



**CHILDREN AND**

**YOUNG PEOPLE**

**Personal Health Budget  
for Wellbeing Pilot**

March 2022-24



NHS Kent and Medway Integrated Care Board partnered with Involve Kent to pilot a project delivering Personal Health Budgets (PHBs) to children and young people aged 0 – 25 diagnosed with, or suspected to have, a neurodiverse condition.

*Note on language:* throughout this report we have referred to ‘neurodivergent young people’, however we recognise that individuals may prefer to identify or associate with alternative terms. When referring to neurodivergent young people, we include all of those who may use this, or associated terms, but have used singular terminology throughout to maintain consistency.

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# 1. BACKGROUND

## Autism prevalence and diagnosis in children and young people in the UK

Autism spectrum disorder is increasingly prevalent in the UK, with approximately 1 in every 100 children having the condition (BMA, 2024). Demand for diagnosis is high, and services are under pressure to deliver quickly using multidisciplinary approaches laid out in NICE guidelines.

Despite a recommendation for a quick diagnosis, the combination of increased demand alongside lengthy assessment processes has resulted in long waiting lists for children and young people awaiting autism diagnosis.

There is an average delay of 3.5 years from the first point of contact with a health professional to a confirmed autism diagnosis (Crane et al, 2016). In some cases, assessment can take 11 hours of professional time to complete over a 12-month period, costing £850 per child (Male et al, 2023). Delayed diagnosis can be harmful for the child or young person, as early intervention is more effective at a younger age and can result in fewer interventions used in future (Perry et al, 2011, Dawson et al, 2010).

Delayed diagnosis is also linked to increased stress for parents/carers (Siklos & Kearns, 2007). Parents/carers are dissatisfied with the diagnosis process (Howlin & Moore, 1997), with concerns relating to the time taken to receive a diagnosis, satisfaction with information provided, manner of the diagnosing professional and with the post-diagnostic support (Crane et al, 2016). Makino's review (2021) found that stress developed whilst navigating health services can last long after diagnosis, with this process being just one part of an ongoing series of adaptations. Several studies have suggested supports identified by parents that could be useful whilst awaiting a diagnosis, including access to therapy, advisors and other case coordination support (Legg and Tickle, 2019; Pearson et al, 2020; Rabba et al, 2019; Tait et al, 2016). Parents are motivated to take up additional support whilst awaiting diagnosis for their children and whilst publicly funded services are overwhelmed with demand, there is a need for innovative treatment models (Makino, 2021).

Once a diagnosis is given, parents/carers report feeling a sense of relief, having their concerns legitimised and being given evidence to access additional treatments (Smith-Young, 2020). Despite this, parents/carers report not being provided with adequate information or support, highlighting post-diagnosis support as being unsatisfactory and a key concern (Crane et al, 2016). Dissatisfied parents and carers are likely to turn to other sources for support, including schools, support groups, the Internet and books (Mansell & Morris, 2004). Many parents were provided with no support at all following diagnosis, with less than a quarter being offered direct offers of help (Crane et al, 2016). Parents and carers who were offered support had higher levels of satisfaction with the diagnosis pathway, particularly those who received a tailored offer, with Crane et al recommending that healthcare providers offer referrals to local support services over providing generic information (2016). Parents also called for support that is family-centred, that understands the needs of the whole family, that builds a close relationship and offers the right support at the right time (Galpin et al, 2018). The more systems that can be put in place, the greater satisfaction there will be amongst families (Altiere & Kluge, 2009). The most common interventions being used by parents and carers are visual schedules, speech and language therapy and Applied Behaviour Analysis, with most parents using more than one (Denne et al, 2017).

## Challenges faced by CYP with autism and their families

There is a higher prevalence of mental health conditions such as depression amongst children with autism, with one in ten children using Children and Adolescent Mental Health Services (CAMHS) also having an autism diagnosis (Read & Schofield, 2010). Young autistic people face several challenges relating to mental health and report feeling generally unhappy, depressed, worthless, lacking in confidence and unable to face up to problems, rating their quality of life as being poor (Crane et al, 2019). They struggle to express their emotions (Hill et al, 2004) and to identify their needs (Nicolaidis et al, 2014) and stigma around their condition created barriers to accessing support (Crane et al, 2019).

Children with autism are at higher risk of loneliness and isolation. They can experience difficulties in making and keeping friendships, putting them at risk of social isolation (Bauminger & Shulman, 2003). They are at an increased risk of bullying (Cappadocia, 2011) and are more likely to feel lonely, with poorer quality of friendships (Bauminger & Kasari, 2000) and having less friendships overall (Rowley et al, 2012).

Families with autism diagnoses face increased financial hardship due to additional costs, including medical/healthcare costs, therapeutic costs, special education costs, costs of informal care/loss of productivity for family/caregivers and costs of accommodation, respite care and out-of-pocket expenses (Rogge and Janssen, 2019). In addition to specialist items, families with children with autism face increased costs for everyday non-specialist goods and services, of which they need a greater number, and which need to be replaced more frequently (Blackwell, 2023). These items are needed to meet sensory, emotional, developmental and physical needs, and include clothing, leisure activities, household furniture and laundry supplies. Blackwell also noted that following diagnosis, activities such as swimming were often recommended by occupational therapists, but this provision is often expensive or harder to access, resulting in a higher cost (2023).

## 2. INTRODUCTION

Reflecting statistics from across the UK, the demand for neurodevelopmental diagnostics is high in Kent and Medway, with over 9,000 children and young people awaiting assessment (Kent and Medway Integrated Care System, 2024).

The wait for an autism assessment is between 36 and 42 months for those children who require a full assessment. Parents and carers report they are not receiving the necessary support during the wait and post diagnosis.

Common issues faced by these children and young people, such as sensory overwhelm and communication difficulty are preventing them from enjoying typical childhood and adolescent experiences i.e. engaging with family and friends, school, clubs, and activities.

These issues and the lack of effective support for them are contributory factors to many systemic issues in the health, education and social care system in Kent and Medway. For instance, neurodivergent children and young people are heavily over-represented in mental health inpatient admissions, school exclusions, and education health and care plans. Families' lack of trust in the system's ability to support neurodivergent children and young people is reflected in the joint CQC/Ofsted inspection of Kent's SEND support, requiring improvement in many areas. Finding effective solutions to improving on these areas is a key priority for NHS Kent and Medway, Kent County Council, and other system partners.

NHS Kent and Medway ICB are modelling and testing a transformed support and diagnostic pathway for children and families with needs around neurodiversity, called 'Making it Work'. Through this programme, they hope to demonstrate the effectiveness of early intervention and support both in meeting the needs of neurodivergent children and their families, and in reducing the pressure on diagnostic provision.

There are many different support offers being tested within and around this programme, of which the Personal Health Budget pilot is a key part.

NHS Kent and Medway Integrated Care Board partnered with Involve Kent to pilot a project delivering Personal Health Budgets (PHBs) to children and young people aged 0 – 25 diagnosed with, or suspected to have, a neurodiverse condition. The pilot took place from March 2022 – 2024.

The purpose of this report is to:

- Demonstrate the impact, findings and opportunities presented by the Children and Young People's Personal Health Budget for Wellbeing pilot delivered by Involve Kent
- Feedback to Kent and Medway Integrated Care Board (ICB), Kent County Council Dynamic Support Service (DSS) and stakeholders with a view to inform the system and secure funding to continue and expand the programme



# 3. DESIGN AND DELIVERY

The Personal Health Budget pilot aimed to offer personalised support to improve the wellbeing of children and young people based on what matters to them whilst navigating neurodivergence support and diagnosis pathways. Feedback from parents indicated gaps in certain types of support while waiting for diagnosis, for example provision of sensory equipment or access to therapeutic/appropriate activities. Involve's team of Children's Health and Wellbeing Navigators based in GP Practices reported that parents often knew what would best support their child, but cost/funding was often a barrier to accessing the most appropriate equipment, items, and services.

It was recognised that particularly in the case of neurodivergence, a personalised approach was key to successfully meet the specific needs of individuals.

It was important to design a programme that was agile and swift to respond with informed, creative, and innovative solutions. Existing funding streams and support provisions are traditionally less dynamic and unable to flex in response to what matters most to each child within an effective timeframe.

Delivery was based around two funding streams and referral pathways, coordinated and managed by Involve's Children's Project Manager.

## **Stream One:**

### Early Intervention Funding

- Funding provided by Kent and Medway ICB
- Aimed at providing early support to young people to minimise the risk of their support needs escalating.
- Referrals received from Involve's Children's Health and Wellbeing Navigators - based in primary care networks across Kent and Medway working with young people and families to understand what matters to them, their concerns and challenges and help to develop and coordinate their personalised care and support plan. They support families to access information and guidance and ensure they are aware of and engaged with relevant services and organisations.
- Delivery commenced October 2022

## **Stream Two:**

### Crisis Prevention Funding

- Funding provided by Kent County Council Dynamic Support Service
- Aimed at supporting young people at risk of requiring Tier 4 intervention, whereby they are admitted to hospital to support their mental health, or stepping down from a Tier 4 placement and supporting their smooth transition back into a community setting.
- Referrals received from KCC Dynamic Support Service – a Key-working service for autistic children and young people, and those with a learning disability, with escalating emotional or mental health needs.
- Delivery commenced February 2023

Eligibility for a PHB was determined by the identification of a clear health and emotional wellbeing outcome that can be reasonably addressed by the delivery of a PHB as determined jointly by the child, young person's parent or carer and Involve Kent.

Personal Health Budgets are issued with a best value approach and not used to fund activities that are offered by existing commissioned services, or where eligible for existing grant applications.

Following referral, the Project Manager contacted families to gain consent to engage in the pilot and get a sound understanding of the child or young person's issues, needs and desires. The parent/carer, child or young person and Project manager then coproduced a plan to identify the best use of a personal health budget to support them to achieve their goals and positive wellbeing outcomes.

An agreed budget is set and agreed with the reasoning for purchasing specific item/s, equipment, or service quantified using a best value approach. A clearly defined wellbeing outcome identified and agreed to ensure the intervention is personalised and the impact measurable. Where necessary, members of the project team also work in collaboration with schools and other healthcare organisations, for example occupational therapy teams, to ensure that the support offered is well rounded and appropriate.

Research for the purchases, financial transactions and delivery are managed internally at Involve by the Project Manager and Coordinator. Families kept informed throughout the process with regular updates to ensure the delivery was efficient and convenient.

## 4. FUNDING

Delivery and Staffing (ICB) Budget	£91,000
Early Intervention PHB Budget	£85,000
Crisis Prevention PHB Budget	£80,000

## 5. SUMMARY OF ACTIVITY

\*At the time of reporting

<b>175</b> Early Intervention PHBs issued	Average PHB Cost	£436.85
<b>46</b> Crisis Prevention PHBs issued	Average PHB Cost	£988.84

## Examples of items, equipment and services purchased:

- Gym membership
- Fishing tuition and equipment
- Mental health workshops
- Trampoline
- Referee course and football equipment
- MMA sessions
- Climbing frame
- Hot tub
- Alexa
- Audiobook subscription
- SEN pushchair
- Weighted blanket
- Seamless clothing
- Gardening equipment
- Swimming lessons
- Wireless headphones
- Ear defenders
- Therapy putty
- Dandelion Time
- Art Therapy
- Piano lessons
- Treadmill
- Summerhouse
- Logic Pro music software
- iPad
- Bike
- Kickboxing
- Rugby kit
- Fidget toys
- Punch bag/boxing gloves
- Sensory items
- Play therapy
- Private OT assessment
- Loop earplugs
- Drama club
- Sensory den
- Weighted jacket
- Hammock
- Laptop

## NEEDS IDENTIFIED

The wellbeing outcomes presented to the PHB team were varied but a few themes emerged during the project.

### Emotional regulation

A common theme was children and young people and their parents feeling they needed support with managing emotional regulation. This particularly included a desire to reduce instances of frustration and anger, or meltdowns, but also included ways to better manage anxiety.

### Sleep

Sleep was often an area of concern for children and families, and they were keen to access resources to aid sleep such as weighted blankets or sound boxes.

### Access to activities

Some children and young people's needs were focused on developing social skills, particularly through accessing specific interest activities.

### Access to education

a significant number of referrals were requesting support with accessing resources to improve access to education, in particular fidget toys to aid concentration in class and loop earplugs to lessen exposure to noise when moving around school.



# THEMES OF PHB'S PURCHASED

## Early Intervention

### Sensory items

Data showed that Sensory items were by far the most popular need identified for Early Intervention PHB's at **48%** of the total purchases. Popular requests were items such as Ear defenders/loops, lighting, fidget toys, sensory boards, weighted clothes, and blankets, which were also provided as bundles to provide solutions to support school attendance and to create sensory spaces in the home. To create safe sensory areas in the home we also funded the conversion of a shed, purchased tents, and fitted curtain rails to close off a bed space.

### Activity or sport-based activity

**26%** of Early Intervention PHB's went towards achieving an active or sport-based outcome.

### Activity or sport-based activity

**30%** of PHB's funding for crisis prevention was allocated to highly personalised bespoke support i.e. Support worker support to attend a concert, video doorbell to relieve anxiety, hair washing at a salon and hospital travel costs for young person to see their Mum who was unable to visit due to costs.

Gym memberships and in-home gym and exercise equipment featured significantly in both funding streams, where young people identified that regular exercise had a distinctly positive impact on their wellbeing as well as providing a social outlet for some.



# MEETING NEEDS IN A PERSONALISED WAY

Personalised profiling and support planning ensured the PHB met a child, or young persons need as specifically as possible, taking a holistic approach to understanding their circumstances.

Our engagement with the family focussed not only on finding out what matters most to them but also how to optimise the efficacy of the PHB by having conversations about:

- Space available at home/garden
- Impact on Siblings of other household members
- Sustainability - Ongoing cost and affordability
- Young person's preferences ie settings, timings, colour, brands
- Child or young person's desires. i.e. ear loops instead of defenders
- Discrete solutions to ensure young people are comfortable using them in their social settings i.e. fidget toys, weighted/sensory clothing.
- Safety – taking into accounts the child's weight, height, ability, and behaviours to ensure the items will not pose a risk and are appropriate

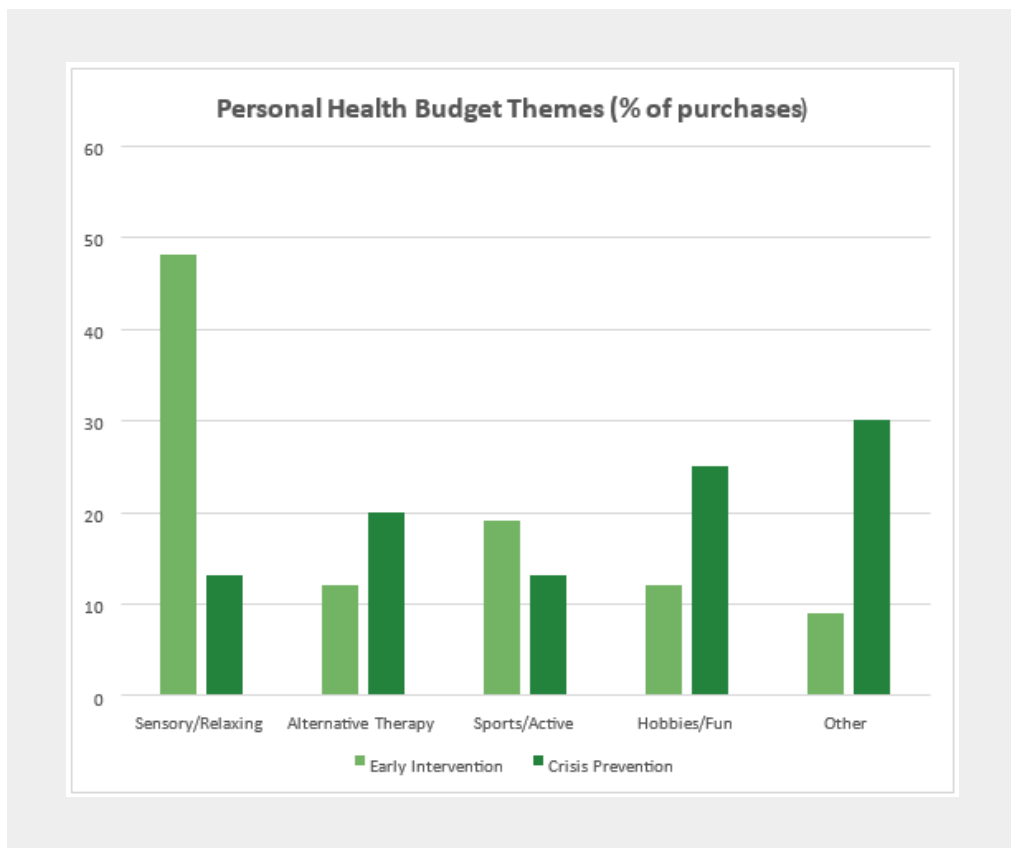
A referral which highlighted the benefits of offering such personalised care involved a Young Person, diagnosed with autism, whom had been assessed by CAMHS and Early Help as requiring therapy for a tissue phobia and violent behaviours that was significantly affecting home, school, and family life.

Within 7 sessions the young person was significantly overcoming their phobia and the aggression towards family members had stopped. Mum shared that by him being able to have the sessions within his school environment, the support has become accessible to him and described the changes in him as 'astounding'.

They had been offered therapy via statutory services; however, it required time out of school which was highly unsettling for this young person and therefore not accessible to them.

The PHB funded an alternative therapist who understood autism and could see the young person within their school environment and achieved some outstanding outcomes.





## 6. IMPACT, OUTCOMES AND FEEDBACK

Wellbeing outcomes were measured through a conversational assessment with or about the child or young person when families joined the pilot and again when they approached exit once their goals had been met.

**The following 4 questions are asked before and after receiving a PHB to measure changes:**

1. On a scale of 1-10 (10 being the best), where would you rate your child's current **physical** wellbeing? (Physical wellbeing = sleeping well, eating well and being physically active.)
2. On a scale of 1-10 (10 being the best), where would you rate your child's current **mental** wellbeing? (Mental wellbeing = how well the mind processes and understands information and experiences.)

3. On a scale of 1-10 (10 being the best), where would you rate your child's current **emotional** wellbeing? (Emotional wellbeing = the ability to manage and express emotions.)

4. On a scale of 1-10 (10 being the best), where would you rate your child's current **social** wellbeing? (Social wellbeing = the ability to develop and sustain meaningful interactions with others.)

**Scores were collated and averaged to show typical improvements.**

Early Intervention - Wellbeing Scores (out of 10)			
From 131 surveys	Initial	Follow-up	Average Increase in scores
Average physical wellbeing score	5.01	7.10	+41.83%
Average mental wellbeing score	4.35	6.57	+51.03%
Average emotional wellbeing score	3.95	6.15	+55.70%
Average social wellbeing score	4.19	6.08	+45.11%

Crisis Prevention - Wellbeing Scores (out of 10)			
From 22 surveys	Initial	Follow-up	Average Increase in scores
Average physical wellbeing score	4.32	5.64	+30.56%
Average mental wellbeing score	3.54	5.55	+56.78%
Average emotional wellbeing score	3.36	5.27	+56.85%
Average social wellbeing score	3.50	5.14	+46.86%

**A further question was asked at the end of the client engagement with the pilot:**

'To what extent do you feel your Personal Budget allowed you to meet your outcomes/s?' (out of 10)

Early Intervention PHB Outcome Score	
To what extent do you feel your Personal Budget allowed you to meet your outcomes/s?' (out of 10)	<b>8.34</b>

Crisis Prevention - PHB Outcome Score	
To what extent do you feel your Personal Budget allowed you to meet your outcomes/s?' (out of 10)	<b>7.57</b>

## Quotes and comments from pilot participants were collected throughout:

**Crisis Prevention** - A client with autism who was issued with a PHB for an annual gym membership shared:

"I have been going quite often, around twice a week. It has improved my mood and helped me to get out the house more often. It has helped me both mentally and physically. I also go to the gym with my friend, so it has given me a social outlet.

I think it helped me with going to school because it has improved my mental health which makes it easier to go to school."

**Early Intervention** - A client with autism and selective mutism received a PHB to purchase Logic Pro so that he could pursue an interest in music production. His Mum shared:

"The Personal Health Budget funding has been most beneficial as it has been able to provide targeted support, which is more beneficial to O. Initially, O was worried that the Navigator would 'make him go to groups and things', so being able to explore different support options and tap into his love of music has been important.

O is using his Logic Pro software every day to make music and to incorporate his music and song writing. He can record his instruments individually then mix everything together and has even released a debut album through Instagram, which is available through Spotify, Apple Music, iTunes and Deezer. As O has selective mutism, this has allowed him to express himself in his own way which is so important for him."

**Crisis Prevention** - A PHB issued for Crochet kit to a young person to support them during an admission to Tier 4 hospital:

“The crochet projects allowed them to keep themselves safe and they can access them independently when needed. It was a game changer at the time for them and they still revert back to the crochet when they are very low.”



**Early Intervention** - The PHB was used to purchase a specialist pushchair for a young person to enable them to engage in activities with their family and feel safe:

“I want to say the BIGGEST thank you for E’s new pushchair. It arrived just before half term so we got to try it out that week & it’s been amazing! I knew it would be helpful but I actually feel it’s been life changing! It’s so easy for us to access so many different places now. And E adores it! She is clearly very comfortable in it and feels safe.”

## Parents shared comments about their experience of the PHB pilot:

“It all happened so efficiently. You have been so helpful and kept me informed all the time. We feel really lucky to have been able to access this support.”

“The day after receiving the ear defenders we went to the Christmas lights turn on in our local town. It was the best experience we have ever had when leaving the house!”

“The biggest impact is it has helped W see that there are people out there who want to help and want the best for him. He has spent his whole life being excluded from school and being told “no”. As part of his journey to better wellbeing, it has ben a really positive step in the right direction.”

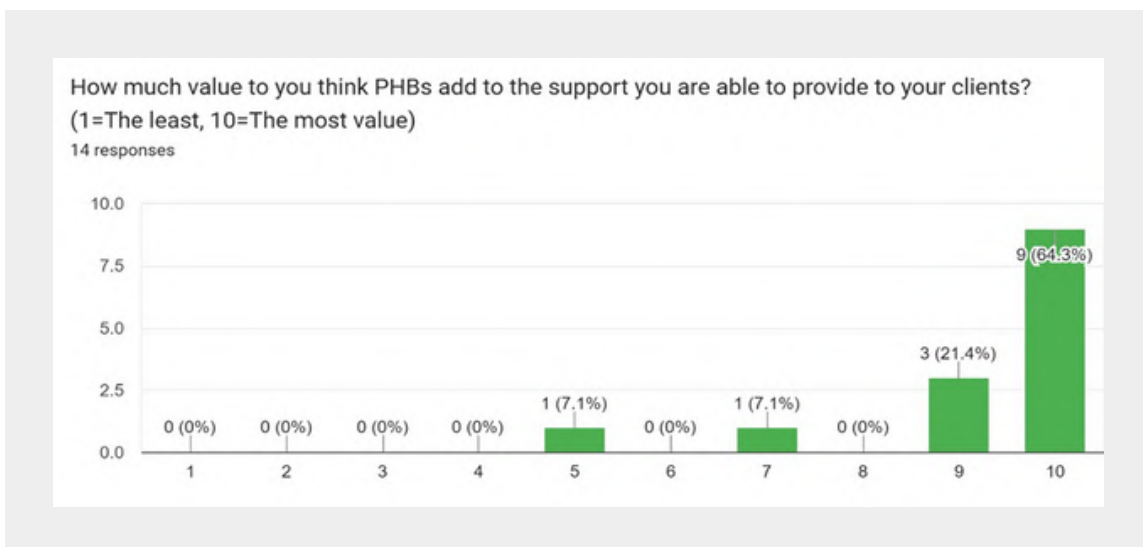
The following Office of National Statistics questions are asked by our Children’s Health and Wellbeing Navigators to gather a snapshot of how a parent (or child) is feeling throughout their support. We have compared scores with clients before they received their PHB compared to after.

Wellbeing Question	Percentage Improvement
Overall, how satisfied are you with your life nowadays?	33.71%
Overall, to what extent do you feel that the things you do in your life are worthwhile?	27.11%
Overall, how happy did you feel yesterday?	39.01%
Overall, how anxious did you feel yesterday?	7.54%
How often do you feel lonely?	17.74%
How often are you physically active?	5.78%
Please tell us how good or bad your health is today?	14.40%
I am able to deal with problems well	22.45%

## Referrer Feedback

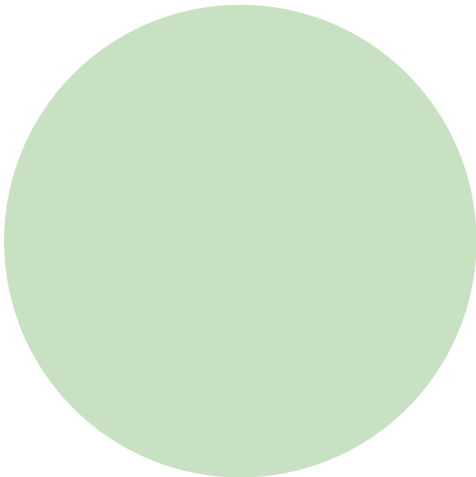
To measure the impact on the workforce and determine whether our process was efficient across the system we sent a questionnaire to all the Children’s Health and Wellbeing Navigators asking them to provide anonymous feedback of their experience of the pilot.

Out of 17 Navigators, we received 14 responses to the questionnaire.



**Overall, do you feel that Personal Health Budgets are a good way of delivering care to Children and Young People who are neurodivergent or suspected to be neurodivergent?**

■ Yes ■ No

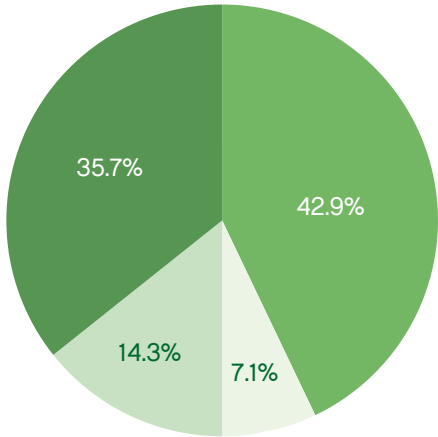


Yes  
100%

The PHB's have funded things which have been really valuable in relation to CYPs mental health and emotional wellbeing. You are able to think out of the box when applying for a PHB, which other funding streams don't always allow you to do so you can really tap into things which are of interest to the children and young people, and which will make a difference to them on an individual level.

It helps families who are in financial difficulties have access to equipment etc. that will make a huge impact to the whole family's wellbeing and health.

It helps to be able to offer funding for my clients that are struggling and didn't think they could get financial support for items to improve their child's wellbeing.



**How much time has referring for a PHB taken you?**

- Less than 5 minutes
- 5-15 minutes
- 15-30 minutes
- 30+ minutes



## Impacting the wider system by making regular data submission to:

### NHS Mental Health Data Set

According to Digital NHS: 'The Mental Health Services Data Set (MHSDS) is a PATIENT level, output based secondary uses data set which aims to deliver robust, comprehensive, nationally consistent and comparable person-based information for PATIENTS who are in contact with Mental Health Services.'

- We have submitted 13 months of data from the PHB pilot and continue to do so
- Following successfully implementing this on PHB pilot, we have since begun to submit data from our PCN Children's Navigation service at Involve

### NHS - ICB Improvement and Assessment Framework

We have also submitted our PHB data to the ICB for submission to NHS England's overall PHB data collection which will be used in the following ways:

'Personal Health Budget submissions will be used as a measure for the ICB Improvement and Assessment Framework every three months. NHS England will use the national headline data in a variety of ways including internal and public reports/publications. ICB level data will be used internally to update regional and NHS England teams to inform ICB assurance. ICB level data will also be given to other relevant NHS England programmes, for example, Transforming Care.'



# 7. LEARNING AND DEVELOPMENT

To ensure continuous improvement as we tested our approach and process. We recorded the challenges and our responses to them.

Some families focus remains on a diagnosis, and this has been a barrier to finding a PHB solution. For example, in one case, the parent wanted a private assessment for diagnosis and was therefore not open to other suggestions. We therefore had very candid conversations with parents and explained that we could not use the funding this way but highlighted the benefits of other forms of support.

We learnt that the most time-consuming part of delivering PHBs is in researching and putting together bespoke solutions for families. Finding bespoke solutions is at the heart of the project so we did not want to lose this, however it was helpful to communicate with the referrers and encourage them to be detailed in their referrals as they already work with the families and are therefore best placed to identify their needs.

Another area which was time consuming was putting together paperwork. We therefore reviewed paperwork to make it as streamlined as possible, whilst still carrying out due diligence.

Initial uptake of Crisis referrals was slow however we identified that this may be due to historic practise of using an alternative fund. To manage this, the project manager met with the referring team on several occasions to continue educating them about the service.

We learnt that using a PHB to fund alternative therapies produced positive outcomes, however, could be difficult to end as families were reluctant to give up a positive service and often alternative therapies are far too expensive for families to privately fund. We addressed this by managing family's expectation from the outset about the limited nature of the funding and planning an exit strategy, e.g. staggering sessions towards the end of the funding to phase-out the therapy and we also supported families to obtain appropriate benefits such as DLA to continue therapies.

We found that some providers were more challenging to purchase from/work with. We aimed to use provider's whom we had had a good experience with, over time beginning to develop a 'bank' of reputable providers.

# 8. CASE STUDIES

## CASE STUDY ONE:

### HIGHLIGHTING LONG TERM OUTCOMES

#### **What were the issues faced?**

Prior to the PHB, R was struggling to access many aspects of school life, he wasn't accessing lessons full time, going to form time, or PE. There were lots of other opportunities he was missing out on because he struggled with noise sensitivity. He had tried noise reducing earbuds before but didn't like to wear them because other children would ask what they were and he felt self-conscious.

R's school were trying to help and had tried various forms of support however these hadn't been right for R. Due to his autism, R found it hard to open up in traditional talking therapy and had spent some time with the school therapy dog, however this had little effect. R had also tried Kooth for quite some time but this had not been a good fit either.

R had keen interests in music, cars and gaming and enjoyed speaking about these subjects.

#### **What were the outcomes identified from the 'what matters to me' conversation?**

The aim for R was for him to be able to attend his lessons full-time, or an increased amount and for him to feel able to talk about his feelings.

#### **What happened?**

R's Mum contacted his GP surgery who put her in touch with Rebecca, the Children's Health and Wellbeing Navigator. Rebecca identified that R could benefit from a Personal Health Budget to provide more discreet ear defenders and some form of emotional support which would be more unique and suited to R's needs.

The PHB Project Coordinator contacted Mum and had a conversation about R's needs and what had or hadn't worked in the past. It was identified that Loop ear defenders may be a good resource for R to use as these can be very discreet and offer varying levels of noise reduction depending on the need.

During the conversation, Mum also shared that she had heard of an online, technology-based, mentoring service called MindJam in a webinar and thought this could really work for R because of his interests in gaming and music. After some liaising with MindJam, it was established that this could work well for R however there was a waiting list of a couple of months. It was decided that this seemed like the most appropriate route for R so joined the waiting list and the ear defenders were purchased in the meantime.

Once a place became available with MindJam, R was matched with a mentor, who is also a musician, and started attending MindJam sessions monthly. The first few sessions were used to talk and build rapport and R then suggested that they focus on making music. During the following sessions, R and his mentor worked on music and even created a song.

## **What was the impact?**

A year on since the initial referral, R is now attending all his lessons at school. Mum shared that this was slow at first but since going back to school in September, he seemed much more positive, and things have been really different. School was really supportive, but MindJam also really helps. Through his love of music his mentor has given him someone outside of his family and friends whom he can rely on.

It has not just helped his mental health, but also has enabled him to learn skills related to something he is passionate about. R had used the software before at school but lacked confidence to use it at home but with the support of his mentor he is proactively progressing with his interest. He is also spending more time in the music department at school because he feels more confident in his music skills.

In addition to MindJam, R is now coping much better with loud noises at school. He no longer wears his earbuds, but he used these at first and they seemed to help whilst he became more used to the noises.

Mum feels that if anything was going to work for R, then this was it and shared that being able to tailor something to R's specific needs was really important.

## **What will the next steps be?**

It would be great if R could continue with MindJam moving forwards as its great for his confidence and a way for him to relax doing a hobby he enjoys. R has exams coming up in the next year or so and it would be good if MindJam could support him to continue at the level he is at.

UPDATE: Due to the success of MindJam, Mum felt it was important for this to continue so Mum and the PHB Coordinator discussed options for continuing this support including the use of Disability Living Allowance which Mum was in the process of applying for and linking Mum to the SEN Support Officer at MindJam. It was agreed that the PHB could be extended temporarily whilst these options were explored. During this time, R's application for DLA was accepted and the family are now able to use this to fund ongoing MindJam sessions.

## **CASE STUDY TWO:** **HIGHLIGHTING HOW SIBLINGS ARE IMPACTED**

### **What were the issues faced?**

Prior to the PHB, L had been diagnosed with autism, sensory processing disorder and showed traits of ADHD. He struggled with loud environments and would wake up multiple times throughout the night, taking about an hour to settle each time. L uses sign language to communicate and would often sign 'loud' and cover his ears in noisy settings. He also wanted to hug Mum tightly at bedtime to soothe himself and go to sleep – this could sometimes hurt Mum's neck. L would seek sensory feedback from standing on items such as books which he would seek out. He would also find bright light difficult, and this caused him distress. Mum was finding it difficult to take L and his sister out the house because he often struggled with external factors, this limited how often L could go out but also impacted his sister and Mum's wellbeing.

### **What were the outcomes identified from the 'what matters to me' conversation?**

L is not able to communicate verbally but it was identified that items to support his sensory needs would help to calm him and reduce stress and anxiety.

## What happened?

L's Children's Health and Wellbeing Navigator identified the need for L's sensory needs to be settled. The PHB project coordinator contacted L's Mum and agreed on items which would meet this need. Mum had done a significant amount of research into L's health conditions and the sensory items which were recommended to support him so was able to coproduce the solution with her input. A PHB was issued to provide a sensory package for L which consisted of ear defenders, a weighted vest, weighted blanket, sensory play mat, black-out sensory den, and a small selection of sensory lighting.

## What was the impact?

The feedback from Mum was that all the items have been excellent, and they have all been used every day.

The ear defenders have made such a positive impact. L is now able to go out in crowded places and enjoy himself, whereas he would have never done this before. The day after receiving them, Mum, L and his sister went to the Christmas lights turn-on in their local town (the first time they went into town in over a year), and this would usually be a really difficult situation for L due to the loud noises, but he asked for his ear defenders and was happy. Mum described it as "the best experience they have ever had when going out the house!"

L really loves the sensory play mat and uses it exactly as Mum predicted, by lining it up so he can walk along it like a path and licking them to gain the sensory feedback. Mum leaves his toys in a trolley, and he always goes to get the playmat. Mum said the mats have 'almost become a part of him and his everyday play.' L loves the blackout den and finds it really funny to go inside it. Mum feels that it has provided a safe space for him. He has recently started saying that there is a spider in his bed (something he is scared of but Mum says is the first time he has used his imagination so she is really pleased! – she wonders if the new toys have helped to spark his imagination) so they will use the blackout den as a safe space where he can still have darkness which settles him. The lights have also been excellent, and L loves the sensory feedback he gets from touching them. Mum has also been able to use the dinosaur lights to support him at night-time when he mentions the spider.

Mum has seen a real improvement in L's behaviours recently and says that the different groups and professionals they have met with recently have commented on L's progress saying that his eye contact has improved, and he is playing more, and Mum thinks the sensory items have had a big impact on this. He is also engaging with his sister for the first time, asking her to smell candles which he likes the smell of.

## What will the next steps be?

Mum plans to continue using the sensory items daily with L and will also try to go to more places outside of the house now that L has a means of reducing anxiety in these circumstances. This will also allow his sister to do more out of the house. Mum will continue to attend groups with L and hopes to carry on seeing the positive outcomes from his PHB.

The Children's Health and Wellbeing Navigator will continue to provide other support which is required.



## CASE STUDY THREE:

## HIGHLIGHTING THE IMPACT ON SCHOOL AND HOME LIFE

### What were the issues faced?

Prior to the PHB, B was struggling to regulate her emotions and energy levels. She was very hyperactive which the GP felt was more likely stimming than hyperactivity. B shared a room with her sister and there could often be tensions because of her high energy levels. B was not sleeping well at all which kept her sister up at night. She would also become upset at school because she struggled to sit still and therefore didn't focus well.

She had an upcoming school trip which she was very anxious about because she wanted to go but was worried that without her home comforts, she would find it overwhelming.

## **What were the outcomes identified from the ‘what matters to me’ conversation?**

What were the outcomes identified from the ‘what matters to me’ conversation?

The aim for R was for him to be able to attend his lessons full-time, or an increased amount and for him to feel able to talk about his feelings.

## **What happened?**

It was agreed that a PHB would be used to purchase items which could create a private space within Bs bedroom which could be used to relax and regulate. To do this, a curtain track and curtain were purchases to go around Bs bunk bed. It was also agreed that a wobble cushion and chair kick-bands would be purchased for use both at home and school so that B could move around in a controlled way which did not distract others but enabled her to release her energy. Finally, it was agreed that a sensory sock would be purchased for use at home to support B with feeling calm and grounded, particularly at night-time. This sock could also then be taken on the school trip to provide comfort and continuity.

## **What was the impact?**

Mum advised that the impact was ‘amazing’. The curtain around her bunk bed and sensory sock enabled B to feel more settled at bedtimes which has significantly reduced tensions between her and her sister. She is now sleeping much better than previously. Mum has since purchased some sensory lighting to create an even calmer space which has worked well.

B also took the sensory sock on her school trip and slept in it every night which made her feel more comforted and secure. Her and a friend even used it on the coach and said it made them feel safer. She loved her school trip and the teachers commented that she was the only one who was enthusiastic and had a smile on her face for every activity. Mum thinks that the comfort of the sensory sock really allowed her to relax and enjoy herself.

She is using the kick bands at school, and this is working well. She now feels calmer at school and is no longer becoming upset because she struggles to sit still. B also uses the kick bands at home, and she no longer kicks her sister under the table which has reduced arguments. She loves the wobble cushion and doesn’t sit on any chair without it.



## **What will the next steps be?**

B is moving to secondary school this year and therefore will continue to use the items to support a smooth transition.

## **CASE STUDY FOUR:**

## **HIGHLIGHTING SOLUTIONS THAT ARE BESPOKE TO THE PERSON AND SITUATION**

### **What were the issues faced?**

Prior to receiving a Personal Health Budget, A's school suspected she may have autism and possible OCD but no referral had yet been made.

A was experiencing anxiety which was preventing them from going to college. When anxious, they would have pain in their legs, preventing them from walking and this was often triggered by being around other people. She was only leaving the house with Mum of for the occasional walk when it was late and others would not be around. Mum had tried to take her to counselling but this would cause more anxiety. A's sleeping pattern was quite poor and they would be awake all night and then sleep through the day, even when taking prescribed medication.

A acknowledged that she might be depressed and was only eating one meal a day and losing a lot of weight.

A had no support in place outside of the family. Early Help could only offer group therapy which A was unable to attend due to their anxiety and therefore Early Help had closed their involvement. A was on a waiting list for CAMHS but had been waiting a long time.

## What were the outcomes identified from the ‘what matters to me’ conversation?

Through an in-depth discussion with Mum, it was identified that A’s only motivator was spending time with animals. Mum had previously considered horse riding but due to cost this had not been an option. It was agreed that the PHB could fund some horse riding sessions with the aim of using this to motivate A to get out the house and into a better sleeping pattern which would then mean they would be able to access other daytime activities or support.

Mum went away and spoke with A as recognised that this needed to come from her and A agreed that they would like to try the horse riding.

## What happened?

The PHB coordinator sourced a riding school which was local to the family and had availability on days which Mum was able to take A. The PHB coordinator then paid for a block of lessons upfront and connected Mum with the school to organise lessons.

Through research, the PHB coordinator also identified that the riding school offer RDA (Riding for the Disabled) sessions at a reduced cost which could be a means of A continuing the lessons longer term if they have a positive impact.



## **What was the impact?**

Upon review, Mum shared that the PHB has had a really positive impact on A. It motivates her to get out of bed and attend which means that she is now leaving the house more. It has not entirely improved A's sleeping pattern however Mum recognises that this is unlikely to be an overnight fix and Mum feels that nothing else would get them out of bed at all. A has made a good relationship with the riding instructor and Mum feels that it has brought her out of herself more.

A has also become more aware of their health and fitness levels as they are keen to improve muscle tone to be strong enough to ride well.

Five months on from when the initial PHB was issued, A is doing a little better and is just about to resume riding lessons through the RDA (Riding for the Disabled Association) which offers riding lessons at a discounted rate which is more affordable for the family. An autism referral has now been made and A is waiting for the outcome of this but recognises that the priority is to find ways of meeting her needs currently, including moving into work rather than education and has some interviews lined up, a big step forward from where she had been earlier this year.

## **CASE STUDY FIVE:** **HIGHLIGHTING THE IMPORTANCE OF MULTI-** **AGENCY WORKING**

### **What were the issues faced?**

N was preverbal and suspected to have autism spectrum condition. He was receiving support from the Portage Home Visiting Service and being referred to a paediatrician following development concerns by the health visitor.

N also became distressed at bath times and did not like the feeling of having a bath. The family did not have access to a shower over the bath and therefore this could be difficult.

N's Mum would also struggle when taking him out the house because he could become very distressed. She noted that she had to wait for her partner to come home from work before she could do the food shopping because she could not take N with her.

N was not yet speaking, and Portage had suspected sensory processing disorder. Mum was keen to support N's development as best she could but did not have access to the resources needed to provide continuity for him between his sessions from Portage.

## **What were the outcomes identified from the 'what matters to me' conversation?**

To have the best support to further development, particularly around communication and to support N to feel less distressed during daily activities like bathing or leaving the house.

## **What happened?**

The Children's Navigator referred N for a Personal Health Budget (PHB) to enable Mum to access resources required for furthering his development and communication. The PHB coordinator contacted Mum to discuss what sorts of resources were needed and it was agreed that both Mum and PHB coordinator would carry out some further research into what resources were available. The PHB coordinator also reached out to Portage to ask what specific resources they used with N so that Mum could provide him with continuity between appointments and Portage were able to provide some information.

A package of items was agreed upon which included spinning bell carousel (specifically recommended by Portage), a sensory feet play mat, a soft play step set, a mini shower (as N struggled with bathing due to not liking the sensory feel of a bath) and a beanbag.

## **What was the impact?**

At evaluation, Mum advised that N was doing really well and engaging with all the items as hoped. He particularly enjoyed the floor tiles and would walk across them with bare feet for the sensory feedback.

Portage continued to visit every other week and the practitioner had highlighted that she felt N's problem-solving skills were improving.

Mum advised that having the items used by Portage at home meant that in his sessions, N would know what to do with them straight away and therefore there was more time for progress within each session. Previously it may have taken N some time to get to grips with each item.

Mum advised that N really enjoyed using the bean bag armchair and despite having the use of 3 other chairs and the sofa, would always take this chair with him so it clearly provides him with great comfort and makes him feel calm.

The shower had a great impact and N now enjoys bath times and likes water, something which could previously be quite difficult. His family had even started to take him swimming. Mum felt that the soft play steps seemed to teach him to walk down steps more safely than he previously did.

The fidget board was also helpful, especially when leaving the house. Previously if the family tried to go for a meal or to the supermarket, N would be very distressed and would scream the whole time. Now, they will take the fidget board with them, and he will play with this, and it helps him to feel calm.

Mum advised that she used to have to wait for her partner to come home before she could go do the shopping so that he could watch N, but now she can take N with her which has had a big impact.

## **What will the next steps be?**

N is waiting for input from various professionals and his navigator is continuing to support the family to make referrals however there may be long wait-times for these referrals, so the PHB has been able to begin N's support whilst they wait.

# 9. CONCLUSION AND NEXT STEPS

The Personal Health Budgets (PHB) pilot has shown positive outcomes for children and young people with autism and their families, with a clear focus on prevention and crisis management. Extensive evidence shows there are significant delays on autism diagnosis, with minimal support offered either during this time or following diagnosis (for example Crane et al, 2016). The PHB pilot service offered support to children, young people and their families during this time to alleviate some of the challenges they may be facing, which included emotional regulation, sleep concerns, access to activities and access to education. Providing this service also helped parents and carers who were facing financial challenges, by providing equipment or services that would make a difference to their family but were financially not viable. The pilot showed that the biggest demand was for sensory items, along with activities (sports-based or other).

One of the most significant findings was the importance of offering a personalised service. Evidence has highlighted a need for personalised services that put the family in the centre of interventions, with appetite for this being higher than for a referral to a generic service (for example Galpin et al, 2018). The PHB pilot service offered a highly personalised service that catered for individual needs that would offer most support to the child, young person or their family.

Amongst feedback provided, one parent highlighted the importance of providing a tailored service as their child had expected to be pressured into attending groups. This shows that there is an expectation from some service users that they will be pressured into things they do not want to do, which may impact on their uptake of services and ultimately delay interventions. By offering a personalised and responsive service, the PHB pilot was able to engage with service users who were distrustful or cautious of accessing services and to build a good relationship, allowing them to access the support they need.

Data and feedback collected showed meaningful impact on children, young people and their families. Wellbeing scores focussed on physical, mental, emotional and social wellbeing all increased by a minimum of 30% per measure per person. The biggest changes were seen in emotional wellbeing scores, with early intervention emotional wellbeing scores increasing from 3.95/10 by 55.7% to 6.15/10 and crisis prevention emotional wellbeing scores increasing from 3.36/10 by 56.85% to 5.27/10.

Qualitative data from children, young people and their families has demonstrated how the PHB pilot service has reduced their isolation by providing

providing items to help them get out and about more, for example ear defenders to help regulate in busy places, or a pushchair to help transport the child. Whilst not formally measured within the pilot, there were several examples of improved attendance at school as a result of accessing the service. Gym memberships, exercise equipment and activity group fees were popular amongst items/services requested through PHBs, resulting in improved social opportunities as well as improved physical health outcomes.

Basing this provision within the Voluntary and Community Sector (VCS) has

demonstrated an excellent return on investment and evidences good practice in partnership work between KCC, NHS Kent and Medway and Involve. The VCS is equipped with highly trained staff and is trusted by communities. The sector can work in a more agile and responsive way, resulting in ability to deliver innovative pilots such as PHB. We hope to continue to work with statutory partners on this and other services, supporting statutory provision with innovative, responsive and impactful services.

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## ABOUT INVOLVE

Involve's mission is to help people live **happier, healthier** lives. Empowering communities to live well by tackling the root cause of ill health, including isolation, loneliness, disadvantage and frailty.

In 2023/24 Involve supported:

**26,655** adults, children, young people parents, and carers.

Involve are leaders in social prescribing and other innovative approaches to improve wellbeing in communities.



## PUBLISHED BY:

### **Ellen Albinson**

Children's Services Operations Manager

### **Katy Abson**

Head of Children's Services

[katy.abson@involvekent.org.uk](mailto:katy.abson@involvekent.org.uk)

### **Jane Thomas**

Director of Services

[jane.thomas@involvekent.org.uk](mailto:jane.thomas@involvekent.org.uk)

### **Lizzie Lowrey-Crouch**

Head of Partnerships and Innovation

[lizzie.lowrey-crouch@involvekent.org.uk](mailto:lizzie.lowrey-crouch@involvekent.org.uk)



[www.involvekent.org.uk](http://www.involvekent.org.uk)  
[hello@involvekent.org.uk](mailto:hello@involvekent.org.uk)

30 Turkey Court, Turkey Mill, Ashford Road,  
Maidstone, Kent, ME14 5PP | 03000 810 005

Charity No. 1066911 | Company No. 3449624