

Review of Promised Actions and Parent Carer Experience: 2022–2025

Executive Summary

This report looks at whether the commitments made by local health and care providers in response to the 2022 *"I am different, not less..."* report have led to better experiences for Parent Carers accessing mental health services for children and young people with SEND in Milton Keynes.

We've drawn on:

- The original 2021 PACA survey, which highlighted key issues,
- The formal action plans shared by CNWL, CAMHS, and the CCG (now BLMK ICB) in 2022, and
- A follow-up survey carried out in early 2025.

The aim is to check whether those actions have been followed through and whether families feel their experience has changed as a result.

Introduction

In February 2022, PACA MK and Healthwatch Milton Keynes published *"I am different, not less..."*, a report built on the real experiences of Parent Carers navigating mental health services in the area. The findings reflected deep concerns about access, clarity, waiting times, and lack of support, as shown in the results of the PACA survey conducted in June 2021.

The response from providers and commissioners was encouraging, with a series of specific actions promised to address the issues raised. However, the landscape changed shortly afterwards when the NHS reorganised commissioning, and the CCG became part of the BLMK Integrated Care Board (ICB). With a new system in place, some commitments risked being lost in the transition.

In early 2025, PACA MK ran a follow-up survey to check whether families were experiencing any difference. This review brings together the original concerns, the promised actions, and the current feedback to see what's changed and where attention is still needed.

Methodology

This report draws on three key sources:

1. **The 2021 PACA MK Survey**, which gathered Parent Carer feedback on service experiences and was the basis for the 2022 report.
2. **The 2022 provider responses**, which outlined the actions CNWL, CAMHS, and the CCG committed to taking.
3. **The 2025 PACA MK Survey**, designed to see whether the services feel different to families now.

We've reviewed these sources side-by-side, pulling out key themes and checking whether the actions taken have addressed the original problems.

Promises vs. Progress

1. Clearer CAMHS Referral Pathways

What was promised:

CNWL agreed to create a clear, visual guide to help families understand CAMHS referral processes. PACA MK was to help share and explain this information.

What families say now (2025):

74% of parents said they know where to find mental health support information – a positive shift. However, only 23% had completed a self-

referral, which suggests families may still need more support navigating the system.

Summary:

Improved awareness, but confidence and clarity still have room to grow.

2. Shorter Waits for Diagnosis and Support

What was promised:

Providers committed to reducing waiting times, trialling new diagnostic pathways (not reliant on consultants), and improving early screening.

What families say now (2025):

The survey didn't specifically ask about current wait times. From earlier feedback, we know some families waited 18 months or more. Without updated figures, it's hard to say whether things have improved.

Summary:

Some changes likely made, but impact not clearly felt or reported by families yet.

3. Better Post-Diagnostic Support

What was promised:

CNWL funded pilot sessions through Autism Bedfordshire and said they would adapt the Bedfordshire Post-Diagnostic Pack for local use in Milton Keynes.

What families say now (2025):

This area wasn't directly addressed in the follow-up survey, so we can't yet assess whether families are receiving this support. We know, however that the newly established Mental Health Support Teams in schools are not able to support children who are on waiting lists for assessments or treatment. These children are being denied the behavioural and wellbeing support that they clearly (by way of meeting the criteria for the waiting lists) need.

Summary:

Little progress – this area needs follow-up and visibility.

4. Support While on Waiting Lists

What was promised:

Families were promised clearer communication, regular updates, and interim support while waiting for CAMHS services.

What families say now (2025):

Again, this wasn't directly asked in the latest survey. Earlier concerns about being "forgotten" and unsupported during long waits were significant, and without fresh insights, it's hard to confirm whether things have improved.

Summary:

Still a known pain point – clearer communication and reassurance are essential.

5. Using 'Condition' Instead of 'Disorder'

What was promised:

CNWL committed to using 'Autistic Spectrum Condition' instead of 'Disorder' in all service language.

What families say now (2025):

There's no indication this change hasn't been upheld – it seems to have been adopted positively and consistently.

Summary:

Actioned and well received.

6. Transitions to Adult Services

What was promised:

A transitions nurse, mentoring pilots, and a dedicated CAMHS Transition Worker were introduced to help bridge the gap between children's and adult services.

What families say now (2025):

This topic didn't come up in the survey data. However, it's an area PACA MK continues to hear about in forums and focus groups.

Summary:

Progress unknown – more targeted feedback needed.

7. Improved Access to Respite and Short Breaks**What was promised:**

The Council pledged to improve short break services and after-school provision, with updates shared on the Local Offer.

What families say now (2025):

This wasn't covered in the 2025 survey.

Summary:

Not assessed – this area needs further attention and communication.

Conclusion and Recommendations

While there has been progress in some areas – especially around awareness and more inclusive language – many of the deeper challenges Parent Carers reported in 2021 are still present in 2025. Several key promises have not yet been actioned.

Making a promise is a good first step. But to truly change experiences for families, those promises need to be followed by regular reviews, honest reflection, and a willingness to listen. That's how we will build a system that works for everyone.