

Kids Policy Solutions: Delivering cost-effective support to tackle SEND waiting lists and reduce the mounting - and costly - crisis in provision for disabled children and their families

October 2024

This briefing summarises:

- **The national picture.**
- **The impact of waiting lists on disabled children and families.**
- **Kids' analysis of short-term and long-term approaches required to address SEND system failures**
- **Two policy solutions to deliver immediate relief.**

1. The national picture

There are over 2 million disabled children in the UK. Kids believes that each child is brilliantly unique and that we should celebrate the increased awareness of individuals' difference.

Demand for SEND support is growing – for those 2 million children, *and* those without a formal diagnosis or who do not identify as disabled but require additional support to thrive.

One important indicator demonstrating the growth in demand, specifically in education, is that the number of pupils in England issued with a special needs support plan has more than doubled in the last eight years. With 180 pupils per day being issued an education, health and care plan (EHCP), a record half a million pupils now have a legal document setting out a child or young person's special educational needs, the support they need and the outcomes they would like to achieve.

The prolonged effect of the Covid pandemic continues to have an impact. This is due, in part, to its disproportionate effect on disabled children at the time (for example, shielding), but also the unmet needs leading to children and young people experiencing more difficulties with their mental health. Speech and language issues went unidentified or unsupported. Families with babies and toddlers struggled to find early support even before the pandemic; the pandemic set this back further and in many cases prevented the interactions with professionals in formal settings where information and knowledge about their child's need should start to be identified. At the same time, families' ability to access family or community support was severely diminished.

The need for children and young people's mental health services has risen across the board, yet it can be overlooked in those with SEND. Some professionals focus solely on the physical or learning disability associated with SEND, and SEND issues are not fully understood by every mental health practitioner.

Pressure is mounting on families and on professionals across multiple public-funded workforces, including local authorities, education settings (from early years to further education), GPs, community healthcare providers, and hospitals.

The Children and Families Act 2024 provides a sound legislative framework, with young people's voices as a key principle, but was not fully implemented or resourced. The Change Programme, which is testing proposed changes to the SEND and Alternative Provision (AP) system in England, is the first step in implementation. In its current form, the programme cannot improve the situation in the 'here and now' for families. It is focused on testing elements in specific areas, that might work in the future, whilst cash-strapped local authorities are struggling with the bandwidth to engage.

Meanwhile, provision is still lacking in all areas and at all ages and stages of a child's life. Families are falling into crisis for want of timely, practical interventions designed to support their child to play, learn, grow and thrive.

2. The impact of waiting lists on disabled children and their families

Rising waiting lists across health, care, education and other services are impacting more and more disabled children, young people and families every day, and the cost to the public purse is escalating. Early assessment, diagnosis and intervention is widely recognised as the right course; but is not happening in practice. A two-year-old child on a two-year waiting list for an assessment will have spent half their life waiting to be seen.

The long waiting lists for assessments or EHCPs are prevalent, with families waiting up to three years instead of the prescribed 20 weeks to get an EHCP and an approximate 12 months to reach a tribunal. The combined impact of being on multiple waiting lists (some of which, like an educational psychologist's report, may be required to secure an EHCP), is having a devastating impact on children and families. A long wait for an ADHD assessment or diagnosis will delay a referral to a paediatrician to support with medication where that is appropriate. A young autistic person can end up in a secure hospital under treatment for an eating disorder because their autism was not recognized and assessed. Long waiting lists for assessment, diagnosis or treatment for mental health difficulties are disastrous for disabled children who often experience worse mental health because their disability-related support needs have not been met earlier in their childhood.

Disabled children often miss out on education because their needs are not identified and met in a timely fashion. A shortage of suitable early years placements for children with additional needs leaves many out of early education altogether, with only 6% of local authorities reporting sufficient childcare places for disabled children. Additionally, a worrying number of students are not in primary or secondary school, because the setting cannot meet their needs.

Waiting lists mean that a child's needs are not identified or understood, and schools are making decisions to exclude on the grounds of behaviour without any understanding of what may be driving this. Many students or families are withdrawing themselves because the school cannot meet their needs. Once out of school, students face delays to access statutory or community services which hampers their chances of being able to re-enter the classroom.

Family life is also severely impacted by long waits for support, with serious implications for the physical and mental health of all family members and the ability of parents to maintain paid work. A report by the Disabled Children's Partnership found that only one in five parents of a disabled child felt their

family received the support needed for their child to fulfil their potential. Taken together, this means that children's health, wellbeing and freedoms further deteriorate, families fall into crisis, and more pressure is put on an already overwhelmed system.

3. Kids' analysis

Kids' analysis, based on frontline experience of directly supporting 18,000 individuals annually and thousands more with lighter touch resources, is that a two-stage approach is required.

First, disabled children and their families must be able to rely on their basic entitlements from public services. This means addressing the waiting lists with value-for-money policy solutions that provide people with immediate help, making an immediate difference to families and starting to ease pressure on the system.

Second, a longer-term programme of transformation over the next decade is essential: to fix a broken system and build a sustainable model of support for disabled children to thrive.

We see strong potential for a mission-led government to break down the silos that impair the support of disabled children who rely on health, care, education, leisure and housing services. Labour's missions to break down barriers to opportunity in childcare and education, and to build an NHS 'where everyone lives well for longer', offer hope for improving the lives of disabled children and young people. So too does the mission to kickstart economic growth with good jobs and productivity available to all, given the high number of disabled young people and parents of disabled children who are not in employment because of a lack of support.

As the fundamental work of reform starts to take shape, immediate fixes are needed to prevent more families with disabled children from falling into crisis because of chronic waiting lists and system failures. In this context we present two tried and tested policy solutions which can make a difference straightaway.

4. Kids' policy solutions

1. The 'Navigator' model - tailored help and guidance

A significant challenge for parents in getting the right help for their child is navigating a complex health, care and education system. Kids has pioneered the SEND Community Navigator model in one local area, providing a single point of contact for rounded support and guidance to ease the burden on families. The SEND Navigators work in partnership with the family to build a personalised support plan, before providing practical and emotional support, connecting families with local services, and working to help the family access the right provision and support. A strong and effective early intervention, we have started to integrate the model into other services. This includes our inclusive nursery in Basingstoke, Hampshire, where tailored support for the families makes a real difference. For example, last year, more than 40% of children in our Basingstoke nursery went into a local mainstream school - rather than special school where they were expected to go.

Case Study

K, aged 4, has an autism diagnosis and digestive problems. Mum has a diagnosis of ADHD, autism and anxiety. The family faced numerous challenges in overcoming the difficulties presented by K's behaviour and poor sleep pattern. There had been a history of missed communications between

professionals and between professionals and Mum. Mum had developed an extreme distrust of professionals because of this. At the time of referral, K's sleep pattern was very poor and he was sleeping 3-4 hours per night. K's digestive problems were not under control and causing a lot of pain. K displayed a lot of sensory seeking behaviours and had very limited communication either verbally or using alternative forms of communication. K and his younger sister could spend very little time together as he became aggressive towards her.

The Kids SEND Navigator team received a referral from a Family Support Worker at the local Children's Centre. As part of the triage process, the team recognised that K would also benefit from attending their local Kids Family Group. The team at Family Group identified that K needed to be referred to the Early Years Inclusion Support Service (EYIS) and worked closely with them to successfully apply for an EHCP.

SEND Navigator Amy began supporting K after he had completed a block of sessions with the Family Group and was just about to start Reception in a mainstream school.

Support given included:

- **In-depth Information and Advice:** Amy provided guidance on K's sleep, communication, sensory seeking behaviour and emotional wellbeing. She equipped Mum with improved knowledge and tools to better understand and address K's needs.
- **Practical Support:** Amy recommended and modelled sensory activities and play strategies to engage K and help improve his relationship with his sister. Amy also gave suggestions about ways to respond to K's challenging behaviour which was affecting his school attendance, along with his poor sleep pattern. Amy recommended sleep hygiene and routine strategies and referred Rebecca for more specialist support. K's sleep and school attendance were beginning to improve by the end of the support given.

K's mainstream school setting was not appropriate for his needs and Amy supported Mum to attend meetings to challenge the setting named on his EHCP and visit Special Schools. This practical support gave Mum the ability to navigate the difficult journey of accessing a special school placement and enabled K to develop his ability to interact with peers and develop his communication skills.

- **Connecting with Professionals:** Amy attended meetings arranged between school and other health professionals involved with the family. Amy advocated for Mum and K in these meetings as Mum initially did not have the confidence to speak out, however her confidence grew as she built a relationship with Amy and the school staff. Through school initiating an early help plan and Amy supporting Mum to engage with this and the Family Support Worker, the joined up working dramatically improved Mum's relationship with school, access to local health services and K's school attendance.
- **Emotional Wellbeing Support:** Amy recognised that Mum was dealing with a lot of stress due to K's needs, the challenge with accessing an appropriate school placement and a poor relationship with school staff. Along with practical support, Amy provided a listening ear and suggested wellbeing activities. This helped Mum to prioritise self-care more and gave her greater patience and ability to implement strategies needed to help K.

Impact

This case highlights the importance of all professionals involved in the family working together to support them. It also emphasises how important it is for parents to have someone who has knowledge and expertise in the field of SEND to help them navigate difficult systems, build relationships with professionals and better understand how to support their child.

The SEND Navigator – a model that works

What is the service?

The Kids SEND Navigator community project was set up in 2021, originally through start-up funding from Birmingham Forward Steps and subsequently bolstered by voluntary income. Over three years, we have helped more than 400 families with one or more children with SEND with:

- Information and advice: routine, behaviour, sleep, eating, emotional wellbeing
- Play in the home, including sensory activities
- Connecting with professionals: Early Support and Inclusion Service, Occupational Therapy, Speech and Language
- Support to apply for financial support, e.g. Disability Living Allowance, carer's allowance, Family Fund grants
- Support to actively participate in meetings with professionals/multiple agencies
- Emotional wellbeing support and mindfulness.

Most referrals come from health visitors; others come from family support services or statutory services.

How much does it cost?

The salary costs of a SEND Navigator for 36 hours per week are £36,973 per year. They can take a case load of 20 families at any one time – anticipated at 60 families per year. This works out at a cost of £616 per family, assuming we work with each one for 12 weeks, though this is not universal as we work with some families for longer periods.

What is the impact?

These families have been supported to get on the right track from the very start of their SEND journey and get into the system, saving more costly interventions in future and keeping families together. Helping to avert future crisis, this support:

- Reduces isolation and increases peer support.
- Increases parental knowledge, confidence and emotional wellbeing.
- Integrates families into the system more easily
- Reaches parents who professionals have struggled to connect with.

- Takes a whole family approach and supports everyone within the household.
- Identifies safeguarding concerns that may otherwise be missed, meaning referrals can be made to appropriate agencies.

100% of families said they found the staff knowledgeable.

97% of families have increased their knowledge and understanding of their child's needs.

85% of families report attendance at Kids Family Groups has increased social contact."

Kids have built strong trusting relationships with other VSC, public sector and health partners; Health visitors are now their highest referrer. This demonstrates that Kids' expertise within the SEND arena is recognised across Birmingham. Kids have developed good relationships with families in Birmingham and are ideally placed to provide this specialist support. They have excellent data and case studies that support this."

Maxine Burrows, Birmingham Community NHS Foundation Trust

"I think that you are better than a health visitor, better than Early Years Inclusion Support, better than my (school family support worker)" - Parent

"I can't thank you enough for what you've done for us. I am so happy with the outcome. Thank you.." - Parent

"You are very understanding and you think outside the box. This was refreshing. I've found your approach was different and very helpful." - Parent

2. Holistic Crisis Intervention

This is a service involving interventions for young autistic people or other neurodevelopmental conditions and their families, that steps in when families, young people or professionals identify that they are at risk of falling into crisis. These interventions complement other services in the community.

In December 2023, there were 172,000 people of all ages waiting for a clinical autism assessment. Of those who had been waiting for more than 13 weeks, only 6% had had their first care contact (post-referral appointment) within the recommended 13 weeks (the waiting time standard). The median waiting time for people having their first care contact was 281 days (40 weeks), which is more than three times as long as the 13-week target. Only a small proportion of the people waiting for an autism assessment have a care contact each month.

Early intervention is vital to successful care and treatment and NHS backlogs are making that harder. Kids' holistic crisis intervention approach is designed to prevent a deterioration which may require potentially intense intervention.

Originally a short-term pilot with funding from NHS England to support children and young people experiencing emotional and mental well-being crisis, core to the project is to reduce the need for this cohort of children and young people to be referred to CAMHS and thus positively impact across CAMHS services including crisis interventions and a reduction in waiting times.

Case Study

C is a 6 year old boy with Social, Emotional and Mental Health (SEMH) needs, EBSA and has a diagnosis of ADHD that requires him to take daily medication. C and Mum were referred to Kids Wakefield Awareness Support Programme (WASP) in November 2022 and the team worked with the family until December 2023.

C's family received a comprehensive support package tailored to both the parent and C's needs. This included workshops, one-to-one sessions and access to resources such as the sensory lending library. Despite the initial support, C continued to face challenges, particularly in managing his anxiety and meltdowns, especially surrounding school. He had not been out of the house in 3 months.

The following were identified and actioned during the work done with C:

- **Support Adaptation** – the need for further and bespoke intervention, WASP amended and extended their support, offering one-to-one Lego/Understanding Me sessions at C's home. These sessions allowed him to build trust and develop a rapport at his own pace, in a familiar environment where his sensory needs could be accommodated.
- **Educational Challenges** – C's difficulties extended to his education, with his SEMH needs preventing him from attending school regularly. Despite multiple referrals and attempts to engage with services like CAMHS, finding suitable support remained challenging. A WASP Senior Practitioner worked closely with CAMHS, CTLD, EWO, WEISENDSS, Family Action, School, WY ADHD and attended EWO meetings so the voice of C and Mum could be clearly advocated.
- **Medical Concerns** – during interactions, C exhibited repetitive behaviours such as coughing, which raised concerns about potential underlying medical issues. The WASP Practitioner raised this with mum and advised to book a GP appointment. However, after medical evaluation, it was determined to be a form of tic or stimming behaviour.
- **Engagement with Activities** – C displayed a keen interest in specific topics such as emergency services, often gravitating towards related activities such as Lego building. However, maintaining focus and following instructions presented challenges, particularly when not on his ADHD medication.
- **Communication and Emotional Expression** – communication proved to be a significant hurdle for C, who often struggled to articulate his thoughts and feelings. This led to difficulties in expressing emotions and needs, resorting to one-word responses or avoidance tactics.
- **Safety Concerns** – C's limited sense of danger was evident when he opened the door to a WASP practitioner unsupervised during a visit, highlighting the importance of ongoing supervision and safety measures needed.
- **Adaptive Strategies** – to address C's communication barriers, alternative methods such as visual aids and sensory tools were explored and used in the one-to-one sessions. Creating a conducive environment and providing clear instructions were essential in facilitating his engagement and regulating his emotions.

C's Mum completed the 10 week Riding the Rapids programme alongside the 1:1 work done with C and she attended all sessions online. This was particularly useful in unpicking behaviours and using

strategies to understand and support C when behaviours are more physical towards mum. As mum could not leave the house due to caring for C, the online sessions enabled her to get the support she needed.

After many months of intervention and support, C, Mum and Grandma attended the WASP coffee morning. It was important that this was planned and Mum used what she had learned on RTR to communicate what the plan was (social stories and aids). The familiar practitioner who C had built up a rapport with over the past months, was there to greet him at the centre with Lego. Discussions were had prior to the coffee morning around not wearing certain clothes with buttons on, which the practitioner did.

Impact

Despite the challenges, working with C and his family proved to be incredibly positive and impactful. C will continue to need support in developing effective communication skills, managing his emotions and integrating into educational and social settings. However, he is now able to go out for a walk and visit more places than when first referred to WASP and has made fantastic progress. By understanding his unique needs and employing tailored strategies, C will be able to thrive and become an active member of his community

Holistic crisis intervention – a model that works

What is the service?

Kids Wakefield Awareness Support Programme (WASP) works with the young person to provide time limited interventions to support their wellbeing and resilience and to signpost to other available services. It can include group work and individual therapy, tailored around the individual's needs. It supports parents by increasing their knowledge and provides peer on peer support to allow parents with lived experience to support others and to build their resilience and confidence in being able to support their young person in seeking appropriate support in the future. A key focus is to prevent families with children and young people that have behaviours that challenge (possibly because of their autism) feeling unsupported at times of escalating difficulty.

How much does it cost?

£225,000 per year which means we can support families for under £500 each.

What is the impact?

Of 100 families who described being in crisis when they reached Kids, only six felt that was still the case after 12 weeks accessing our services (according to evaluation of the first 18 months of the service).

75% of families reported that after receiving support they felt more confident about managing as a parent and saw an improved relationship with their child. 70% were better able to stay calm when things went wrong and 78% felt better able to understand their

child's behaviour. Over 82% felt they were therefore better able to manage the behaviour of their child.

When families were asked about the possible outcomes had they not been able to access the service, an overwhelming 84% felt their situation would have deteriorated.

"I am finally being heard. This information I have will help towards helping with [my daughter's] needs." – **Parent**

"WASP really has been a lifeline for us in a difficult time whilst awaiting a diagnosis. We were at a point we were doubting ourselves as parents and struggling to be heard." - **Parent**

"If it weren't for yourselves, I don't know where I'd get help. Thank you all" - **Parent**

"They are unique in that it offers support to both parents and children and has different targeted levels of intervention; which is bespoke." **CAMHS practitioner**

"WASP is unique in Wakefield and possibly wider, as it's a service which is based on the child and young person's presentation and needs and not on diagnosis. It is led and delivered by those with lived experience." **Commissioning Manager for Children and Young People**

Many organisations such as Kids provide practical support solutions for disabled children and their families. Some are specifically aimed at supporting families on long waiting lists; others are naturally filling in gaps as delays for assessment, diagnosis and treatment grow longer. All are vital in plugging a short-term gap whilst longer term, sustainable solutions are identified and enacted. However, complicated procurement practices are making it harder for voluntary and community organisations and statutory organisations to collaborate to deliver sustainable, value for money services. In addition, SEND issues can be left out of procurement instead of being thought about at the outset, when, for example a generalist mental health provider and a SEND specialist could forge a solution together to the high prevalence of mental health issues experienced by disabled young people (often linked with a failure to meet needs earlier on). However, there are places where commissioners, providers, young people and families are working in concert to develop and deliver flexible, value for money and impactful services. In Essex, for example, three Integrated Care Boards came together with Kids to commission a new service for young people (and their families) who are on the autism pathway or have just received a diagnosis of autism to understand the condition, develop their own coping strategies and build a peer support network. The resulting autism hub, with bite-size resources, interactive webinars and signposting to link people to local services gives a replicable model of needs-based, flexible and joined-up commissioning based on genuine co-production with young people and their families.

5. Recommendations

- The Government should create commissioning guidance to steer the flexible local commissioning of early intervention services that are proven to help families with disabled children on multiple long waiting lists. Commissioning guidance should support ‘invest to save’ principles, to prevent escalation and reduce the need for more costly specialised interventions down the line.
- The Government should work with providers of SEND community services to collect and disseminate the best examples of waiting list initiatives specifically able to meet the immediate needs of disabled children and their families and alleviate the subsequent need for costly crisis intervention.
- The Government should reform procurement rules and practice to address the rigidity of current process and make it easier for statutory and voluntary and community organisations to work - in partnership and not in competition - to address out-of-control waiting lists with services that provide immediate relief.

These recommendations support the two-stage approach that is needed. Firstly, they ensure that families can rely on their basic entitlements from public services to be met - addressing waiting lists with value for money policy solutions that provide people with immediate help, to make a difference to families in the here and now. Secondly, they support a longer-term programme of transformation over the next decade which ultimately fixes a broken system and builds a sustainable model of support for disabled children to thrive.

About Kids

Kids is a leading charity for children and young people with special educational needs and disabilities (SEND) and their families. For over 50 years, Kids has created life-changing opportunities by providing a wide range of support for children and young people with SEND, empowering them to stand up for their rights. We turn practical expertise and trusted relationships with families into advocacy. By putting the voice of those with lived experience at the heart of driving essential systemic change, better access to services, consistency and outcomes are achievable.

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