

Autism Community Partnership Group (CPG) Narrative Summary Report Meeting held 4th March 2026

Purpose of the Meeting

The Autism Community Partnership Group (CPG) brought together autistic people, carers, voluntary sector organisations, health and social care professionals, and local partners to share lived experience and explore how autism services across Central Bedfordshire can be improved. The meeting formed part of the wider Community Partnership Group programme commissioned by Central Bedfordshire Council and facilitated by Healthwatch Central Bedfordshire.

The session focused heavily on the realities of accessing support, the impact of late diagnosis, gaps between services, and the need for more personalised and coordinated care pathways. Throughout the evening, participants consistently highlighted the importance of being listened to, understood, and actively involved in decisions affecting their lives.

The meeting agenda was designed to explore lived experience through open discussion and reflective conversation, with a strong emphasis on understanding what effective support should look like for autistic people across the lifespan.

Key Themes Emerging from the Meeting

1. The Emotional and Practical Impact of Late Diagnosis

Guest speaker Toni Horn shared her experience of receiving an autism diagnosis in adulthood after many years of feeling **“different”**, misunderstood and unsupported. Her presentation resonated strongly with attendees and prompted open discussion around the emotional impact of growing up undiagnosed.

Participants spoke about anxiety, masking, exhaustion and self-doubt, alongside the relief and validation that diagnosis can bring. However, many also described feelings of grief and frustration around missed opportunities and years without appropriate support.

A consistent theme was the lack of meaningful post-diagnostic support, with several attendees describing diagnosis as being **“left to get on with it”** or **“feeling stranded”** following assessment. While many participants described feeling relief and validation after finally receiving a diagnosis, this was often followed by frustration at the lack of follow-up support, guidance or coordinated care.

Participants also highlighted concerns that some healthcare professionals appeared to have limited understanding of autism and autistic experiences, contributing to feelings of mistrust and difficulty accessing appropriate support. There was a strong feeling that

clearer pathways, better coordination and improved autism awareness across services are needed, particularly for women and girls who often experience additional barriers to diagnosis.

2. Long Waiting Times and System Pressures

Attendees expressed significant concern regarding lengthy waiting times for autism and ADHD assessments, with some describing waits of several years and ongoing uncertainty around referral pathways.

Participants described the impact of delays as far-reaching, including increased anxiety, deterioration in mental health, delays in educational support and families feeling unsupported whilst waiting for assessment. Some individuals reported disengaging from services altogether.

There was also discussion around inconsistencies in access to services across different areas, often described as a “*postcode lottery*”. Several attendees noted they had only learned about alternative routes such as “*Right to Choose*” through peer support networks rather than through formal professional advice.

The discussion reinforced that delays are affecting not only diagnosis, but also timely access to therapeutic and follow-on support.

3. Gaps Between Autism, Mental Health and Social Care Services

A strong theme throughout the meeting was the perception that many autistic people are falling between service thresholds, particularly between autism, mental health and social care pathways.

Participants reported difficulties accessing coordinated support, especially for autistic adults who do not meet social care criteria but still require ongoing assistance. Families often described themselves as the main coordinators of care, particularly during periods of crisis.

Concerns raised included inconsistent crisis responses, poor communication between services, delays in carers assessments and limited opportunities for regular reviews with professionals. Several attendees also felt that support reduces significantly once individuals transition into adulthood.

There was particular concern for autistic people who may struggle to communicate distress or seek support independently, increasing the risk of isolation and unmet need.

4. The Importance of Communication, Understanding and Relationships

Participants consistently emphasised that positive relationships and effective communication are central to good support experiences.

Attendees valued professionals who listened without judgement, communicated clearly, understood autistic experiences and provided continuity and consistency. In contrast, negative experiences were associated with feeling dismissed, unheard or excluded from decisions.

Discussion also highlighted the importance of recognising different communication styles and avoiding assumptions about autistic people. Behaviours often described as “**non-compliance**” were reframed by participants as possible indicators of overwhelm, distress or unmet need.

The emotional impact of masking and continually adapting to non-autism-friendly environments was also discussed as a significant source of exhaustion.

5. Limited Choice, Accessibility and Personalisation

Many participants felt they had limited choice or influence over the support they received. Concerns included restricted choice of professionals, limited involvement in decisions during crisis situations and financial barriers to accessing specialist or private services.

Attendees also described inconsistencies in service quality and availability depending on location, alongside difficulties accessing suitable supported living options.

A recurring theme was that systems often feel process-driven rather than person-centred. At the same time, participants recognised the important role voluntary and community organisations play in filling gaps in support, despite often operating with limited funding and capacity.

Autism Bedfordshire, MIND and peer support networks were repeatedly highlighted as valuable and trusted sources of support, advice and connection.

6. Loneliness, Isolation and the Need for Safe Community Spaces

Loneliness and social isolation emerged as significant emotional themes throughout the meeting.

Participants described how autistic people can struggle to feel understood, access social opportunities or discuss concerns openly within mainstream settings. However, there was also a strong desire for connection, belonging and safe spaces where people feel accepted.

Attendees highlighted the value of peer support groups, safe online communities and community-based services that promote independence whilst providing stability and understanding.

The discussion reinforced that emotional wellbeing, social inclusion and community connection should be viewed as essential components of autism support, rather than secondary considerations.

Opportunities Identified Through the Discussion

Participants identified several opportunities to strengthen autism support pathways and improve the overall experience for autistic residents and their families. Key themes included:

- The importance of clearer post-diagnostic support and signposting.
- Improved coordination between health, social care and voluntary sector services.
- Greater autism awareness and understanding across frontline services.
- More accessible community-based, housing and preventative support.
- Consistent access to services regardless of location, financial circumstances or ability to self-advocate.

There was also strong recognition of the valuable role played by voluntary and community organisations, peer support networks and autism-informed services in supporting autistic people across Central Bedfordshire.

Overall Reflections

The meeting provided a valuable insight into the lived experience of autistic people and carers across Central Bedfordshire. While participants acknowledged examples of positive and compassionate support, many described services as difficult to navigate, inconsistent and heavily reliant on individuals and families advocating for themselves.

Importantly, the discussions remained constructive and solutions-focused throughout. Participants demonstrated a strong willingness to work collaboratively with commissioners, providers and community organisations to explore practical improvements and shape more accessible, joined-up and person-centred services.

Key themes included:

- The need for stronger post-diagnostic support and continuity of care.
- More joined-up, personalised and autism-informed services.
- Earlier intervention and preventative support.
- Greater involvement of autistic people in shaping future services.
- The importance of lived experience in commissioning and service design.

The meeting also reinforced the value of the Community Partnership Group model itself. Bringing together autistic residents, carers, voluntary sector organisations and professionals created a constructive environment where concerns could be openly discussed alongside potential solutions.

The willingness of participants to engage thoughtfully, share experiences honestly and contribute ideas for improvement demonstrated the significant potential of the group to support ongoing co-production and future service development.

The Community Partnership Group continues to provide an important mechanism for capturing authentic experiences, identifying emerging issues and shaping future commissioning priorities through collaboration, shared accountability and co-production.