



**Community**  
NETWORK

# Community Network survey

**on waiting times in children  
and young people's services**





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## on waiting times in children and young people's services

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## Introduction

Community health providers deliver essential services for children and young people, including community paediatrics, autism spectrum disorder diagnostics, health visiting, and speech and language therapy. Alongside support from education and social care, these services are critical in enabling children and young people to live well and to develop and fulfil their potential.

The COVID-19 pandemic caused huge disruption across society with well documented and significant **impacts on a generation of children and young people**. The pandemic has exacerbated backlogs of care and demand for children and young people's community services.

We carried out this survey of 65 community provider leaders between 15 March and 21 April 2023 looking at waiting times in children and young people's services.

Since we initiated this survey, NHS England (NHSE) has helpfully begun to publish regular data on community waiting lists including for children and young people's community services. The figures show that whilst the number of adults waiting for community services has increased by 3.2 per cent since October 2022, wait lists for children and young people's services have increased by 10.2 per cent over the same period to 227,490. It is also deeply concerning that 6 per cent of children and young people on community waiting lists (13,670 people) have been waiting for over 52 weeks.

NHSE's data echoes our survey findings which show that, despite the best efforts of community providers, there are still concerning waits for children and young people's services with significant impacts for children and families, and for staff morale. Although this survey is focused on waiting times for community services, it is worth noting that demand and waits for children and adolescent mental health services have also **increased significantly** since the pandemic, as has pressure on acute, specialist paediatric beds.

Without recognition of these challenges and nationally co-ordinated action children in need of support risk slipping through the net.

# 1 Key findings

- 1 All respondents (100 per cent) were either moderately (23 per cent) or extremely (77 per cent) concerned about the impact of long waits for community children and young people's services.
- 2 Almost three quarters (72 per cent) of respondents were extremely concerned about the impact of long waits for community children and young people's services on staff morale.
- 3 Almost nine in ten respondents (88 per cent) reported that current waiting times for children and young people to access initial assessment and treatment for community services have increased either significantly (48 per cent) or moderately (39 per cent) compared to pre-pandemic figures. For example, on average, respondents estimated a waiting time of 40 weeks for an initial assessment of a neurodevelopmental pathway and a waiting time of a further 32 weeks for treatment.
- 4 The most common consequence of long waits for community services on children and young people highlighted by respondents were delays in social development, education and communication.
- 5 Respondents also described long waits exacerbating health inequalities with a disproportionate impact on vulnerable communities.
- 6 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) and simplified commissioning and contracting structures for children and young people (39 per cent).
- 7 Community providers valued the role of partnerships within integrated care systems (ICSs) in reducing waiting times for children and young people's community service.

# 2 Solutions

Community providers remain committed to reducing long waits for children and young people and understand the consequences of delays in diagnosis, treatment and support. However, despite their best efforts, our survey, and NHSE's data, demonstrate the persistence of these long and unacceptable waits. Leaders from across the community healthcare sector would value the following support to enable them to make a difference in waiting times locally:

## Government funding and national prioritisation

66 per cent of respondents highlighted the value of greater investment in prevention and early intervention for children and young people. This is particularly important for this group of patients given the disproportionate impact of a delay on an individual's educational and social development.

58 per cent of respondents believe that access to additional government funding would ensure children and young people's community services were given due priority within national and local policy frameworks and enable providers to reduce the length of waiting times by, for example, scaling up and expanding innovative work. Leaders in community providers are also supportive of NHSE's commitment to develop more timely and transparent national data on backlogs of care in the sector.

"Needs same priority and focus as adults services and as acute services; need to support coordination across system partners"

"There is currently a great deal of focus on emergency care services and we (as a system) need to ensure that children's service are given the same focus and prioritisation as adult services and funded appropriately."

## A fully funded and costed NHS long term workforce plan

Over 97 per cent of respondents were moderately to severely concerned about the impact of long waits on staff morale. Highly skilled and specialist staff deliver children and young people's community services. More support is needed to ensure there is a pipeline of the right number and skills mix of these staff to keep pace with rising demand.

"Community services are working hard with clinicians and commissioners to understand local issues and try to address them. The workforce is tired but committed. Investment and support in workforce supply and development are crucial!"

"Funding for training programmes to support training and salary to train people in local community to develop skills."

# 2

## **A shared national vision and cross-departmental strategy to support children and young people's services, overseen by a lead minister. Less fragmented policymaking and commissioning for children and young people**

Pressures on wider public services such as schools, public health and social care mean that children are increasingly presenting in the health system due to a lack of alternative support. 66 per cent of respondents believe the increased investment in early intervention and prevention services would support the reduction in waiting times for children and young people's community services. We would therefore urge the government to consider a national strategy for children and young people that would ensure a range of services are responsive to children and young people's needs.

Many respondents also told us that commissioning and contracting for children and young people's services is often fragmented and complex, with potential for much better co-ordination across government departments and agencies. Partnerships between the NHS, education and social care remain particularly critical.

Community provider leaders also see an important role for their own roles as co-leaders of systems and for ICS colleagues in supporting local partnerships and local workforce development to ensure staff have the right mix and level of skills to support children in different settings.

"Supporting with workforce challenges by helping to find different ways of addressing issues as a system rather than relying solely on health to find solutions."

"The thinking needs to be on a par with adult services and the profile needs to be raised to enable this to happen. We need national joined-up thinking with education. Much of the work can be done in schools however they are under pressure too and this is not about pass the parcel but about a joint collective effort across the country."

"Improve commissioning of these services, recognise the increased demand, prioritise additional funding for these areas, review local offer and work with providers to maximise the use of resources in place. Act in a supportive and facilitative way and not as a commissioner."

"A joined-up approach across education, health, CAMHS and social care: early intervention for behaviour, sleep, toileting should be prioritised."

# 3

## About this survey

The Community Network is the national voice of NHS community providers. Hosted by the NHS Confederation and NHS Providers, we support trusts and not-for-profit organisations providing NHS community health services to deliver high-quality care by influencing national policy, sharing good practice and promoting a vision of integrated care in the community.

- 67 leaders from trusts and community interest companies responded to the survey. The responses were from 53 unique trusts, accounting for 62 per cent of the sector that provide community services. A further 7 community interest companies responded to the survey.
- All regions were represented in the responses.

**Figure 1**

Trust types

Trust type	Count	per cent
Acute specialist trust	1	1 per cent
Acute trust	9	13 per cent
Combined acute and community trust	16	24 per cent
Combined mental health/learning disability and community trust	16	24 per cent
Community trust	14	21 per cent
Mental health/learning disability trust	4	6 per cent
N/A	7	10 per cent
Grand total	67	100 per cent



# 3

**Figure 2**  
Regions

Region	Count	per cent
East of England	8	12 per cent
London	6	9 per cent
Midlands	17	25 per cent
North East and Yorkshire	9	13 per cent
North West	11	16 per cent
South East	6	9 per cent
South West	3	4 per cent
N/A	7	10 per cent
Grand total	67	100 per cent

**Figure 3**  
Job roles

Role	Count	per cent
Chair	3	4 per cent
Chief executive officer	1	1 per cent
Chief operating officer	15	22 per cent
Financial director	1	1 per cent
Medical director	6	9 per cent
Strategy director	2	3 per cent
N/A	7	10 per cent
Other (including associate director, head of children's services, general manager, chief of staff, performance and access manager)	32	48 per cent
Grand total	67	100 per cent

# 4

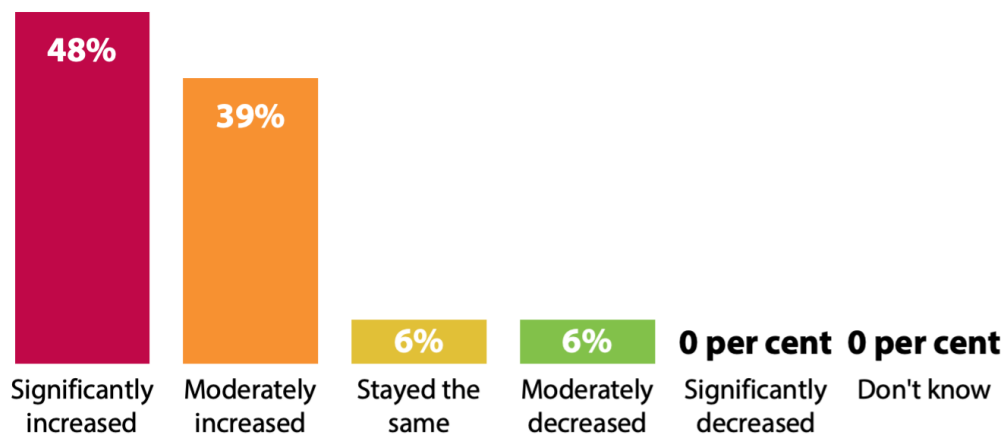
## Survey results

**Compared to pre-pandemic figures, current waiting times for children and young people to access initial assessment and treatment for community services provided by your organisation have:**

**Figure 4**

**Current waiting times for children and young people to access initial assessment and treatment for community services compared to pre-pandemic**

(n = 66)



- Almost nine in ten respondents (88 per cent) reported that current waiting times for children and young people (CYP) to access initial assessment and treatment for community services have increased significantly (48 per cent) or moderately (39 per cent) compared to pre-pandemic figures. Just 6 per cent said that they have either stayed the same or moderately decreased.

**Please could you provide an estimate (in weeks) of the average waiting time for an initial assessment in the following community children and young people's services (if you do not provide any of the services listed below, or if you do not know, then please leave the box blank):**

**Figure 5**

Estimated average waiting time (weeks) for an initial assessment in the following community children and young people's services

Community children and young people's service	Average	Minimum	Maximum
Neuro-developmental pathways	40.3	0	104
Community paediatrics	33.1	5	104
Speech and language therapy	20.2	2	51
Occupational therapy	19.7	3	104

# 4

Physiotherapy	13.7	2	51
Audiology	11.8	2	30
Child and adolescent mental health services	10.3	4	25
Mental health school teams	3.4	0	8
School nursing	3.3	0	13

- When asked to provide an estimate in weeks for the average waiting time for an initial assessment in various community children and young people’s service, neuro-developmental pathways were estimated to have the longest waiting time, with responses averaging 40.3 weeks. This service also had the largest range in estimated waiting time; with respondents estimating between 0 weeks and 104. Community paediatrics was the service with the second longest estimated average waiting time at 33.1 weeks, also with a large range between 5 and 104 weeks.
- The services with the shortest estimated average waiting times were mental health school teams (3.4 weeks) and school nursing (3.3 weeks). These services also had the shortest maximum waiting time and smallest range (0-8 weeks for mental health school teams; 0-13 weeks for school nursing).

**Please could you provide an estimate (in weeks) of the average waiting time for treatment after an initial assessment in the following community children and young people’s services (if you do not provide any of the services listed below, or if you do not know, then please leave the box blank):**

**Figure 6**

Estimated average waiting time (weeks) for treatment after an initial assessment in the following community children and young people’s services

Community children and young people’s service	Average	Minimum	Maximum
Neuro-developmental pathways	32.4	0	104
Community paediatrics	22.7	0	60
Child and adolescent mental health services	20	4	80
Speech and language therapy	16.4	0	76
Occupational therapy	14.7	0	104
Audiology	11.7	0	26
Physiotherapy	7.9	0	23
School nursing	3.4	0	13
Mental health school teams	3.4	0	10

# 4

- Respondents were also asked to provide an estimate in weeks of the average waiting time for treatment after an initial assessment for the same community and young people's services. Neuro-developmental pathways had the longest estimated average waiting time at 32.4 weeks. This service also had the largest range with estimates between 0 to 104 weeks. This was followed by community paediatrics, where respondents estimated an average waiting time after an initial assessment to be 22.7 weeks. Responses ranged from 0 to 60 weeks.
- School nursing and mental health school teams had the shortest estimated average waiting time again, with responses for both averaging at 3.4 weeks. These services also had the shortest estimated maximum waiting time and smallest range (school nursing: 0 to 3 weeks; mental health school teams: 0 to 10 weeks).

**If you would like to highlight a children and young people's service with concerning waits that is not covered in the list above, then please write in the box below. If possible, please include an estimate (in weeks) of the average waiting time for treatment.**

- There were 26 responses to this question. Several respondents highlighted neurodevelopmental pathways, emphasising this as the most concerning wait list. One respondent estimated an average wait time of 30 weeks for attention deficit and hyperactivity disorder (ADHD) treatment, another estimated the wait for neurodevelopmental assessments to be 42 weeks, and another respondent estimated a wait time of 52-56 weeks for autism spectrum disorder (ASD) pathways. One respondent mentioned that this is due to significant increases in referrals.
- Another service mentioned by several respondents was dietetics. Estimated wait times varied for this service, one respondent answered 19 weeks, while other responses included 22 weeks for an initial assessment, four weeks for treatment, and six months for paediatric dietetics.
- Other services highlighted by respondents include eating disorders, special educational needs and learning disabilities, enuresis, orthodontics (longest wait at 96 weeks), and dysphagia assessments (longest wait for initial assessment being 40 weeks).

**What is the longest waiting time a child or young person is facing to access a community service delivered by your organisation? If possible, please name the type of service and the length of time (in weeks) someone has been waiting to access an initial assessment or treatment.**

- One respondent stated that the longest waiting time a child or young person is facing to access a community service was four years, for community paediatrics. This service was mentioned by several respondents, and estimated waiting times ranged from 40 to 208 weeks (four years), with an average wait time of 90 weeks.
- Speech and language therapy was highlighted by the most respondents as having the longest waiting time, with estimations ranging from 12 weeks to 90, and averaging at 45 weeks.
- Another common community service noted by respondents was autism spectrum disorder (ASD) assessments, with wait times for these ranging from 42 weeks to 160, averaging at 91 weeks. Neurodevelopmental assessments in general were mentioned by several respondents, with estimated waiting times for these starting at 45 weeks and reaching up to 152, with an average of 87 weeks. More specifically, attention deficit hyperactivity disorder (ADHD) assessments were also highlighted as having long waiting times, with estimations for these being 72, 130, and 207 weeks.
- Other services with the longest waiting times mentioned by respondents were paediatric occupational therapy (minimum 26 weeks; maximum 87 weeks; average 58 weeks), school nursing (estimates of 8 and 12 weeks) and CAMHS (estimates of 12, 74, and 104 weeks).

# 4

Respondents told us:

“Longest wait time is four years for community paediatrics. This is because we have been prioritising pre-school children and those raised as urgent (for variety of reasons – could be safeguarding/ school refusal). This has led to school age, non-priority CYP waiting four years. Currently starting to outsource our longest waiters for ASD assessments.”

“Neurodiversity assessments and treatment demands have doubled post pandemic. Currently, children are waiting over 52 weeks for commencement of assessment and then up to six months for intervention. The longest waiting patient is currently 152 weeks.”

“Waiting times for neurodevelopmental assessments and follow-up have seen the most dramatic increase. CYP will be waiting over two years for a first appointment from July 24. Currently 99 weeks in community paediatric services.”

“ADHD and paediatric assessments have the longest waits, there is an increase of 360 per cent referrals to these services post pandemic some have been on the waiting list in excess of 18 months.”

“This is difficult to ascertain as some waits maybe caused through parental choice as the appointment offered may not be suitable and although we work closely with families this does cause longer waits. CDC (neurodevelopment is 45.1 weeks).”

## **What would you say are the main consequences of long waits for community services on children and young people?**

- The most common consequences of long waits for community services on children and young people cited by respondents were delays in development, education, and communication. Another common theme was delay in receiving the right support and treatment or a missed opportunity for early intervention.
- The impact of long waits and uncertainty on the individual’s mental health and the stress for families were mentioned by many respondents.
- Respondents particularly highlighted the impact on those children presenting with more complex or specialist needs. They said that deterioration in conditions over time could lead to increased needs when the individual is seen, as well as more children presenting at A&E or in crisis.
- Respondents were also concerned about the impact of long waits on children and young people’s education, school readiness, social skills and ability to learn and achieve their full potential given optimal development windows can be short.

Respondents told us:

“Potential risk of children and young people not accessing the correct services to facilitate their wellbeing and achievements such as readiness for school. Excessive stressors for parents as carers as they fight to access the services their child requires. Potential safeguarding concerns may be missed as child does not access services appropriately. Potential deterioration in condition as CYP not seen timely.”

“Consequences vary depending on reason for referral, but impact on children and young people’s mental health has been noticeable, especially relating to coping with impact of neurodiversity, anxiety and gender identity. Delays to speech and language therapy impact on speech development, school readiness and linguistic development.”

# 4

“Huge increase in referrals post pandemic to community diagnostic centres (CDC) and therapy services. Children have much more complex presentation and later presentation in some areas. Increased demand and same capacity with COVID-19 backlog is a huge challenge from both workforce issue and estates capacity.”

“Impact on the young person/child’s ability to access education and achieve their full potential. Difficulties for families to access the right support from EHCP and SEND processes. Potential for increased difficulties within social settings. Increase on family systems, leading to family breakdowns with implications for social care. Potential for increase in comorbid mental health conditions.”

“Research shows that a late diagnosis for neurodevelopmental conditions has an adverse impact on the future lives of children and young people. In many cases this can lead to social, emotional and mental health difficulties in the home, school and community settings. The cost to the wider health, social care and justice systems of not addressing ND concerns in childhood is significant.”

“Not meeting potential in education and reduced emotional and physical wellbeing for children and young people and for parents, carers and family members. We also know from longitudinal research that lack of adequate support early in life leads to health and social difficulties later on, meaning increased burden on adult services in future.”

“Long waits impact the mental health of the child/young person and their families. Families who may not have reached crisis point if they had access to services earlier are more likely to. I feel service users lose faith and therefore become less engaged in trying to access services if they feel support is not timely. Service users’ access to education is impacted whilst awaiting assessment and diagnosis, as support provisions in school are less likely to be funded and implemented without a diagnosis.”

“Long waits for community services can delay the diagnosis and treatment of conditions that affect children and young people, which can cause conditions to worsen, leading to more severe symptoms, complications and longer recovery times. Long waits could also increase emotional distress in children and young people, especially when they are struggling with mental health or other issues and are having to wait for services. They may feel frustrated, anxious, and depressed, which could further exacerbate their condition. Long waits could also lead to social isolation. Again if a child is struggling with a mental health condition or disability and does not receive support, they may find it difficult to participate in social activities.”

## **More specifically, how do you think long waits for particular services are impacting existing health inequalities?**

- Respondents noted that existing health inequalities have been greatly exacerbated by long waits. Many highlighted how vulnerable communities are impacted disproportionately as more affluent parents can pay for private healthcare for their children, access alternative solutions or escalate their case more effectively.
- Families from deprived communities may not be able to source additional support or have difficulty in accessing online support. One respondent highlighted the geographical differences that exist, as waiting lists vary.

# 4

Respondents told us:

“Increasing impact on health inequalities as a result of long waits for particular services. Long waits also disincentivise families to access services and/or result in people with financial means identifying alternative (private funded) alternatives. Both these approaches result in an increase in health inequalities.”

“Health inequalities are widened as an impact. Families who can afford private assessments, get needs identified earlier which may lead to needs being met by public services earlier. Families on waiting lists are often offered online support while waiting but this is not accessible to all. Geographical differences broaden as waiting lists also vary dependent on recruitment and retention of workforce and commissioning priorities.”

“Those facing existing sources of adversity and disadvantage and who lack contextual protective factors will be most affected by the mismatch between capacity and demand.”

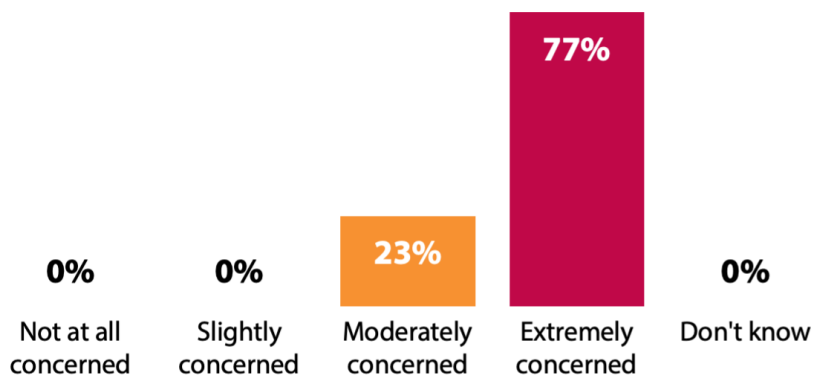
“Longer waits further exacerbate the needs within vulnerable groups who already are disadvantaged within the health system. If unmet need is increasing where there are already complex issues, the longer-term health outcomes for children will be potentially worse than if they were getting timely access to support in a way that engaged them in a way where outcomes could be improved.”

## Thinking about the impact of long waits for community children and young people’s services, how concerned are you?:

Figure 7

### Level of concern about the impact of long waits for community children and young people’s services

(n = 64)



- All respondents (100 per cent) were either moderately (23 per cent) or extremely (77 per cent) concerned about the impact of long waits for community children and young people’s services.

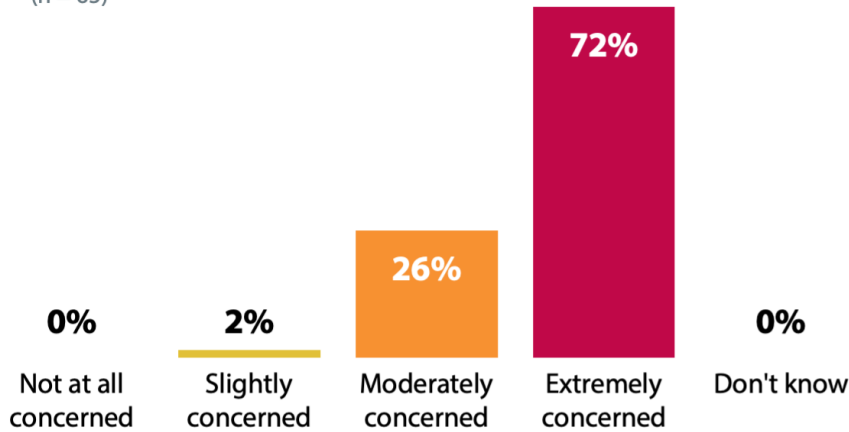
# 4

## Thinking about the impact of long waits for community children and young people's services, how concerned are you about the impact on staff morale?:

Figure 8

### Level of concern about the impact of long waits for community children and young people's services on staff morale

(n = 65)

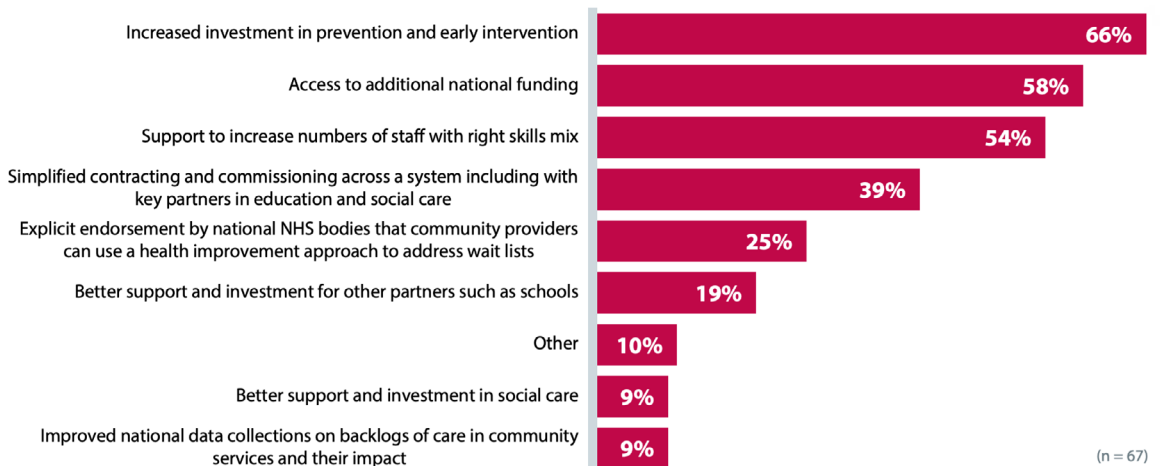


- All respondents reported some level of concern about the impact of long waits for community children and young people's services on staff morale. Almost three quarters (72 per cent) were extremely concerned, just over a quarter (26 per cent) were moderately concerned, and 2 per cent were slightly concerned.

## What do you think are the most important national enablers that would help your organisation address wait lists and reduce waiting times for children and young people's community services? (Please select 3):

Figure 9

### Most important national enablers to help organisations address wait lists and reduce waiting times for children and young people's services



(n = 67)



# 4

- The top three most important national enablers to help organisations address wait lists and reduce waiting times for children and young people’s services were increased investment in prevention and early intervention, selected by almost two thirds (66 per cent) of respondents, access to additional national funding (58 per cent), and support to increase numbers of staff with right skills mix (54 per cent).
- Almost two in five (39 per cent) selected simplified contracting and commissioning for children and young people’s community services across a system including with key partners in education and social care.
- A quarter of respondents (25 per cent) believed explicit endorsement by national NHS bodies that community providers can use a health improvement approach to address wait lists to be one of the top three most important national enablers, while around two in five (19 per cent) chose better support and investment for other partners such as schools.
- One in ten (10 per cent) believed another national enabler to be most important, 9 per cent selected better support and investment in social care and improved national data collections on backlogs of care in community services and their impact.
- There were seven other national enablers suggested by respondents, mainly focused on staff training and changes to neurodevelopmental diagnosis and support.

Respondents told us:

“We would also suggest a greater level of training so there is a higher number of professional staff to recruit.”

“Greater access to phlebotomy in primary care.”

“Support for dual qualification workforce.”

“Change in process for neurodiverse children. Too much time currently spent on diagnosis not on support.”

“Neurodevelopmental diagnosis and treatment – requires firmer parameters, more flexibility to use skill-mix and greater resource for prevention.”

## **What do you think is your local integrated care systems’ role in supporting the reduction of waiting times for children and young people’s community services?**

When respondents were asked for their view on what the role of an ICS is in supporting the reduction of waiting times for CYP community services, the predominant theme was better partnership working. Many respondents highlighted the need for coordination across system partners, working with providers to maximise resources, and understanding the whole system with a shared approach. One respondent also noted that workforce challenges can be supported by finding different ways of addressing issues collectively as a system. Respondents highlighted the need to improve commissioning, make clear commissioning decisions, adapt commissioning priorities to meet new challenges, and have a consistent and appropriate approach to commissioning services.

- Some respondents highlighted the need for ICSs to provide a greater focus on child health as well as adult and acute services and/or to increase investment into early years intervention. Another common theme was for ICSs to recognise and help understand the increased demand and referrals to these services.

# 4

Respondents told us:

“Supporting with workforce challenges by helping to find different ways of addressing issues as a system rather than relying solely on health to find solutions.”

“The risk has been highlighted to the system. The ICB’s role is to ascertain what can be done collectively to improve the position and champion this. The pressure on funding and targets set Nationally around urgent care, elective and mental health means that children’s services are not prioritised or considered during planning.”

“The health and care sector plays a crucial role in supporting the reduction of waits. Provider collaboratives will bring providers together to achieve the benefits of working at scale across multiple places, to improve quality, efficiency and outcomes and address unwarranted variation and inequalities in access and experience across different providers.”

## **Is there anything else you would like to share with us regarding waiting times for children and young people community services?**

- There were 37 responses to this question, mainly focused on the importance of early intervention, the need to reform community services, funding, workforce, and a disproportionate focus on adult and acute services.
- There were several comments about the need for investment and support for workforce supply and development given vacancies and skills shortages are exacerbating delays. One respondent reported their concern about the impact of relentless pressure and high caseloads of complex cases on staff health and wellbeing.
- Several respondents highlighted the significance of prioritising early intervention and prevention to reduce impact on services in the future. There were also several comments about the importance of giving due national priority and funding to children and young people’s community services with comparisons drawn to the political and policy focus on acute care, mental health and urgent and emergency care.
- There were a few comments relating to the benefits of dedicated investment. One respondent stated they have received investment over three years and at the end of the second year have started to see reductions in waiting times for treatment. Another reported having received significant funding, which they believe will help with therapy waiting times. One respondent said that an ongoing challenge for local authority commissioned CYP services is the impact of insufficient central funding for pay awards for staff on Agenda for Change contracts, which leads to a real-term cut to provision of services each year.
- Finally, some respondents mentioned a role for agreed standards for community services. Others suggested a change towards being more needs-led or considering measures such as the quality of assessment and intervention.

Respondents told us:

“There needs to be national targets set to give any chance for children’s services to meet the needs of the young people. If we do not get services right for children, we will be in a circle of high spend.”

“Demand has rocketed for children’s services over the past two years. We need to change the pathways and protocols so that we can assess those most in need of urgent assessments/diagnosis.”

# 4

“Waiting times for community services are a deteriorating picture and we are becoming faced with a reducing workforce who have the right skills, knowledge and expertise.”

“Evidence clearly outlines the importance of early identification and early intervention yet these services are rarely prioritised in a health system which results in unacceptable waiting times and longer-term costly interventions.”

“The impact of the relentless pressure and high caseloads of complex CYP on the health and wellbeing of our staff is of concern. Significant additional funding has poured into mental health, virtual wards and urgent and emergency care and yet services for CYP with physical disabilities, ASD, ADHD and SEND have been left in the wilderness.”

“We can make vital improvements by moving away from a narrow medical model or ‘health dominated’, reactive approach to waiting lists. We must take a ‘needs-led’ rather than a ‘service-led’ approach. This means many of the familiar approaches to addressing wait lists in other parts of the NHS are not appropriate to CYP, maternity and family services. Involvement of VCSE, education and local authorities is essential.”



# Community

NETWORK



157-197 Buckingham Palace Road,  
London SW1W 9SP  
020 7304 6977  
[enquiries@nhsproviders.org](mailto:enquiries@nhsproviders.org)  
[www.nhsproviders.org](http://www.nhsproviders.org)  
[@NHSProviders](https://twitter.com/NHSProviders)



18 Smith Square, Westminster,  
London SW1P 3HZ  
020 7799 6666  
[enquiries@nhsconfed.org](mailto:enquiries@nhsconfed.org)  
[www.nhsconfed.org](http://www.nhsconfed.org)  
[@nhsconfed](https://twitter.com/nhsconfed)