover large geographical areas (typically a population of more than 1 million people) and as a result, much of the activity to integrate care, improve population health and tackle inequalities will be driven by commissioners and providers collaborating over smaller geographies within the ICSs (often referred to as 'places') and through teams delivering services working together on even smaller footprints (usually referred to as 'neighbourhoods'). (Kings Fund, 2022)

A Health Needs Assessment was completed for each of the sites. Data was extrapolated from national systems: NHS Digital, Public Health England (PHE) and the Office for National Statistics (ONS). This was supplemented by data extrapolated from local systems and sources, including the Joint Strategic Needs Assessments, County Council websites, and Public Health Observatory's.

Similarities and differences between the two sites, in terms of characteristics, can be seen in figure 18 below:

Figure 18: Characteristics of the two Deep Dive sites

	Site A **ICB 1**	**Site B** **ICB 2**
Setting	Outside London Coastal and rural	Inner London Urban
Total population	661, 600	298, 653
CYP population	183, 400 (27.7% of the area's population are children and young people)	88,024 (29.4% of the area's population are children and young people)

4.8.1 Size and structure of each ICB footprint

Both ICBs serve a relatively similar population size, but their structure and composition are different, with ICB 1 covering more local authority areas than ICB 2.

ICB 1

ICB 1 was established in 2021, with its 8 clinical commissioning groups merging to form one ICB organisation, serving a population of around 1.9 million across the ICB footprint. There are four place-based health and care partnerships in the county and one of these has served as site A. There are 12 boroughs / councils in the county in total and there are 5 based in the place-based area of site A.

ICB 2

ICB 2 was established as London's first Integrated Care System, with its 6 clinical commissioning groups merging to form one ICB, serving a diverse population of around two million across the ICB footprint. There are six place-based health and care partnerships in the county and one of these has served as site B. These 6 places serve as local authorities' areas and 1 of these is based in the place-based area of site A.

4.8.2 Patterns of deprivation for each site

Deprivation is a proxy for health inequalities and both site A and B have been identified as having the highest areas of deprivation within the South Thames region.

Site A

There are a higher number of children aged 0-24 in area A, compared to the regional average and national average. Site A has significant 'pockets' of deprivation, and 55% of the most deprived areas in the county are located in site A. According to the Income Deprivation Affecting Children Index (IDACI), a larger number of neighbourhoods and local authority areas within site A are highlighted as being amongst the 20% most deprived in relation to those who are aged 0-15 years and live in income deprived households.

Site B

There are a higher number of children aged 0-24 in area B, compared to the regional average and national average. In recent years, site B has become more deprived compared to other areas of London, whereas it has become less deprived compared to other areas of England. According to the Income Deprivation Affecting Children Index (IDACI), the number of children residing in the site B area who are under 16 and living in families with low income is higher than in other areas of the region, but lower than the national average.

4.8.3 Child health indicators for each site

Despite both sites having similar levels of deprivation, they have very different strengths and challenges according to child health statistics, which determines the unique local needs of their population:

Site A

According to 2024 statistics, site A is performing **better than the national average** for the following indicators:

- Levels of childhood obesity
- This area has a lower percentage of children in Reception (21.3%) and in Year 6 (35.8%) who have excess weight.
- 77.1% of children aged 2 to 2½ years were at or above the expected level of development in all five areas of development (communication, gross motor, fine motor, problem-solving and personal-social skills) in the financial year ending 2022.

According to 2024 statistics, site A is performing **worse than the national average** for the following indicators:

- The rate of child inpatient admissions for mental health conditions at 111.5 per 100,000
- The rate of self-harm (10 to 24 years) at 525.7 per 100,000 and the trend is increasing.
- In the financial year ending 2022, there were 74,180 A&E attendances by children aged four years and under. This rate is worse than the national average. A&E usage is increasing in the area overall, but neighbourhoods and local authorities with greater deprivation are showing significantly higher usage patterns compared to others.
- The number of 6 to 17 year olds not in education, employment or training (NEET)
- The MMR immunisation level does not meet recommended coverage (95%). By age 2, 89.0% of children have had one dose.

Site B

According to 2024 statistics, site B is performing **better than the national average** for the following indicators:

- 69.6% of children have achieved a good level of development at the end of Reception, which is a proxy indicator of school readiness.
- The rate of young people being admitted to hospital as a result of self-harm
- 85.1% of children aged 2 to 2½ years were at or above the expected level of development in all five areas of development (communication, gross motor, fine motor, problem-solving and personal-social skills) in the financial year ending 2022.

According to the latest statistics, site B is performing **worse than the national average** for the following indicators:

- Prevalence of child obesity. 11.3% of children in Reception and 25.9% of children in Year 6 are obese.
- First time entrants to the youth justice system
- Households with children homeless or at risk of homelessness is significantly higher than national average. Homelessness is associated with severe poverty and is a social determinant of health. It often results from a combination of events such as relationship breakdown, debt, adverse experiences in childhood and through ill health
- There has been a decline in recent years relating to the housing domain of the index of multiple deprivation. This relates to issues relating to access and affordability of housing, as well as geographical barriers relating of the physical proximity of local services.
- A&E attendances 0-4 years

- The MMR immunisation level does not meet recommended coverage (95%).

4.8.4 Good practice examples from each site

We asked therapists about examples of good practice in their services, and which things they would share with a neighbouring team. Although not an exhaustive list, figure 19 below illustrates some of the examples that were given:

Figure 19: Good practice examples from each site

Site A	Site B
Job fairs Career insight days Staff allocated working days to support transition to adulthood Tiered model of service delivery to manage waiting lists whilst still offering interventions Strengthening targeted support Parent workshops using a coaching model Links with access sport and other local community club leaders The training offer Development of training for schools re. accessible sport for CYP Therapists trained in innovative treatment approaches i.e. MAES (Movement, Assessment, Education, Systems) Tour of the area for new starters Drop in clinics	CYP Therapies website with access to resources, training, advice Balance system Strengthening targeted support Mock internal CQC inspections Business management support CYP and family involvement and engagement (PPI) Working towards service wide model (instead of place / borough based) The training offer Links with acute trusts to develop pathways of care i.e. Orthopaedic physio Telehealth appointments Utilising wider workforce i.e. school Robust processes i.e. CPIPs assessment & review Telephone adviceline

4.8.5 Most prominent challenges from each site

We triangulated the views of parents, therapists and commissioners from each site, to identify local challenges and barriers to accessing and receiving children's therapies. Figure 20 summarises the findings.

Figure 20: Summary findings from each site

Site A		Site B	
Topic	**Summary**	**Topic**	**Summary**
Delays to social care interventions • Respite / carer support • Equipment • Housing	Prominent theme amongst parents and exacerbated by socioeconomic status such as deprivation and safety at home	Time for direct, face to face therapy vs. telehealth	Parents and therapists have different perspectives on the universal service offer and the move towards delivering services online.
Transferability of therapy to the home setting	Prominent theme amongst parents	Diagnosis	There were differences of opinion within and between stakeholder groups, about whether or not a diagnosis influences the service a child receives.
Transition to adulthood	Same theme, different perspectives across stakeholder groups	Transition to adulthood	Same theme, different perspective across stakeholder groups
Waiting lists	Consensus across all stakeholder groups	Waiting lists	Consensus across all stakeholder groups
Lack of digital infrastructure for recording outcomes	Prominent theme from therapists and commissioner	Increase in statutory demand	Same theme, different perspectives

Illustrative quotes for each of the two sites can be found in appendix 6. These quotes are not exhaustive, but intend to demonstrate narrative accounts of the most commonly cited areas of need.

In summary, the two local sites experience different challenges. However, there were also some similar, shared challenges across both sites, which were also consistent with the results obtained from the regional data capture:

- Both sites had geographical variation in commissioning across the ICB footprint, creating gaps in provision and inequity in what children and families receive.
- Parents from both sites raised issues with the transferability of therapy programmes and advice to the home context. Many felt there was a mismatch between the child's functioning and abilities at school and their child's achievements at home. Many parents raised issues with the advice they were given by therapists working in a clinic setting, but not being transferrable to the home environment.
- Both sites raised issues with equipment and workforce.
- Both sites commonly cited the EHC process, with differing perspectives between parents and providers in particular, about whether obtaining an EHCP is a barrier or enabler to children having their needs met.

4.8.6 Top priorities for change from each site

We triangulated the views of parents, therapists and commissioners from each site, to identify their top priorities for change, as illustrated in Figure 21.

Figure 21: Top priorities for change from each site

	Site A	**Site B**
Stakeholder group		
Parents	• More funding (for staff recruitment, to match demand with capacity) • Faster response (less waits) • More frequent therapy	• Easier access • More choice re. where therapy takes place • More frequent therapy
Head of therapy	• Reducing waiting lists (to release time for early intervention) • Improve workforce supply • Increase SEND support	• Reducing waiting list • Parents and schools to be confident to manage children's needs • Shared responsibility between parents, schools and therapists
Therapists	• Increasing recruitment and retention • Reducing waiting list to ensure that service is able to offer timely and effective intervention. • Managing demand for EHC & SEND support - ensuring correct skill mix exists in the team to do this	• Children being able to access support in the educational environment • Maintaining direct ('hands on') therapy time • Early intervention, research and evidence-based practice
Commissioners	• Reducing waiting lists • Improving recruitment and retention • Increasing funding for SEND support	• The development of national joint commissioning guidance • Clarity around joint commissioning responsibilities • Equity across the ICB footprint

The findings from the 'deep dive' of two sites in different geographical areas, not only highlights the differences between local contexts, but also emphasises the need to understand and consider local health priorities and contextual factors when planning local services for children and young people.

5. Triangulation of main findings

This programme of work has triangulated the findings across four stakeholder groups, using a mixed methods approach to identify:

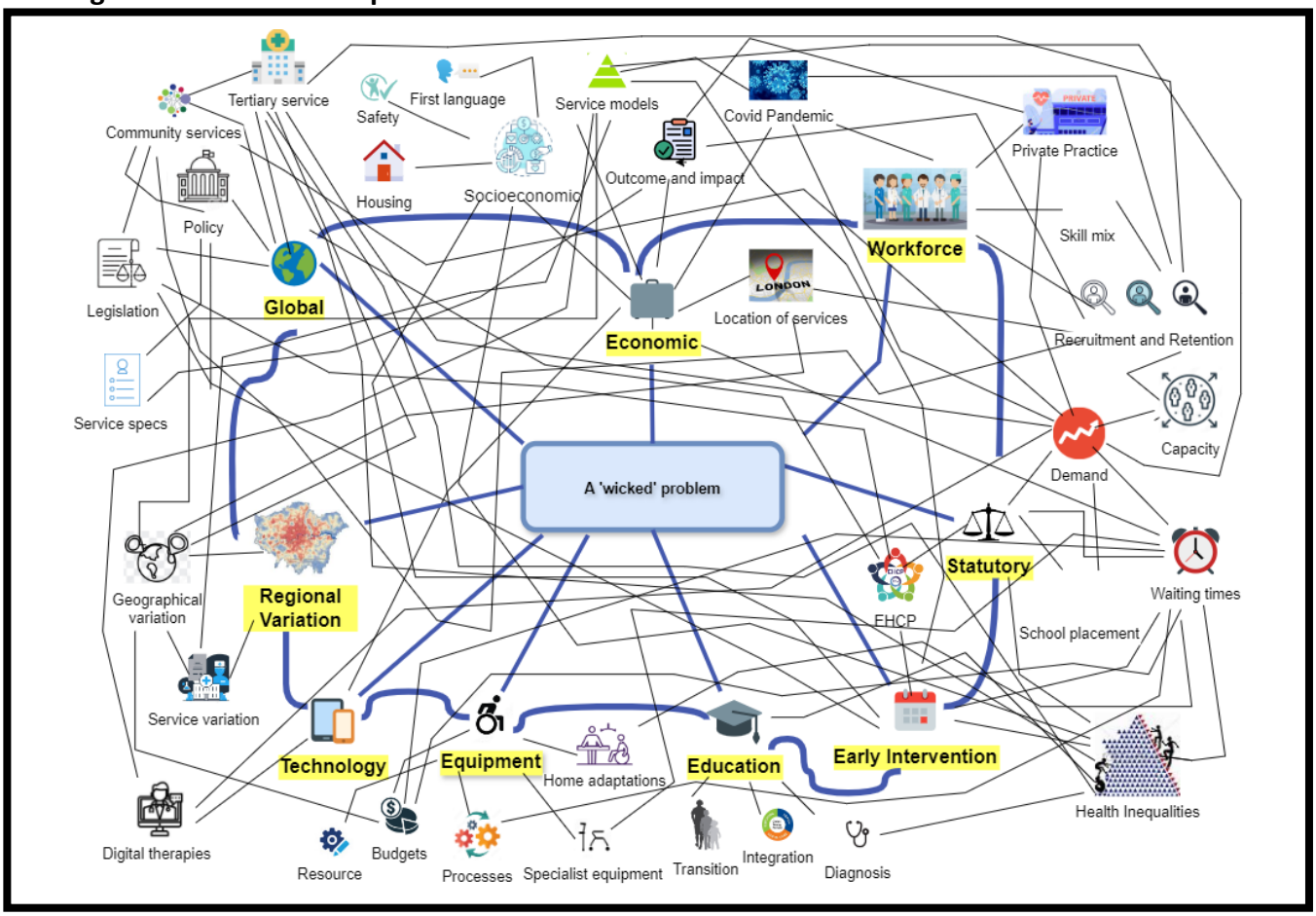
- The barriers and enablers to accessing and receiving rehabilitation services for children and young people
- The unmet needs of children and young people
- How children with complex needs and their parents view current rehabilitation service provision, and to what extent it is meeting their needs
- What services require to sustain and deliver effective, need-led rehabilitation to children and young people (with a particular focus on community services)

To address this nationally important issue, primary data has been generated through a regional survey, interviews and focus groups. Secondary data sources have been reviewed, including recent research studies and policy documents. Data has been extrapolated from official statistics and published datasets.
We bring together the data from all of these sources, to present you with the findings.

5.1 Barriers and enablers to accessing and receiving rehabilitation services for children and young people

This work has generated 9 key themes across stakeholder groups, that act as barriers and enablers to accessing and receiving therapy services. They exist irrespective of a child's condition or diagnosis. Figure 22 is a final thematic map that illustrates the relationships between the 9 key themes that have been drawn out from triangulating the data.

Figure 22: Thematic map



There are interdependencies between each of the themes, which present complex and interconnected challenges, with one problem being the symptom and/or cause of another. They arise from a number of variables, including systemic and structural barriers.

Each of the 9 main themes that emerged from the data, and the associated subthemes are explored below:

Theme 1: National Health Service System and Structures

Firstly, Integrated Care Systems are at varying states of maturity and have gone through many stages of service redesign. This has had an impact on how they work, particularly in relation to navigating new relationships to achieve an integrated approach to commissioning, between the NHS and Local Authority. Some have less history of integration and therefore find it harder to make decisions and agree service changes.

> ***"We've gone through a merger, so we've gone into one ICB right in the middle of a global pandemic. We've come out of the other side now, after going through yet another service redesign. And I'm saying this because the reality is… this does impact on how we work and our working environments"*** **Commissioner**

Historical commissioning models are no longer fit for purpose:

> ***"There were days in CCG land where you could put sticking plasters on things, and access a pocket of money. I don't mean to be flippant, but public money was a bit more fluid. Now I have to work out if I've got enough money for that child to get their needs met. That's not a comfortable place to be, because if I say yes to Peter one day, what happens if Paul comes along and I haven't got any money left within our contract"?*** **Commissioner**

Secondly, there is an unintentional, yet established hierarchy between community and tertiary providers. Many stakeholder groups spoke about their perception of what constitutes as "specialist". It was evident that parents felt they were getting something from the tertiary hospitals that they don't get in their local communities:

> ***"Many of our parents would rather go to the Evelina than our local [community] services. And our local services would refer to the Evelina if they had any concerns or they weren't sure"*** **Parent**

One therapist said:

> ***"... the more you're referring into those [tertiary] services from Community, the more you're feeding into that perception"*** **Therapist**

Many parents are willing to spend time travelling and pay expenses in order to access a tertiary service, even if this is not close to their home:

> **"you *have* to take that appointment, so you *have* to travel to London, out of county… at whatever expense…. you know, upset the sibling, put money in the car that you haven't got… buy train tickets you can't really afford" Parent**

One therapist from the community said:

> ***"we have to be the specialists, because while there are options to refer [to tertiary], we are the ones who will be providing the follow up and the day-to-day intervention."* Therapist**

Therapists working in the community often referred to tertiary services as the "specialists":

> ***"We think we've got our offer right, but we're having to argue against these specialists who are saying, they must have direct intervention from a specialist therapist and we're trying to look at what our local community offer can look like"* Therapist**

There were examples of community services relying on tertiary services. Often this was due to capacity issues in the community service, rather than lack of skill mix to deliver the interventions that were required.

> ***" … it's a vicious circle … we have to refer into the specialist service because we're not currently commissioned to provide some of these things… so there would be no point in developing a specialist pathway here because we wouldn't have the finance to fund that post or … to develop the training."* Therapist**

Lastly, there was reference to the temporality of the systems and how existing structures, policies and processes impact on the ability to influence change at an organisational and wider system level. One interviewee noted that:

> ***"There are service-wide constraints on service delivery. NHS care pathways are restrictive and there is a lack of funding for specialist services"* Therapist**

Theme 2: Economic

Access and provision of therapies is influenced by the economy. Subthemes in this category include waiting lists, the COVID-19 pandemic, service location, socioeconomic factors and service models.

Firstly, many therapy services have changed since the COVID-19 pandemic and this was acknowledged by all stakeholder groups. However, there was a mismatch between how these service changes were perceived, from the perspective of parents and therapists.

Since the COVID-19 pandemic, parents have reported a reduction in the therapy being offered to their child, and in some cases, therapy intervention has been non-existent:

> ***"Weekly therapy was crucial when my son was younger (although covid stopped this happening for months)"* Parent**

Whereas some therapists remarked on what they had learned about delivering services differently:

> ***"The COVID pandemic really changed the service offer, but this was important. We learned a lot about what needs to be done by a therapist and what can be done by other people"*** **Therapist**

Parents themselves gave examples of their socioeconomic status, and the impact that they feel this has on accessing services that will support their children's developmental outcomes:

> ***"In this country we have lots of parents and English is the second language. …it says for example, go to occupational therapy, physiotherapy, speech and language therapy, but how to do that? Most of the parents, they don't know that. … It is a big barrier"*** **Parent**

For some parents, their homes were not suitable for their children's needs and posed risks to their safety.

> ***"He has Autism and challenging behaviour. He is very hyper.… we are living on the second floor of a high rise building. He goes to the balcony and he is not aware of danger. One time he jumped. Luckily there is a net … but he was just there. Even though he is unsafe, he can't speak. He can't shout. His mum was in the kitchen. She didn't know he was down there."*** **Parent**

Waiting lists were frequently cited as a concern across all four stakeholder groups.

> ***"It took a really long time to be seen"*** **Young Person**

> ***"The therapies are a brilliant service, they really are. But the waiting is a joke"*** **Parent**

> ***"the waiting times went up during the COVID pandemic, and the referrals increased too"*** **Therapist**

> ***"when you've got long waits, that reduces your capacity to be able to respond at the right time"*** **Therapist**

> ***"the waits for Allied Health Services are fairly substantial. What you tend to find is that families will then opt for private therapy support… or the local authority itself can actually buy in private therapy support as well, where we can't meet that need. It isn't ideal, but it's kind of a stopgap, and at least young people are getting something"*** **Commissioner**

In addition to this, there are long waiting lists for diagnostic assessments, and as a result, diagnosis is being made later on in a child's life. There were differences of opinion within and between stakeholder groups, about whether or not a diagnosis influences the service a child receives. Many

parents, and some schools, were of the opinion that their child needs to have a diagnosis in order to be able to access therapy support:

> ***"It is the fact that they have to wait so long for any type of assessment or diagnosis. Although everybody says no, you don't need a diagnosis in […]. But If you haven't got the diagnosis, you don't get the support in school"*** **Parent**

Another said:

> ***"The school are saying they can't do this, because they haven't got diagnosis. It is still going on. Not every school… As I say, it's, you know, some are great. But there is still a good handful, if not more, of schools that just won't get that support in place"*** **Parent**

There was less consensus amongst therapists. For example, one therapist said:

> ***"There are long waiting list for diagnostic assessments – later diagnoses means less opportunities are open to these children. No diagnosis means less therapeutic support"***

Whereas other therapists said:

> ***"The diagnosis doesn't make a difference to us in terms of what we deliver because it's based on the need and presentation"***

In some cases, therapists cited the contrast between the needs led ethos of their service and the policy drivers which are diagnosis led:

> ***"It is interesting that there is a particular focus on ASD from NHS England. Those children come through the door with coordination and sensory difficulties …. we see them, but not because they have ASD. It's very much about they're functional difficulties".***

Service specifications were discussed as a way of ensuring that children without a diagnosis are not excluded from accessing services, however, more work needs to be done to achieve this in some areas:

> ***"There wouldn't be exclusion criteria based on diagnosis within the service specification. I think we do understand needs to a point, but there is some acknowledgement around updating our service specifications"*** **Commissioner**

Secondly, service delivery models in community therapy services are generally top heavy or bottom heavy, with an under investment in targeted provision:

> ***"I think we went through a period then of having quite good universal advice, and having specialist stuff that we were doing too. But the targeted bit in the middle wasn't really happening. I do feel we were 'all or nothing' in a way"*** **Head of CYP Therapies**

Parents and therapists have different perspectives about the local service offer and the tiered model of service delivery. For example, parents did not recognise the 'universal' offer that is being provided as intervention at all, particularly when this diluted or removed the face to face contact time with a therapist:

> ***"I want proper one to one sessions with a speech therapist, whereas they have been saying 'I will speak to the teacher and they'll tell the class what to do'. It's just bad, really bad. I haven't had any positive experience with anything in therapies yet".*** **Parent**

Another said:

> ***"They have never received any direct therapy. It has always been with the parent and then signed off. My child never hit the quota to receive any therapy, which is awful to be quite frank".*** **Parent**

Another parent reflected that the provision is too generic and not tailored to individual need:

> ***"not all the children are the same. They did not work with my son. That kind of therapy, what they showed me in that session, it didn't work with him." Parent***

Lastly, all three stakeholder groups (parents, therapists and commissioners) raised issues with borough boundaries, where children are 'slipping through the net' when they have their school, home and their GP in different catchment areas. This creates inequity of access and provision:

> ***"Therapy service provision is very, very different, depending on where the school is based. Knowing the availability of school places in the area, lots of children with additional needs may not go to their local school".*** **Parent**

Another parent said:

> ***"The therapy input is based on where your child goes to school. So when my son went to school in [X area], we had [X area] therapists, not [Y area] therapists. So I had to travel to the school to see the therapists, or they had to travel further out, to our house. I don't have any local therapists… physios were seeing him at school, so I'm not at the appointment".*** **Parent**

Therapists said:

> ***"Sometimes the family will want the therapy to be happening in a school setting. But then actually some of them are wanting it face to face, at home. And I think it is getting that right at the beginning, and having that communication. And so***

hopefully people are, you know, asking the child or young person and the parents what they would like and establishing those expectations at the beginning." **Therapist**

"We're working very much about bringing together the service as a whole. It's kind of been working in locality pockets, so we're now working towards a service wide way of working rather than individual localities" **Therapist**

Commissioners said:

"Some clarity and guidance around boundaries would be helpful so that we are all using the same approach essentially. That would be helpful for consistency". **Commissioner**

Theme 3: Statutory

The rising number of EHC assessments and EHC plans being issued means that therapists are delivering less and less direct clinical time to children and young people. This is having a knock-on effect on children's outcomes:

"Our capacity is taken up by EHC Needs Assessments - these have to take priority even though they may not reach the children who are clinically the most in need" **Therapist**

Commissioners and therapists alike have raised issues with the time being spent on EHC related activity, which means that there is no scope for early intervention to take place:

"I think it is wrong that EHCP provisions are prioritised above early years intervention due to legal requirements, when treatment should be allocated based on need and evidence" **Therapist**

"The EHCP referrals become a priority as a result of the statutory time frames. These are not always referrals that clinically we would deem to be a priority" **Therapist**

"It is like a black hole, so it sucks in a lot of people's time and activity. This is statutory. And we have to do that. So it comes down to the have to's" **Commissioner**

Whilst the SEND system was a commonly cited theme across all stakeholder groups (parents, providers and commissioners), the perspectives of parents often differed from therapists and commissioners. Some parents seemed to feel it was important for their child to have an EHCP in order for their needs to be met:

"The local authority did everything in its power to deny my quite obviously extremely vulnerable daughter access to everything she was entitled to. The

therapists were not out to deliberately obstruct us, but they said quite openly that they couldn't be too prescriptive in their reports about what my daughter needed. As soon as we paid a fortune for private reports and lawyers and took the local authority to a tribunal, they were very quick to back down and give us everything we wanted at the 11th hour" **Parent**

Another parent said:

" I am waiting for an EHCP to ask them for more, because my daughter is starting to make some kind of babble, so I think she should have some help" **Parent**

In some cases, parental experience of needing an EHCP for their child was corroborated by other stakeholders:

"There is no hiding from the fact that there are children that will only receive provision because they have an EHCP" **Designated Clinical Officer**

Therapists in particular expressed their concerns about the parental perception that a child has to have an EHCP in order to have their therapy needs met:

"EHCP's are, if you like, seen as a bit of a ticket to accessing therapy services. I think we have to really think about that, because it generates an awful lot of complaints, because essentially what we would be saying is: an ECHP isn't necessarily the magic ticket anymore to therapy. We are looking much more at need" **Head of therapy**

A therapist said:

"Families feel that the EHCP gives them that safety, it tells them what their child needs. Some families will cling onto the need for direct intervention because it was said in the EHCP, and so, you know, you can end up at tribunal, you can end up in lengthy meetings to say: your child doesn't need that, because now they need this …. but they still have the paperwork that says they do need it because it hasn't been updated" Therapist

In the same vain, parents have given us examples of a seemingly low threshold for obtaining an EHCP, which has resulted in some children receiving specialist school placements in the absence of appropriate send support. One parent said:

"I am aware of one child who got an EHCP, because no one could support them walking around the school… and so they went to a specialist school, which to me, is crazy" **Parent**

A head of a therapy service said:

"I think there does need to be a recalibration nationally around thresholds for obtaining an EHCP. It leads to a really disproportionate allocation of resources to a

> ***very, very small group of children. People know exactly what to say to get an EHCP"*** **Head of therapy**

And yet, many families have reported that despite the EHCP, their child's needs are not being met:

> ***"Even with an EHCP plan, some schools aren't giving the support they should be"*** **Parent**

> ***"My child hasn't been assessed since they first got their EHC plan which was…. 5 or 6 years ago. The needs are very different by then. It needs to be reviewed"*** **Parent**

> ***"There has been no Occupational therapy for over a year for my son, even though he has an EHCP. I had to put in a complaint with Pals to get somewhere. Now we are getting what is in the EHCP, but again, it was another fight and time spent sorting it out"*** **Parent**

Furthermore, the increase in statutory demand has contributed to many children not having their needs met by NHS services. As a result, there is a rise in the number of families accessing independent sector provision:

> ***"What you've got is a whole private practice boosting up. And that's fed really by our SEN system, as you know, because people ask for an EHCP and they want a whole load of sensory integration work, for example. And we can't offer it in a community service. It's quite complex, but the therapists have got the skill set, and they have been trained up in the NHS, so they leave and then they go and do it privately. So we fed the system. We do feed it again and again"*** **Commissioner**

Some NHS providers in the region have had services decommissioned, so that they are no longer delivering interventions that are outlined in a child's EHCP:

> ***"The actual capacity that the team has means that we are not able to deliver the EHCP provision to children in that area. So that area is assessment only. So they come in for their assessment and we do the advice. We do it and then we close them, even if they have an EHCP"*** **Therapist**

There are also concerns about the governance of private provision, particularly in instances where commissioners are paying for a private provider to deliver therapy:

> ***"I have to pay for private providers to get to you and I can't govern that private provider, so I'm really worried about that"*** **Commissioner**

In summary, there is a contrast between the priorities for change when it comes to statutory provision, with the views of parents being starkly different from therapists and therapy managers. Parents of children who do not have an EHCP, are significantly invested in obtaining one:

"They deliberately make the report so vague (at the LA's request) to ensure that it cannot be relied upon by parents in accessing more 'expensive' resources like specialist schools, even where it would clearly meet the child's needs to do so" **Parent**

Whereas therapists and therapy managers say that they want an increase in SEND support and early intervention, so that children can be supported in education settings earlier. In some cases, they believe that this will reduce the need for an EHCP in the first place:

"The providers are definitely saying to us, we need help in terms of… How do we grow the send support and the early intervention, to release longer term capacity around that EHCP package? So that we can make sure we get the balance between statutory and clinical support… and that is across all therapies" **Commissioner**

We need to acknowledge that the cost of not providing robust interventions and services in childhood leads to significant costs in teenage years and adulthood, both in relation to the child and their families physical and mental health, as well as their well-being and ability to access and contribute meaningfully within society" **Therapist**

Theme 4: Workforce

Recruitment and retention is a problem nationwide. In many areas in the region, the demand for therapy provision is outstripping the capacity that is available to deliver it:

"I think it's just there is such a shortage of colleagues. I think that is the biggest thing that's impacting, is the actual shortage of professionals. We keep getting told that it is because they haven't got any staff …and that professionals have left the career. That is the biggest issue for a lot of parents. And that obviously impacts the support that is put in place" **Parent**

"It's really hard because we're trying to see the children that a therapist needs to see and use a wider workforce, but that wider workforce feels like it's shrinking" **Therapist**

"One of our providers significantly struggled with recruitment at one point. I think they were holding almost a 70% vacancy rate. They just could not get therapists" **Commissioner**

"We are desperate to provide an excellent service (we have the specialist knowledge and expertise to do so), but our ability to provide any therapy that is going to be effective and transformative (as it should be) is being restricted more and more each year and it is becoming difficult to see what we can achieve as a profession within the NHS" **Therapist**

Some of the service managers have told us that they have had no choice but to reduce the therapy offer within their service in order to meet the demand:

> ***"That came out of necessity, out of really long waiting times"*** **Head of therapy**

Similarly, therapists told us:

> ***Unfortunately I am not able to offer the standard of care I aspire too as I simply have too many children on my caseload. I am not as reactive as I would like to be, to the needs of the young people and families"*** **Therapist**

There are also factors affecting the workforce, which are specific to a community setting:

> ***"Recently we've had staff that have wanted paediatric roles, but actually, I think are more suited to the acute setting, and the complexities of community working isn't what they thought it was going to be. Paediatric community is… I feel like it's a very complex area to work in, because you're managing your own diary a lot of the time, but you're coordinating a lot of our band 5s and 6s. They find it really, really, quite challenging to be on top of that… and managing, you know, time management… because you're liaising with parents for your caseload of children. We don't have enough admin support. So we have to, you know, do all our own reports and text messages… and things like that and coordinating our own diaries for our caseload, children and school contacts and things like that. So contacting the SENCOs, telling the parent that we're going into the school to see the child. People not getting back to us, to say actually that child's not come in today. So you might go and visit a school and the child's actually not there. Um, you know, the sort of frustrations in how long it takes sometimes to plan these things and then if everybody isn't sort of remembering these appointments. So, you try and send as many text reminders as you can, to make sure that it's not a waste of time and it's a successful contact. But that takes a lot of time and planning and energy and is incredibly frustrating when it doesn't go right"*** **Therapist**

There are also workforce issues that are specific to the field of paediatrics:

> ***"Over two thirds of my therapy staff are locums as we cannot recruit into permanent positions. This is a huge problem nationwide. British trained therapists are not given enough training in paediatric practice, so therapists rarely come with the skills we need, even at band 6 & 7, so we always need to train them up"*** **Head of therapy**

Similarly, therapists rely on the school, as part of the wider workforce for delivering therapeutic support. This is particularly evident in areas where there is a high level of deprivation affecting parents and carers:

> ***"Our sort of Episode of Care Pathways really is dependent on schools and parents requesting a review at appropriate times. So, we try and advise parents, but obviously you've got the parents that are able to process all of that and keep on top of that. But we've got other families that obviously have more chaotic lives, for whatever reason, or maybe they're doing 2 jobs or they're a single parent, or they're unwell themselves or for many, many reasons… they might not have English as their first language…. All of the deprivation for certain families that will cause difficulties to trying to provide a treatment block"*** **Therapist**

Challenges with recruitment and retention also results in other roles that exist within the team being used inappropriately:

> ***"The clinics we run, they are coordinated by our band fours …. so they are doing quite a lot of admin tasks, whereas their skills are also in therapeutic handling and other practical skills as well. But they're… they spend a lot of time organising our clinics"*** **Therapist**

> ***"OTs and PTs are in limited supply, around 1 full time equivalent to every 100-150 children. We are able to cope by using well trained therapy assistants to provide treatment when able, but the therapists do not regularly provide therapeutic intervention apart from assessment and creation of programmes for the education staff or families to complete"*** **Head of therapy**

Similarly, therapists who may be ready for more senior roles are difficult to retain unless there's an opportunity for career progression:

> ***"Unless there is some sort of progression and career development pathway, to enable them to progress to a band 7, then they will need to look somewhere else, if they want to develop their career further"*** **Therapist**

More therapists are leaving the NHS to work privately because they want to utilise their training, which relates to doing 'hands on' therapy with children. Some areas in the region are commissioning a lot of independent provision to manage the shortfall in the NHS workforce:

> ***"There are ridiculously long waiting lists when you are at your most desperate, leaving your child completely unsupported unless you can pay for private help, which we have had to do for years"*** **Parent**

> ***"It seems more and more families are seeking the support of private therapies, which is understandable when they feel they may not get as much input as they would like from the NHS, however this can cause issues, duplicating/conflicting therapy advice"*** **Therapist**

Therapists and therapy managers gave various examples of strategies that they were using to try and increase the workforce capacity:

> ***"We talk a lot about trying to grow our own workforce more and… and develop the flexibility of that work force to be able to work across different disciplines… ….Both to grow capacity in some of that earlier phase, but to give people perhaps more interest and more varied approaches and techniques regardless of what specialty they end up going down. So I think there's something about that entry level piece and how we keep and grow our own"*** **Commissioner**

> ***"We have been very strategic about how to attract people and so I think that's worked well.. and that obviously will have a knock on effect for our children and young people in terms of being able to able to get the services that they need. We've looked at the posts, and previously, in speech and language therapy, we've always had posts that are either education based or clinic based, but we've now been providing posts across that, because it is what people seem to want at the moment. So especially for some of our band fives and some of the band 6 posts… they are, across schools and clinic or even special schools and clinic, which we haven't had before."*** **Therapist**

> ***"We have been visiting a student 'job fair' to talk about [place] and raise the profile of [place]. Private practice gives a very hard sell when students qualify, and we wanted to give the other side of that. That actually, working in the NHS is a really valuable thing to do and there's a lot of advantages to working in the NHS, that I don't think people necessarily know about"*** **Therapist**

> ***"Re-grading jobs, where we haven't been able to recruit at one level, we might recruit at a different level"*** **Therapist**

> ***"we had to recruit a locum this year, to try and reduce the episode of care waiting list, because there were a lot of people sitting on there for nearly eighteen weeks. She came in for two months and did numerous treatment blocks to reduce that waiting list"*** **Therapist**

> ***"There's way more opportunities with apprenticeships as well. So I'm sure that band fours will be offered apprenticeships in the future, that will maybe go on to support growing own again, as our future band fives"*** **Therapist**

It was evident that the factors that contribute to NHS recruitment and retention is multifactorial and is influenced further by the local context and the associated employee benefits:

> ***"There are local complexities which impact on recruitment and retention. The local authority changed their parking regulations. So NHS health professionals will no longer get subsidised parking. If the trust is saying we are no longer going to pay***

for the parking passes, does that mean it's less attractive?- It is not necessarily just about the salary. It is about all the non-tangibles" **Commissioner**

Similarly, another commissioner spoke of the negative emotions that therapists experience when they join the NHS:

"There is a moral injury for people coming into the profession, who had good intentions. And then they are overwhelmed, chugging out assessment after assessment after assessment… and actually those core beliefs, intentions and values that people came into it for, have got lost along the way" **Commissioner**

Another said:

"Certainly the therapists are reporting that actually, I didn't spend years training only to qualify to assess - that was never my ambition" **Commissioner**

Speaking of the benefits of working in private practice, one person said:

"ultimately you get paid more, don't you? You go and do an assessment and you get four hundred pounds. I'll do a couple of them a week and I won't have to work 37.5 hours" **Designated Clinical Officer**

The same person also reported generational differences in values, expectations, perceptions and motivations in the current workforce, which impact on engagement:

"This generation of graduates have a completely different ethos on their life. My adult children have a completely different viewpoint. When I came out of school, I wanted a vocation. They don't want a vocation anymore. They want to go to work. They want to earn money to go and do really lovely things with their life and absolutely they should do that. But it is completely different and I think the NHS has not moved into that space. It has not changed or morphed so that it supports the younger generation and their ethos. We just sit in an organizational framework, which the older ones of us just comply with, but the younger ones don't. They don't want to do it" **Designated Clinical Officer**

A commissioner said:

"We do need to have a better work life balance within the NHS as a whole. I've always felt this is the only way someone will fix the NHS, is to over recruit everywhere, so rather than award an establishment with 30 nurses, we're going to give you 45. That means your staff can have flexible working patterns that fit around their life. They can have time within their working hours to do their audits. And I just think that way, we will cut down on an awful lot of agency work. But to do that, someone's going to have to throw billions at the NHS and actually bite the bullet and go for it, because until the staff get better working conditions, and the

ability to have the work life balance they need, and not be so overworked and overstretched, it's never going to change. There's always going to be somewhere that people think will give them a nicer life. A lot of people are leaving and just joining an agency and working the hours they want to work, when they want to work, and getting more money for it" **Commissioner**

Theme 5: Early Intervention

Whilst the case for early intervention is supported by national frameworks [35, 36, 37] and is was well-known amongst therapists and commissioners, the benefits are often accrued in the long run. It is often harder to protect these services, when there are more immediate funding pressures:

"The impact of early intervention is accumulative and can be unseen initially. We need to argue for different service delivery models in the NHS, with some evidence to back it up" **Therapist**

The lack of resource for preventive work and early intervention services, is leading to further escalation of children's needs and increasing pressure on other parts of the system:

"We had to increase the age limit for referrals into the service. Children aged three years and up can be referred. So that was really difficult for our health visiting teams, because it didn't really fit with how they were working, in terms of that two year check, which was often the point at which they would make a referral to us" **Therapist**

This in itself is a vicious cycle. There is a lack of investment in early intervention to prevent acute need from developing in the first place, but if community services are being delivered at the right place, and at the right time, more care can be shifted out of the hospitals and into the community:

"What the NHS does need to do is not minimise demand, because if you turn everybody away, they'll only come back much worse later on. So it's about how you make sure that children are accessing your services at the right time. And I think we probably know that in most cases, that's about early intervention. One of the things to think about is when you've got long waiting lists, that reduces your capacity to be able to respond at the right time" **Head of therapy**

A parent also commented on the waiting list and the impact this has on early intervention:

"Waiting for a year to two years is a very long time, and a lot happens in terms of children's development during that time. I've come to appointments and I am just thinking, I can't remember what the original referral was for! The needs have changed…" **Parent**

Public services are caught in a cycle of increasing demand and late intervention when it comes to addressing children's needs [38] and this leads to an exacerbation of developmental problems which continue to manifest across the life course, with children and families often reaching crisis point before being able to access early help and support:

> ***"I had to get our MP involved when my son was suicidal"*** **Parent**

> ***"Now that my son has had an accident and the worst Crisis happens, then they come!"*** **Parent**

There is also a misconception that early intervention is for certain cohorts of children, and not for others. And yet, it is evident that the positive impact of early intervention is widespread, and can produce meaningful outcomes for children and their families, regardless of their developmental trajectory. We spoke to Physiotherapists and Occupational Therapists working in children's hospices, who gave examples of how early identification of a life limiting condition enabled them to provide early support, so that young people could be discharged from hospital to be with their families, with the postural equipment and moving and handling facilities that they need to maintain their safety and dignity and receive palliative care in the comfort of their home.

Theme 6: Education

Subthemes in this category include numbers of children in special schools, integration (across health, education and social care), wider workforce and transition.

Therapeutic intervention can often be delivered in the school setting, however, this context is missing from existing rehabilitation guidance which is adult focused:

> ***"It misses out the education context. So obviously a lot of our children and young people will be in an education context. And you know, that would need to be brought into this [rehabilitation guidance]"*** **Therapist**

Special schools are doubling in size & infrastructure, in some boroughs in particular. This is an indicator of the growing numbers of children & young people that are receiving EHCPs and moving out of mainstream school provision. And yet, according to parents, there are not enough special school placements to meet need:

> ***"There are inadequate school places for those with complex needs in […]"*** **Parent**

> ***"Knowing […] and the availability of school places, lots of children with additional needs and so on, may not go to their local school"*** **Parent**

School-based therapists were positively regarded by some parents:

> ***"With the physiotherapy at school, I am very happy with it, because he has a walker and I have a walker at home for him. And he was in his walker today, and they sent a picture of it and I am very happy. He tries to walk one step, two step, three step… so I am really happy with the Physiotherapy in school"*** **Parent**

> ***"My child attends a special school for children with complex needs. She has physio, OT and SALT in school and therapists visit at times. The care is good but…. it is so hard as it's never the same therapist, they are leaving in droves. So we can never build up any relationship with them as parents because it's always someone new"*** **Parent**

Whereas other parents shared negative experiences:

> ***"Two therapists said that my daughter was very difficult to examine and work with because she didn't respond to direction... but she is a child with severe learning disabilities and other conditions and they are working within a special needs environment, so I shocked to hear comments like this"*** **Parent**

Secondly, schools are delivering interventions that have a positive impact on children's health outcomes. As a result, schools can be seen as a lever to improving population health:

> ***"For my son… his best moment is when he is coming to school. I think because, the things he needs, the services he needs, is provided there. He gets the services and resources that he needs. When he gets his needs met, he is calm"*** **Parent**

> ***"He is loving [special school]. At the mainstream, he was like no.. no. But with the [special school], anytime you dress him up, he is ready to come. He is very happy. I don't know what they are doing to him but when I was taking him to the mainstream, he would cry. I know that he doesn't like it himself. But when we moved to [special school], he is very ok!"*** **Parent**

Therapists are also increasingly relying on schools as a key source of information, and identify children's needs as early as possible:

> ***"We get a lot of referrals across the board actually… more primary school age than secondary. And I think that's early identification. Primary schools are quite good at picking up children…. so by the time they get to secondary, they might already be known to the service" Therapist***

> ***"Our Episode of Care Pathways really are dependent on schools and parents requesting a review at appropriate times".*** **Therapist**

"We do encourage the SENCO to refer because we need that richness of information from the school setting, when we are triaging" Therapist

Schools in some areas were considered to have a well-established system for integrated working:

"Multi-agency working is robust, with health, education and social care working together. The Local Authority have recognised that an integrated, trans-disciplinary, multiagency model is required to: 1) enable children with the most complex needs to be safeguarded effectively and stay in their local area and 2) that all school staff need high levels of ongoing training and support to meet the complex needs of our pupils" **School leader**

Whereas other geographical areas reported practical challenges associated with achieving integrated system working:

"In the special schools, there are specific ways of working. The school will say we want you to book this room in advance, and: 'you can't come into the classroom at that time because we've got this activity going on'. So you have to book ahead. But if that child is not in school, you can't book another child, because you haven't booked in advance. These are the sort of barriers to maximising your contact time with children" **Therapist**

"He's in a residential school from Monday to Friday. They are brilliant physically. But education, it's not quite where we need… it's bringing that package together isn't it? We want our child to educationally reach their full potential, and also in a health aspect reach their full potential" **Parent**

There was a tension between how therapists and parents viewed the role of schools and education systems in meeting children's therapeutic needs.

There were differing perspectives across stakeholder groups, with therapists in particular giving examples of how they work with schools as part of the wider workforce:

"A couple of our band 7s, have been working quite hard over the last few years to try to develop some training for mainstream school teaching Assistants, teachers or SENCOs, as well as parents, to explain how and why children with disabilities can…. It's important for them to see how sports can be adapted for them. I think we're doing that really well" Therapist

"In many, many schools, we might be handing over information and programmes and advice. Some of it quite highly skilled to…. to a TA that is working closely with the children" Therapist

This way of working was not always valued by parents and school staff:

> ***"NHS service leaders are living in a "can't do, "won't do" and "we are not commissioned to do that" service led culture, with education staff having to pick up more each year - the child and their family are rarely at the centre of their decisions making"*** **School leader**

> ***"I know they want to be able to go into the school and see the child… but it is a lot easier for parents if they have local appointments"*** **Parent**

> ***"I want proper one to one sessions with a speech therapist, whereas all they have been saying is: I will speak to the teacher and they'll tell the class what to do"*** **Parent**

Commissioners were also aware of the challenges that this way of working presents:

> ***"Generally, it's our special schools that will raise issues of not having a named or dedicated OT to their school, and quite a lot of the challenge that the provider has is actually… if we want to upskill some of the school settings to do some more, that will involve an OT stepping out. And I think been quite challenging for them"*** **Commissioner**

A recent school readiness survey [39] further illustrates the stark contrast in perspectives, with differing views about the role of the school, in equipping children with the pre-requisite and developmental skills needed to learn. For example, 47% of MPs felt that parents are solely responsible for teaching their child to dress themselves, with the remainder saying that the responsibility lies elsewhere, including with schools.

Similarly, when asked who is most responsible for other child development milestones, such as toilet training, 57% of teachers and 54% of MPs said that this was completely the responsibility of the parent, whilst 50% of parents felt that this responsibility lies elsewhere, including with schools.

For almost all skills tested, including developing independence with eating and drinking and dressing, parents assume at least some responsibility sits with schools.

Parents and therapists both reported on the transition to adult services:

> ***"I think because she's 16, you sort of drop off a cliff don't you, when you come to the end of paediatric services. So it is kind of in the back of my mind that we need to get some more input before she's an adult"*** **Parent**

> ***"We start seeing them for transition from 14, so that we are really building on empowering them and making sure they are aware of what the changes will be from the earliest possible stage, and then we would review them at sixth form. So sort of 17-18.. because we need to make sure that everything's….. any needs that are identified at that stage, we actually have time to address them before they [transition]. We can't see them over the age of 19 so."*** **Therapist**

The transition between hospital and community settings was also considered, including the suitability of advice from the acute setting into the education context:

> ***"Somebody who's been in hospital following a road accident, and they've had speech therapy and OT and physio….and they're coming back into the community. That kind of transition I think can be a bit challenging"*** **Therapist**

> **"Sometimes they [the hospital] will say, this is what they need in schools. And you think, oh, are you going to go and do it then? No, no, *you [the community]* have got to go and do it, but there is perhaps a mismatch. And it is vital that their transition into the community goes well" Therapist**

Preparing children for starting secondary school was also reported:

> ***"we've done a session in the past for parents of secondary school, around that transition. And we did get a few parents coming. I think at school age, when it's not a special school or a resource base, it is more challenging to engage parents. I think just because of their work and you know, there's kind of … different pressures that families have"*** **Therapist**

Theme 7: Equipment

Several children are facing delays for assessment and provision of wheelchairs and specialist equipment:

> ***"They [wheelchair services] take ages and so we basically bought one of those slings for our baby. At one point, I had the little one in a front sling, and an oxygen tank on my back. Luckily my baby walked within a year, but you have a few months where you can't physically carry both of them". Parent***

> ***"It's all good giving a piece of equipment. But if that doesn't enable the child to participate in daily activities, it feels like they're probably missing out"*** **Commissioner**

> ***"I spend a lot of time ordering equipment, chasing equipment, and completing lengthy forms. This is time that we could spend with children"*** **Therapist**

> ***"I had a baby when my daughter was small and we were going to a lot of appointments… and I felt like I was always going out with her grandmother, but there was no other option but to take someone… it was so annoying. But part of the problem, and I hear this a lot, is there's no equipment available"*** **Parent**

Parents and therapists also reported challenges home equipment and adaptations:

> ***"Even the windows are unsafe for a child with challenging behaviour. But still they*** **[Social Care Occupational Therapy]** ***give me an appointment for over 8 months'***

time… for a child, where the window is broken, he can jump and he has had an accident. It is only when the MP intervenes, action is taken" **Parent**

"Parents are really struggling in the home, especially overnight, with children who have no safety awareness. It becomes quite dangerous, because they can't be left unsupervised. Sometimes services ask us to provide a bed.. you know, they want to put a child in a "safe space", and I understand what they are saying … but we don't do safe spaces. We have a bed criteria and it is not for these children. Then it's like, well… who out there does help with that?" **Therapist**

"We had to wait a year to get the adaptations… so we spent a year with inadequate facilities" **Parent**

Theme 8: Technology

Digital technology is increasingly being used as a mode of service delivery to reduce community therapy waiting lists, including the use of online (virtual) appointments, online training for parents and schools, telephone consultations and advice lines, and websites to disseminate advice.

Anecdotal evidence of the effectiveness of this mode of service delivery was evident from speaking with stakeholder groups, but this is evidently subjective.

Examples of good practice that were shared include:

- Initial screening assessment

  "The therapist watched a video of the parent with their child, and then they were doing a coaching session. Two localities were offering to take case history by telephone. The locality that wasn't doing that had a higher did not attend (DNA) rate" **Therapist**

- Routine monitoring

  "Other telehealth appointments would be for things like hip surveillance, which we do adhere to within our team to make you less appointments" Therapist

- Obtaining service user feedback

  "We're also trialling sending out a link via text message to evaluate our community paediatric services, and that's been really well received by parents" **Therapist**

- Dysphasia management

  "We have started to request videos of children eating, so that it could be done in their usual chair at home. And you know, prime times for these appointments would be lunchtime, tea time and breakfast, you know, because we want to see them eating. When COVID was here we had a chat about whether we should we

continue our dysphasia service. And we knew that there were other services around us that were pausing theirs, but actually because of that work that we've been doing, we were actually able to carry on. We did still do face to face appointments but that initial screening is via video" **Therapist**

- Delivery of training

"We are looking at how our Occupational Therapy services can be delivered in a different way because previously it wasn't an effective use of our time. So, for instance, each base was providing a sensory workshop and so as a therapist would set the room up and you would deliver that sensory workshop. It was the same presentation each time. So now… that's been recorded and parents go on in their own time to be able to watch that, so it's things like that which have made a big difference. And for the families, because some of them were finding it hard to access on that particular day" **Therapist**

- Engagement of wider workforce

"Sometimes if you are there **[at the school]** ***as a therapist, the staff member could be passive. Whereas if you are on a screen they could … they can't be passive. They've got to be active, because they are the one that is actually facilitating and engaging. So I think there are benefits"***

Challenges that were shared include:

- Managing child and family expectation

"They suggest to me, if it is possible to do online… not a face-to-face appointment. But if you do not see my son, how can you see what he is able to do or not? They should see him more…" **Parent**

- Issues of access creating health inequalities

There are geographical areas within the region that have greater deprivation than others. Families with affluence are able to navigate the system to obtain services, compared to those living in deprivation and from low income households

"It'd be amazing to be able to move communications to platforms such as WhatsApp. It's so much simpler to send a message directly to the person you need rather than trying to go through admin personnel" **Parent**

Whereas others cannot afford to pay for travel to appointments and purchase of technology equipment:

> ***"One of the things that COVID taught us was around IT poverty. So when we started to look at digital therapy delivery, people didn't necessarily have access to the Internet, or didn't have credit on their phones"*** **Therapist**

- Funding of electronic devices for children

> ***"Having enough communication devices to trial for an assessment is a challenge if other team members also require these at the same time. Also having enough affordable devices to trial, because the costs of dedicated devices (e.g. eye gaze devices) is very high, so our budget is stretched very thin and occasionally we are needing to delay some assessments to the next financial year, when budgets can't meet need"*** **Therapist**

Theme 9: Regional variation

Regional variation exists across services, which produces considerable inequity in the access and provision of children's therapy service across geographical catchment areas.

> ***"As a professional observing, it seems there are often inequalities between what therapy support the children receive even with similar difficulties. This could be about the areas they are getting support from or what is available"*** **Portage manager**

Indeed, even within the same ICB catchment area, individual trusts are commissioned to provide different therapy services. This is particularly evident in ICBs that have got multiple provider trusts, serving different place-based areas within the ICB footprint:

> ***"We're reaching a point where we are having to think creatively in how we deliver the service and we were very conscious of little pockets of difference. So in the north for example, they were not able to deliver a school service for such a long time because they haven't had any school therapists… whereas the West and East have been able to deliver it."***
> **Business manager**

> ***"So in two of our localities, the East and the West, if a child has an EHCP, then they're able to access the intervention that's written into their EHCP's, whereas in the North, because the team is so small, we are not able to deliver to the EHCP's in that area. So that area, is assessment only"*** **Therapist**

> ***"In the east, they're probably more advanced in terms of their progress so far. They've got clinics and, you know, parents can self-refer - turn up at a session which they advertise widely. However, in the West, they've got a telephone advice line that parents can use, if they're concerned or they're not quite sure or they're sat on a waiting list, they can go through that route. So it's different models that are currently being trialled"*** **Commissioner**

This inequity and unwanted variation in care evidently leads to unmet need and risk of poor long-term outcomes for children and young people.

Some believe that one of the ways to address inequity of access is to have the same standards and criteria across all services within an ICB, which are written into service specifications:

> ***"I do feel there should actually be National standards of what community therapists should provide. There should be national service specification, so we can't pick and choose, so everyone has to deliver to the same level. So it's not a post code lottery"*** **Commissioner**

However, as mentioned earlier in this report, the need for service specifications to have a specific, versus a broad remit, was frequently debated.

Furthermore, we have established that there is variation in the size of waiting lists and the workforce composition of individual MDT teams, between therapy disciplines, and also between community services. This has been illustrated earlier in this report.

There is also variation in:

- The degree to which health, social care and education collaborate.
- The criteria for accessing and receiving services
- The services received depending on school setting and postcode of residence

5.2 Top priorities for change across stakeholder groups

Overall, the top 6 priorities for change across stakeholder groups are:

1.	Increasing time for direct patient care and delivering well-coordinated early intervention
2.	Recruiting and maintaining a skilled workforce
3.	Demonstrating outcomes and impact of therapeutic interventions
4.	Increased system working between health, education and social care
5.	Funding for both services and equipment provision
6.	Achieving equitable access and provision

6. Limitations

While we had positive and proactive engagement from stakeholders, we cannot be certain that this represents the views of all of those across the network, however, our findings give an indication of the experience of using therapy services and the services available, and the results do triangulate across stakeholder groups.

The South Thames Paediatric Network has a well-established network of district general hospitals which supported our ability to reach across the region. This project has enabled us to engage with the ICS community-based therapy service providers. One of the legacies of this project is that this resource can further support networking and partnering opportunities, across health, education, charitable and private sectors.

7. Recommendations

This project provided the opportunity to collate the feedback from service users, therapy service providers and commissioners across both a wide geography (South Thames Region) and in more detail in two areas within that region.

7.1 System wide recommendations

Recommendation 1:

A national service specification and/or quality indicators for children's therapy-delivered services.

The following actions regionally could support this development

a. Collation of exemplars of good practice nationally to inform future service delivery models
b. Identification of a suitable approach to capacity and demand modelling
c. Ensure that meaningful and comprehensive job plans are in place for AHPs to support therapists and service leads to self-advocate, plan and articulate their service capacity pressures in order to meet demand
d. To support systematic data capture of population level need, to inform the delivery of therapy services and wider paediatric services
e. Interprofessional approach to outcomes capture and evaluation
f. Co-design with children, young people and parents/carers around what good looks like

7.2 Locality and Integrated Care System levels

Recommendation 2:

The opportunity and visibility of Allied Health Professionals, children and young people and their parents/carers in system evolution and design.

The following actions could support this

a. Integrated Care Systems should ensure that AHP leaders and managers are active members of committees, boards and other groups, and demonstrate how they connect and feed into one another. For example, Paediatric AHP representation should be included in the Integrated Care Partnership (ICP), place-based partnerships, and committees of the ICB, with mechanisms in place to achieve this.

b. Ensure there is a paediatric AHP voice in trust and other leadership structures

   e.g. local CYP Transformation Network; local AHP CYP networks including peer networks to support leaders/mentoring/coaching opportunities; engagement with the national AHP CYP network to support collaborations and national learning

c. Opportunities to present, inform and collaborate around systems that capture therapy outcomes and co-design therapy delivery models

d. Using AHP CYP networks as a source of local knowledge to increase retention and recruitment e.g. flexible working, service delivery models that maximise direct clinical time

e. Consider where good practice exists between schools, health, private and charitable sectors in locality, and how these can be rolled out more widely across professions and across the region

f. Consider a standardised service offer for community services within an ICB footprint – to support delivery, evaluation, and commissioning.

Examples of where this have been done are:

The Ready Steady Go roll out (https://www.kentcht.nhs.uk/service/childrens-therapies-2/);

THRIVE model Surrey Heartlands (https://www.surreyheartlands.org/download.cfm?doc=docm93jijm4n1513.pdf&ver=1595); Kessler report recommendations (https://kclpure.kcl.ac.uk/ws/portalfiles/portal/264198403/Kessler_2024_Therapists_for_Children_and_Young_People_with_SEND.pdf)

7.3 Therapy Services

Recommendation 3:

Promotion of therapy services at local, regional and national level:

a. Increase the visibility of good practice through engagement in national and regional networks, presentation at conferences and multiprofessional meetings, and advocate for representation within leadership structures at trust and ICS levels
b. Presentation of locally held, service level intelligence around both service innovations and where inequity is evident e.g. according to diagnosis, presence / absence of EHCP, age, geography
c. Consider how local intelligence of population needs, workforce availability, intervention offers can be collated and made visible to the trust/employing organisation that would supplement currently existing sources of data (for summary of data sources that relate to therapy services for CYP with SEND see the report by Ian Kessler and Annette Boaz [26].

7.3.1 For therapists and other Allied Health Professional groups to:

a. Make connections with the right leaders in their local system, in order to demonstrate evidence of impact and influence the direction of new structures, plans and priorities, including service models and workforce delivery.
b. To understand the role of the local AHP council and AHP faculty within their local integrated care system https://www.england.nhs.uk/publication/allied-health-professionals-within-integrated-care-systems-guidance-for-system-executives-and-senior-leaders/
c. Develop communities of practice which are relevant to local need, which bring colleagues and teams together, and provide fertile ground to share good practice and operational solutions.
d. Work collaboratively with professional and trust therapy leads to report on the effectiveness of various treatment modalities for children, record children's outcomes, and identify where associated cost savings can be made.
e. Consult parents and carers for feedback to inform wider service planning and decision making, so that local provision can better meet the needs of families. Mechanisms to achieve this could

include parent's evenings, parent newsletters and having co-production champions in teams.

7.3.2 For clinical leaders and community therapy service managers to:

a. Partner and engage with the NHS England and Improvement (London region) Babies, Children and Young People (BCYP) Transformation Programme. NHS England — London » London Babies, Children and Young People's Transformation Team

b. To proactively scope out the architecture of the Integrated Care System (ICS) in which they work, in order to influence and increase AHP visibility. Guidance for system executives and senior leaders can be found here: Allied health professionals within integrated care systems (england.nhs.uk)

c. Connect with AHP Councils and Faculties at system and regional level, to act as a driving force for change.

d. Consider economic appraisal of therapeutic interventions at locality, ICS or regional levels to guide commissioners and policy makers on purchasing decisions.

e. Advocate for the prioritisation of children's community services within local integrated care systems, so that there is parity with adult services.

f. Influence policy and decision making (particularly relating to early intervention and prevention) and ensure that children's community therapy services are reflected within strategic priorities and joint forward plans.

g. Work across systems, with education and social care partners to address the needs of children and young people and enable them to live well at home and in the community for as long as possible.

7.4 Service Users

Recommendation 4:

There are examples of opportunities for parents/carers and young people to be supported by each other and statutory services – these could be rolled out more widely with a focus on reaching families who may not yet engage with the established forums.

a. Ensure all nursery, school, children's centres and community child health hubs have forums that offer the opportunity for co-design.

b. These forums should be based on patient need, rather than diagnostic criteria, and should be inclusive of the language, spoken communication preferences and healthcare needs of children and families.

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APPENDIX 1 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Survey (total n=63)				
		Parents	**Allied Health Professionals**	
Total respondents by stakeholder group N (%)		**N=25 (100%)**	**N=38 (100%)**	
Location of respondents N (%)				
SE London		N=10 (40%)	N=5 (13%)	
SW London		N=3 (12%)	N=8 (22%)	
Kent		N=8 (32%)	N=18 (46%)	
Surrey		N=1 (4%)	N=6 (16%)	
Sussex		N=3 (12%)	N=1 (3%)	
Respondents by profession N (%)				
Physiotherapist			N=20 (53%)	
Occupational Therapist			N=10 (26%)	
Speech and Language Therapist			N=6 (16%)	
Other			N=2 (5%)	
Work setting N=number of times mentioned *NB: Some respondents work in more than 1 setting*				
Acute			N=4 (9%)	
Community			N=30 (65%)	
Schools			N=10 (22%)	
Other			N=2 (4%)	
Age in years				
51 and over			N=10 (26%)	
46 - 50			N=6 (16%)	
41 – 45			N=9 (24%)	

36 - 40			N=3 (8%)	
31 - 35			N=6 (16%)	
26 - 30			N=4 (10%)	
Gender				
Female			37 (97%)	
Male			1 (3%)	
Respondents by first Language				
English		N=24 (92%)		
Portuguese		N=1 (4%)		
Other (not listed)		N=1 (4%)		
Respondents by Ethnicity				
White British		N=21 (84%)	N=20 (53%)	
White other		N=0	N=7 (18%)	
Asian/Asian British		N=2 (8%)	N=0	
Mixed/Multiple Ethnic Groups		N=2 (8%)	N=0	
Chinese		N=0	N=2 (5%)	
Prefer not to say		N=0	N=9 (24%)	
Interviews (total n=24)				
	Children and young people	**Parents**	**Providers**	**Commissioners**
Total interviews by stakeholder group N =	**N = 6**	**N = 4**	**N = 10**	**N=4**
Total interviews by location N (%)				
SE London	**N=6 (100%)**	**N=3 (75%)**	**N=5 (50%)**	**N=1 (25%)**
SW London				**N=1 (25%)**
Kent & Medway		**N=1 (25%)**	**N=5 (50%)**	
Surrey				**N=1 (25%)**
Sussex				**N=1 (25%)**
Focus group (total n=3)				
	Children and young people	**Parents**	**Providers**	**Commissioners**
		N = 13		**N = 5**

APPENDIX 2 LIST OF KEY STAKEHOLDERS

A	ASSOCIATION OF YOUNG PEOPLE'S HEALTH
B	
C	COUNCIL FOR DISABLED CHILDREN CHARTERED SOCIETY OF PHYSIOTHERAPISTS
D	DEMELZA DEPARTMENT OF EDUCATION DEPARTMENT OF HEALTH
E	
F	FLARE CHILDRENS ADVISORY GROUP
G	
H	
I	INSTITUTE OF WOMEN AND CHILD'S HEALTH
J	
K	KINGS COLLEGE LONDON KENT AND MEDWAY ICB
L	
M	
N	NHS ENGLAND NHS BENCHMARKING
O	
P	
Q	
R	ROYAL COLLEGE OF OCCUPATIONAL THERAPY ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPY
S	SOUTH EAST LONDON ICB SOUTH WEST LONDON ICB SURREY HEARTLANDS ICB SUSSEX ICB
T	TOGETHER FOR SHORT LIVES

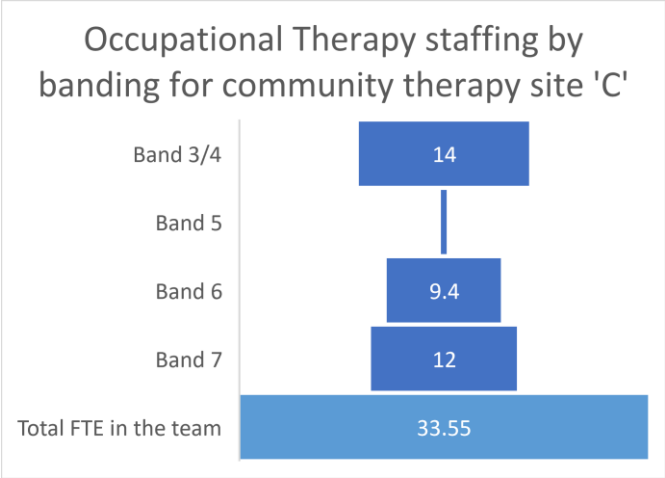
APPENDIX 3 EXTRAPOLATED SEN DATA

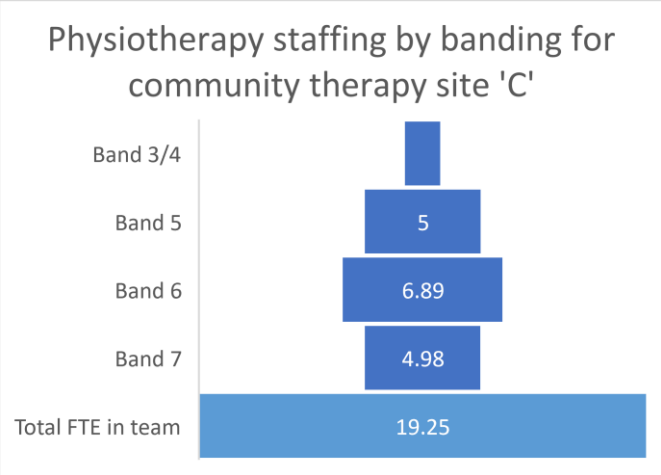
Numbers of pupils with SEN support needs and EHC Plans in England, and within the South Thames region between 2021/22 and 2022/23

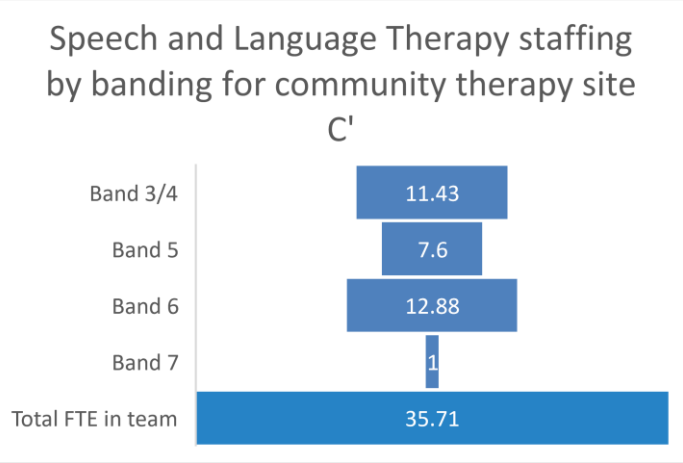
			No. with EHC plan 2021/22	%	No. with EHC plan 2022/23	%	Trend	No. with SEN support (without an EHC plan) 2021/22	%	No. with SEN support (without an EHC plan) 2022/23	%	Trend	Total no. of CYP with EHC & SEN Support (Combined) 2021/22	Total no. of CYP with EHC & SEN Support (Combined) 2022/23	Trend overall
England			355,566	4.0	389,171	4.3	up	1,129,843	12.6	1,183,384	13.0	up	9,000,031	9,073,832	Up
South Thames Region	South East London ICB	Bexley	1,686	3.8	1,877	4.2	up by 0.4%	4,635	10.4	4,722	10.6		44,603	44,399	Down
		Bromley	2,534	4.3	2,694	4.6	up	6,830	11.7	7,365	12.6	up by 0.9%	58,419	58,449	Up
		Lambeth	2,154	5.5	2,212	5.7	up	5,396	13.8	5,391	13.9		39,193	38,712	Down
		Southwark	1,961	4.0	2,095	4.3	up	7,461	15.2	7,123	14.5	down by 0.7%	49,167	48,992	Down
		Greenwich	1,897	3.9	2,085	4.3	up by 0.4%	7,024	14.5	7,581	15.5		48,354	48,780	Up
		Lewisham	1,895	4.6	2,020	5.0	up	5,929	14.5	5,955	14.8		40,820	40,371	Down
	South West London ICB	Merton	1,657	5.1	1,869	5.7	up by 0.6%	4,241	13.0	4,418	13.5		32,569	32,742	Up
		Richmond	1,189	3.0	1,269	3.2	up	4,594	11.8	4,353	11.0		39,051	39,540	Up
		Croydon	2,604	4.0	2,811	4.3	up	8,562	13.1	8,941	13.6		65,368	65,890	Up
		Sutton	1,640	3.9	1,809	4.2	up	3,837	9.0	4,112	9.6		42,450	42,971	Up
		Kingston	1,244	4.0	1,356	4.3	up	3,115	9.9	3,551	11.3		31,351	31,512	Up
		Wandsworth	2,435	5.6	2,539	5.9	up	5,794	13.2	6,004	13.9		43,770	43,292	Down
	Sussex ICB	Brighton and Hove	1,431	4.0	1,524	4.3	up	5,346	14.9	5,618	15.7		35,930	35,699	Down
		West Sussex	4,969	3.8	5,360	4.1	up	18,953	14.7	19,914	15.2		129,075	130,867	Up
		East Sussex	2,869	3.9	3,095	4.1	up	9,787	13.2	10,259	13.7		74,252	74,778	Up
	Kent and Medway ICB	Kent	12,698	4.8	14,143	5.2	up by 0.4%	29,944	11.3	30,778	11.4		265,806	269,791	Up
		Medway	2,114	4.2	2,196	4.3	up	6,698	13.2	6,879	13.4		50,672	51,431	Up
	Surrey Heartlands ICB	Surrey	9,247	4.6	9,786	4.8	up	26,259	13.0	28,348	13.8		201,993	204,800	Up

APPENDIX 4 EXAMPLES OF WORKFORCE COMPOSITION ACCORDING TO FULL TIME EQUIVALENT (FTE) HOURS

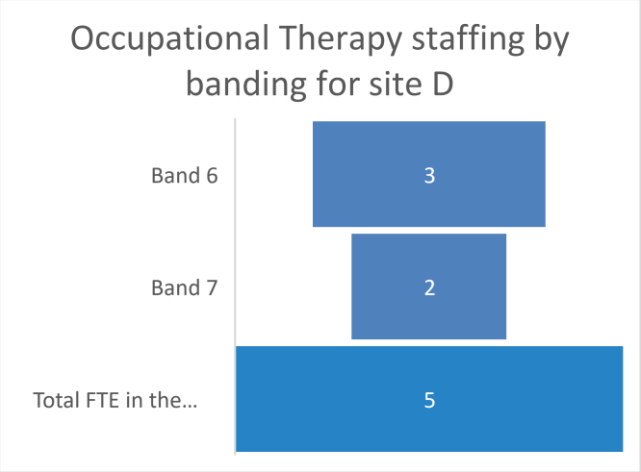
Site C

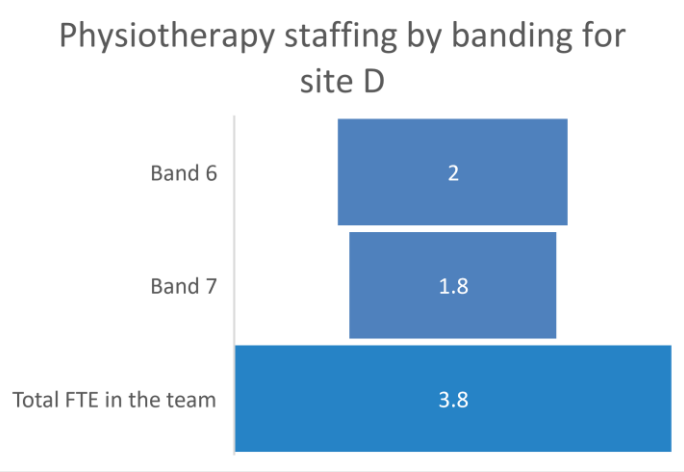


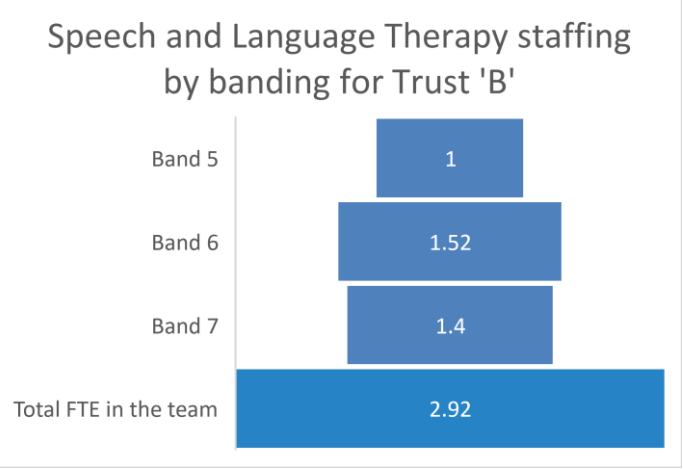


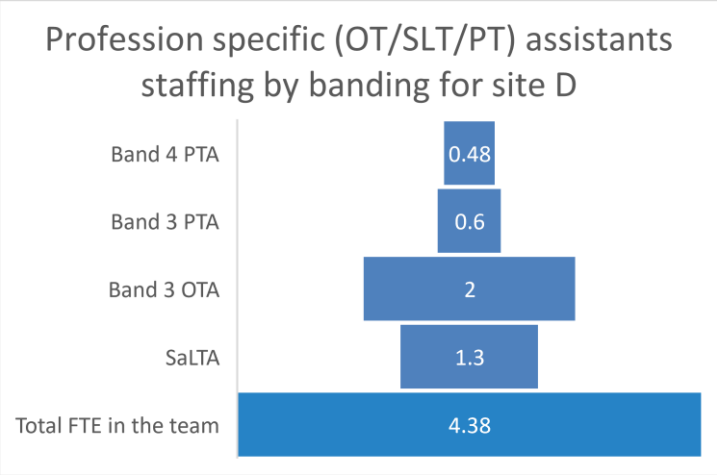


Site D

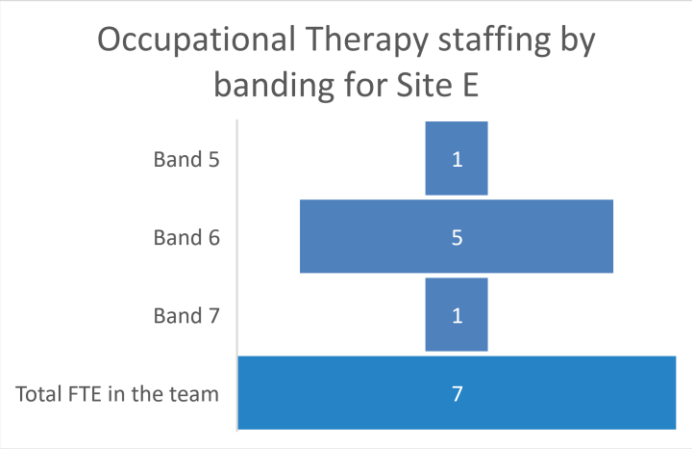


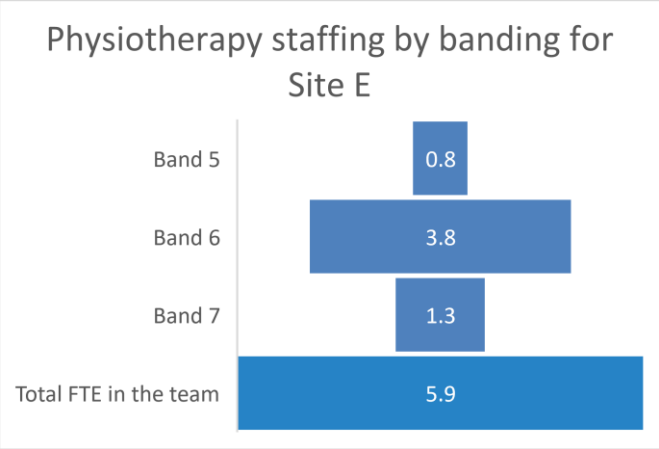


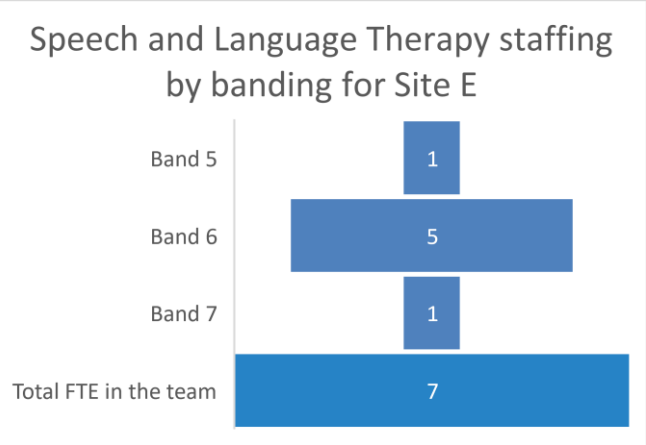



Profession specific (OT/SLT/PT) assistants staffing by banding for site D
Band 4 PTA
0.48
Band 3 PTA
0.6
Band 3 OTA
2
SaLTA
1.3
Total FTE in the team
4.38

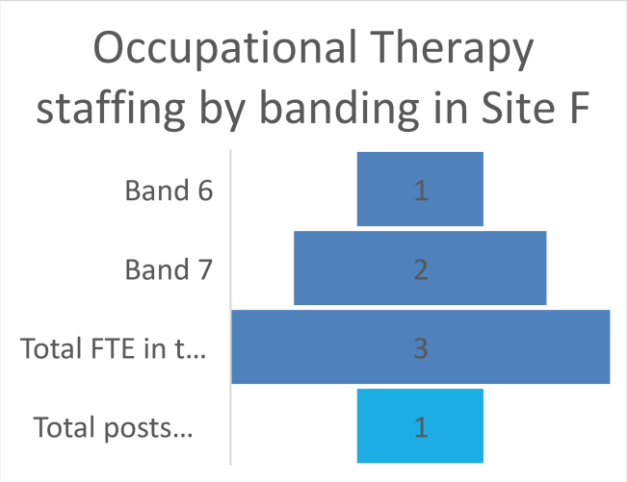
Site E

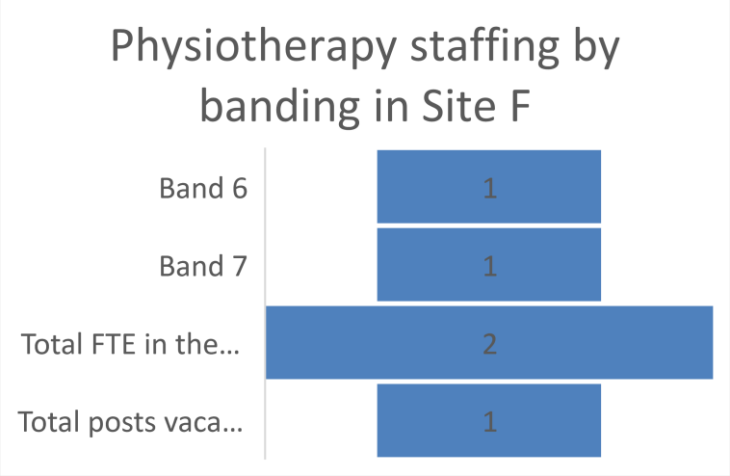

Occupational Therapy staffing by banding for Site E
Band 5
1
Band 6
5
Band 7
1
Total FTE in the team
7

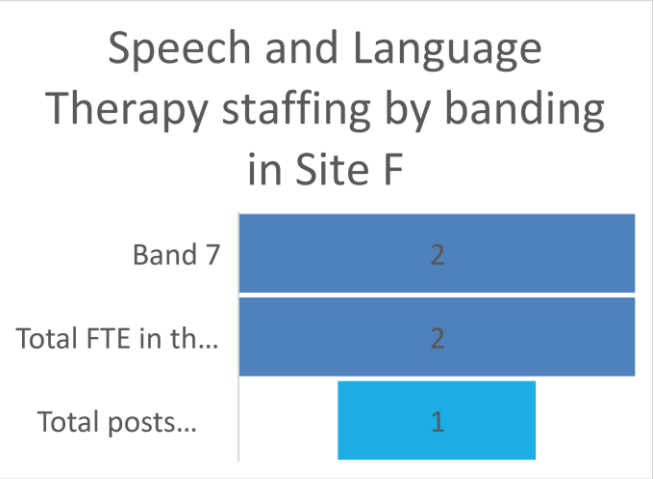

Physiotherapy staffing by banding for Site E
Band 5
0.8
Band 6
3.8
Band 7
1.3
Total FTE in the team
5.9


Speech and Language Therapy staffing by banding for Site E
Band 5
1
Band 6
5
Band 7
1
Total FTE in the team
7

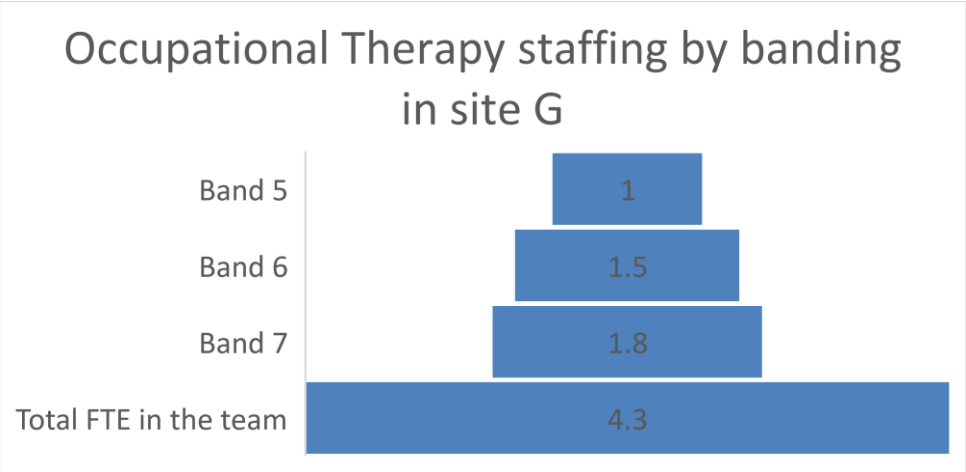
Site F

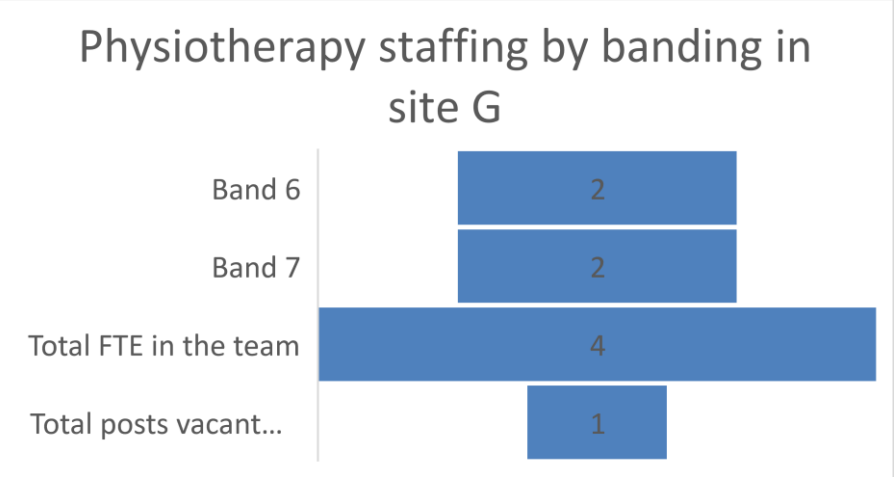

Occupational Therapy staffing by banding in Site F
Band 6
Band 7
Total FTE in t...
Total posts...
1
2
3
1


Physiotherapy staffing by banding in Site F
Band 6
Band 7
Total FTE in the...
Total posts vaca...
1
1
2
1

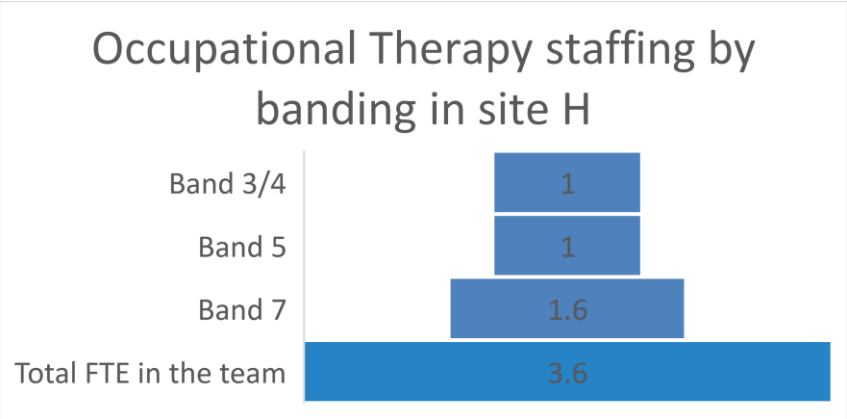

Speech and Language Therapy staffing by banding in Site F
Band 7
Total FTE in th...
Total posts...
2
2
1

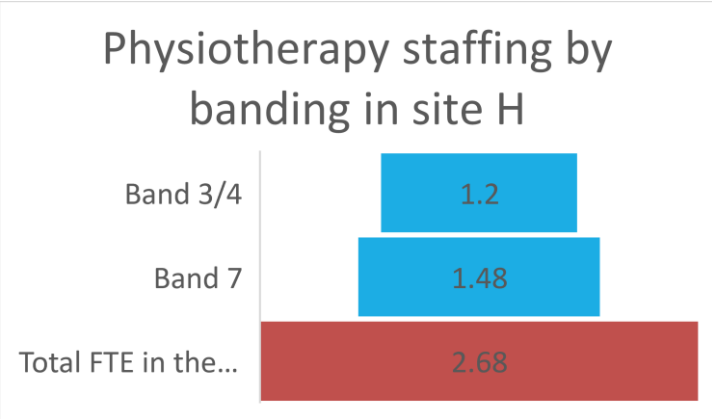
Site G

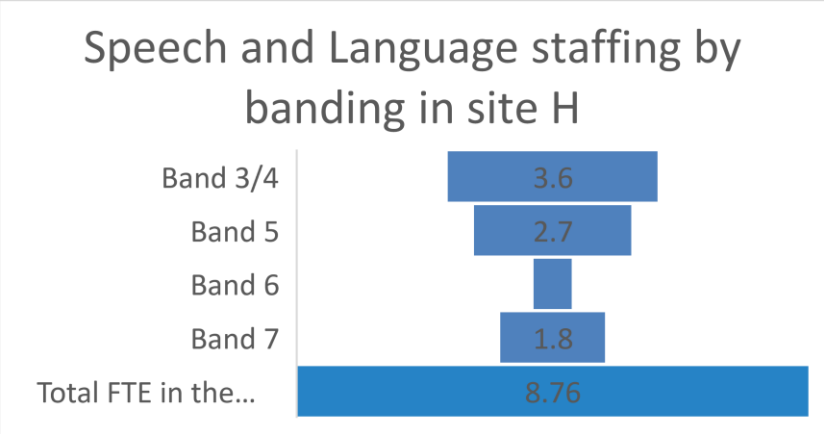

Occupational Therapy staffing by banding in site G
Band 5
Band 6
Band 7
Total FTE in the team
1
1.5
1.8
4.3


Physiotherapy staffing by banding in site G
Band 6
Band 7
Total FTE in the team
Total posts vacant...
2
2
4
1

Site H


Occupational Therapy staffing by banding in site H
Band 3/4
Band 5
Band 7
Total FTE in the team
1
1
1.6
3.6


Physiotherapy staffing by banding in site H
Band 3/4
Band 7
Total FTE in the...
1.2
1.48
2.68


Speech and Language staffing by banding in site H
Band 3/4
Band 5
Band 6
Band 7
Total FTE in the...
3.6
2.7
1.8
8.76

Appendix 5: CYP case examples

Parents, teachers and school staff supplied the project team with information about each child's communication methods. They supplemented the information that was gathered from young people, in order to further evidence the support that they needed, and what was available to meet their needs. This included explaining the unique, observable indicators that each of the children show, to express enjoyment and to communicate that they would like an activity to be stopped.

1. Judith* (*Pseudonym)

Age	Gender	Diagnosis Y/N	Condition / Needs	EHCP Y/N	School setting	Domains of complex need
7yrs	F	Y	Evolving Motor Disorder & Significant Visual Impairment PMLD Wheelchair user Complex communication needs & using high tech AAC	Y	Special school	PD SEN SLCN

Judith is a wheelchair user with a four limb movement disorder. She has profound and multiple learning difficulties and a significant visual impairment. She communicates non-verbally. She uses a symbol grid that plays an audio description of each option before she makes her selection. She turns her head to the right to press a switch, which starts the auditory scanning of the symbols on the grid. She turns her head a second time to press the switch again to confirm her selection.

Judith demonstrated observable indicators of distress when she arrived into the room. She cried, closed her eyes, grimaced and turned towards the door. Judith was asked to tell the therapist what was wrong.

Judith showed intentional and purposeful movement to press the switch and select the option 'I want to leave'. The therapist asked her what she would like to do instead. Judith selected the option 'I want to come out of my chair'. Her keyworker confirmed that she had understood Judith's request, and asked if she would like to lie down on the mat. Judith smiled and vocalised. Her keyworker confirmed that this is an observable indicator that can be interpreted to mean 'yes'. Judith was asked what ele she liked. Using her switch, she selected 'sleeping' on her communication grid and voalised with a big smile.

2. Alex* (*Pseudonym)

Age	Gender	Diagnosis Y/N	Condition / Needs	EHCP Y/N	School setting	Domains of complex need
	M	Y	Genetic disorder (Chromosome deletion) & Visual Impairment PMLD Wheelchair user Learning to use cane Mix of AAC (symbols) & 1-2 words	Y	Special school	PD SEN SLCN

Alex has a profound and multiple learning disability. He has a visual impairent and uses a wheelchair for long distances. He is able to mobilise with the assistance of one person and is learning to use a cane to explore his environment and navigate his surroundings. Alex can use 1-2 spoken words at a time and communicates using tactile symbols that can be recognised by touch. He was able to communicate his likes and dislikes using tactile symbols on a communication board. Alex likes music and indicated this by finding the corresponding tactile symbol on the board. He confirmed the reliability of his choice by humming the tune of his favourite song and rocking in his seat. When asked what helps him to move around the school, Alex searched around his wheelchair and retrieved his cane. Alex communicated that he did not like swimming and hydrotherapy.

3. Thomas (*Psedonym)

Age	Gender	Diagnosis Y/N	Condition / Needs	EHCP Y/N	School setting	Domains of complex need
4yrs	M	Y	Global developmental delay Mix of AAC (symbols) & 1-2 words	Y	Special school	SEN SLCN

Thomas is independently mobile. He has global developmental delay and communicates using a mixture of single spoken words and phrases, gesture, and a combination of objects of reference and symbols in a communication book. Thomas pointed to a symbol to indicate that he was feeling sad, and then pointed to a picture of the swimming pool. He then pointed out of the room to where the hydrotherapy pool was located. His teacher asked him 'are you feeling sad because the hydrotherapy pool is closed'? and Thomas nodded. He pointed to the 'like' symbol and then to the symbol of the pool. His teacher said 'Thomas likes the pool' and Thomas smiled and nodded. Thomas used makaton signs to communicate when he wanted 'more', and gestured to adults by pointing, when he wanted the same question to be answered by them. Thomas was shown how to use the talking mat communication tool. Using the talking mat, Thomas communicated that he did not like having personal care. He recognised the photographs of his therapists and positioned them on the talking mat to indicate that they make him happy.

4. Jade* (*Pseudonym)

Age	**Gender**	**Diagnosis Y/N**	**Condition / Needs**	**EHCP Y/N**	**School setting**	**Domains of complex need**
8yrs	F	Y	Visual Impairment PMLD	Y	Special school	PD SEN SLCN

Jade is independently mobile with a mild visual impairment and profound and multiple learning difficulties. She communicates using body language, gesture, and a mixture of objects of reference and symbols. Jade was shown how to use the talking mat communication tool. Using the talking mat, she communicated that she liked sleeping, she did not like brushing her teeth and she was not sure whether or not she liked swimming and hydrotherapy. Jade's keyworker asked her some more specific questions about her food and play preferences. She made eye contact whilst flapping her arms to indicate when she liked something, and shook her head and looked away when asked about thing she did not like. In this way, Jade communicated with her keyworker that she liked cars, peppa pig and she did not like fish fingers.

Appendix 6: Illustrative quotes from two deep dive sites

Site A		
Topic	Illustrative quotes	Summary
Delays to social care interventions • Respite / carer support • Equipment • Housing	"It takes a long time to actually get someone [social care OT] out" Young person "It is difficult to increase care support at home. We never have any respite" Parent *"He has Autism and challenging behaviour. He is very hyper.… we are living on the second floor of a high rise building. He goes to the balcony and he is not aware of danger. One time he jumped. Luckily there is a net … but he was just there. Even though he is unsafe, he can't speak. He can't shout. His mum was in the kitchen. She didn't know he was down there."* **Parent** *"Even the window is unsafe for a child with challenging behaviour. They gave me an appointment for over 8 months, for a child where the window is broken"* **Parent**	Prominent theme amongst parents and exacerbated by socioeconomic status such as deprivation and safety at home
Transferability of therapy to the home setting	"Everything is going from better to worse, because all the therapies the school gave me I'm not able to apply. Why? My home is not conducive for him. It is enclosed. It is not safe" Parent "not all the children are the same. They did not work with my son. That kind of therapy, what they showed me in that session, it didn't work with him." **Parent**	Prominent theme amongst parents
Transition to adulthood	*"I think because she's 16, you sort of drop off a cliff don't you, when you come to the end of paediatric services. So it is kind of in the back of my mind that we need to get some more input before she's an adult"* **Parent** *"We start seeing them for transition from 14, so that we are really building on empowering them and making sure they are aware of what the changes will be from the earliest possible stage, and then we would review them at sixth form. So sort of 17-18.. because we need to make sure that everything's….. any needs that are identified at that stage, we actually have time to address them before they [transition]. We can't see them over the age of 19 so."* **Therapist** "So in speech and language therapy for example, we have a member of staff who specifically has a transition role. They work across children's and adult speech and language therapy services" **Therapist**	Same theme, different perspectives across stakeholder groups

	"We have very, very close links with the physio from the adult with learning disability team. He's also been around for many years and, so I think that sort of stability sometimes helps with coordinating things" **Therapist**	
Waiting lists	"They took a long time" Young person "The therapies are a brilliant service, they really are. But the waiting is a joke" Parent *"when you've got long waits, that reduces your capacity to be able to respond at the right time"* Therapist "I think the key priority at the moment is about making sure that we're getting waits down. So that children, particularly, get the benefits of early intervention" Deputy general service manager "So the waits for that can be… you know, fairly substantial. What you tend to find is that families may opt for private therapy support or the local authority itself can actually buy in separate, kind of, private therapy support as well, where we can't meet that need, which… isn't ideal, but it's…. it's kind of a stopgap and at least young people are getting something" Commissioner	Consensus amongst all stakeholder groups
Technology • Lack of digital infrastructure for recording outcomes	"We are not able to fully utilise the capabilities of our electronic systems to help report on and develop the service using data" Therapist "One of the key things we tried to implement was the Therapy Outcome Measures (TOMS). And I think the local trust have had real issues implementing an IT system to be able to do that. It's been on our To Do List since I started in 2018. So we want to try and develop that system much better, so we can more accurately identify positive therapy outcomes. Not just for the individual, but for the service, to understand what actually is more effective and what works" Commissioner	Prominent theme from therapists and commissioner
Site B		
Topic	Illustrative quotes	Summary
Time for direct, face to face therapy vs. telehealth	"My child has never received any direct therapy. It has always been with a parent and then signed off. My son has never hit the quota to receive any therapy, which is awful to be quite frank" Parent "We have certainly moved away from those initial face to face appointments and families are very much signposted to the stuff on the website as a first instance" Therapist "For some children, it works better virtually and they can't tolerate face to face appointments" Therapist	Parents and therapists have different perspectives on the universal service offer and the move towards

		delivering services online.
Diagnosis	“The school are saying they can't do this, because they haven't got diagnosis. It is still going on” Parent “There are long waiting lists for diagnostic assessments. Later diagnosis means less opportunities are open to these children. No diagnosis means less therapeutic support” Therapist “The diagnosis doesn't make a difference to us in terms of what we deliver because it's based on the need and their presentation” Therapist “There wouldn't be an exclusion criterion based on diagnosis within the service specification” Commissioner	There were differences of opinion within and between stakeholder groups, about whether or not a diagnosis influences the service a child receives.
Increase in statutory demand	“In […], the numbers of EHCP requests is a big outlier compared to the national picture. Particularly in terms of parental requests for EHCP assessment” Head of therapy “There is no hiding from the fact that there are children that will only receive provision because they have an EHCP” Designated Clinical Officer	It is unclear whether or not parents from the local area agree with these views.
Waiting lists	If something is wrong you have to wait for a month to been seen” Parent “waiting times were getting longer and longer and children were waiting for intervention and it just wasn't suiting the families because they weren't getting what they needed. And it also wasn't working for the service, because we weren't meeting that need as well as we wanted to be”. Head of therapy “Instead of having children on waiting lists waiting for something but not receiving something, they're receiving a much smaller offer but they were able to receive things more regularly”. Therapist “In […], they've got a telephone advice line that parents can, you know, if they're concerned or they're not quite sure or they're sat on a waiting list, they can go through that route”. Commissioner	Consensus across all stakeholder groups