mASCot Position Statement

Risk, Responsibility & Hidden Need in Neurodivergent Pathways
Summary Version

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Introduction

mASCot is a parent-carer led autism support community with around 2,500 member families across Brighton & Hove and East & West Sussex. We work closely with neurodivergent children, young people and their families, and regularly engage with local services and system partners, including the Autism Partnership Board.

This statement follows discussion at the December 2025 Autism Partnership Board, where significant concerns were raised about access to Sussex Partnership NHS Foundation Trust support and related pathways, including waiting times, pathway gaps, family strain, crisis risk and the lived experience of autistic people and families. [1]

mASCot's position is that the issue raised at that meeting was not primarily about participation, consultation or further experience-gathering. It was about what is happening in practice for autistic children, young people and adults whose needs are not being clearly held across current pathways.

This is not a new issue and not an information gap. A substantial body of evidence already exists locally and over many years, describing unmet need, long waits, exclusion from services, inconsistent responses after private or Right to Choose diagnosis, family trauma and wider community impact.

The central question is no longer whether these experiences can be described. They have been described repeatedly. The question is what has changed in response, and who is taking responsibility when need remains unmet.

1. This is not new

mASCot has been raising concerns about unmet neurodivergent need since it began in 2008, including with local authority and health partners.

These concerns include:

- unmet need
- exclusion from services and pathways
- long waits

- inconsistency after private and Right to Choose diagnosis
- family trauma, exhaustion and financial burden
- wider community impact
- lack of clarity about who holds responsibility when people fall between services

These issues have also been relevant since the 2014 Brighton & Hove Autism Scrutiny Process and subsequent scoping work. [8]

The concern is not that no one has ever listened, or that no change has ever happened. The concern is that these issues have been raised repeatedly over many years, yet the larger questions remain unresolved:

- What has changed in practice?
- Who has checked that change has happened?
- How is improvement being evidenced?
- Where do the consequences of unmet need go?
- Who is expected to absorb those consequences?
- Who is now leading the response at system level?

2. This is not an input gap - it is an action gap

mASCot has already contributed extensive evidence and lived system intelligence over many years. The issue now is not whether parent-carer or neurodivergent voices can be invited into another room. The issue is what services are doing in response to what has already been raised.

Across recent system discussions, the focus remains heavily on development, redesign, communications, pathway refinement, engagement activity and measurement. These may all have value, but they do not answer the central question:

What has tangibly improved for autistic children, young people, adults and families in practice?

This concern is reinforced by recent CAMHS material, including the question: "How many people actually get better by accessing CAMHS?" The point is not whether activity is taking place, but whether that activity is producing meaningful improvement in people's lives, and how that improvement is being understood and measured. [2]

Recent LEAP minutes show that neurodevelopmental pathways are still being refined, including work on patient communications, standard operating procedures, template letters, text messages, escalation routes and processes for people not accepted onto the pathway or becoming unwell while on it. [3]

This indicates that key operational elements are still being shaped while families continue to experience delay, uncertainty and unmet need.

Further engagement activity can create the appearance of movement without resolving the underlying gap. Repeated engagement without corresponding action stops functioning as meaningful involvement and begins to function as delay.

3. This is a responsibility-for-risk problem

The issue underneath all of this is harm, distress and responsibility.

Neurodivergent communities are already known to face elevated levels of self-harm, suicidal distress and crisis. Local public health data cited in APB-related correspondence indicates that 36% of neurodivergent adults reported having attempted suicide, compared with 12% of the general population. [6]

Recent national research also reinforces concern about elevated suicide risk among autistic people and links this with systemic factors including delayed diagnosis, unmet need and negative service experiences. [7]

Recent CAMHS material described waiting not as a pause, but as a period of harm, uncertainty and deteriorating trust. Young people described feeling forgotten, invalidated and forced to get worse before they could access help. [2]

This means harm is not only occurring outside the system. It may also be arising within current system conditions.

Families experience this when they are passed repeatedly between GPs, mental health services, social care and neurodevelopmental pathways without clear ownership, continuity or resolution.

This creates a revolving-door experience in which responsibility is displaced rather than held.

In some cases, families describe children and young people in acute distress, including suicidal distress, being told that no support can be offered. This is experienced not simply as a system under pressure, but as a system that may fail to respond even when need is acute, visible and clearly beyond any reasonable threshold for concern. [9]

Where harm is recognised but not clearly owned, families and voluntary-sector organisations are left carrying it informally.

4. A high-risk group may remain structurally under-recognised

A significant concern is that a high-risk group of autistic people remains insufficiently recognised within current pathways and service design.

Recent CAMHS material refers to over 11,200 young people waiting for neurodevelopmental assessment in Sussex, with a five-year wait for ADHD and autism assessment, growing by around five months per calendar month, and around 900 referrals per month. [2]

Separate LEAP minutes refer to a 12,000-person list, while noting that the pathway targets only a small portion of that population. [3]

This shows the scale of the mismatch. The issue is not only that pathways are under pressure. It is that a large population is living with neurodivergent need that is not being meaningfully held through the pathway itself.

This includes people who:

- are waiting for assessment
- are using Right to Choose or private routes
- do not meet thresholds
- are not accepted onto pathways
- become more unwell while waiting
- have needs that are recognised but not met through existing services

There is also a specific concern about autistic people without a learning disability. While this group is increasingly recognised in policy, their needs are not consistently translated into accessible and effective support.

Their needs may be less visible to services, less likely to meet existing thresholds, or less easily recognised within standard service models.

This is not simply an engagement problem. It is a system-design problem.

If services are designed around the parts of need that are easiest to see, measure or manage, then they may miss the fuller reality of autistic need across the population.

5. Who is not reached by engagement

There is a broader structural issue about who is reached through engagement and co-production processes, and who is not.

Some autistic people and families are unable to access, tolerate or participate in standard consultation, involvement or feedback mechanisms.

This may be because of:

- high distress
- communication differences
- sensory overload
- shutdown
- burnout
- trauma
- fragmented access to support
- socio-economic barriers
- ethnicity or other intersectional factors
- lack of trust in services

This means that some of the people least well held by the system may also be the least likely to appear in the routes through which the system tries to understand itself.

Services may then be designed and evaluated based on feedback from those who can engage, while those who are most overwhelmed, least reached or most unsupported remain largely unseen.

Engagement cannot substitute for system reach.

Nor can the presence of voluntary organisations like mASCot in engagement spaces be treated as evidence that the system has properly reached or understood the wider population affected.

In this case, a wider APB concern was raised and SPFT was asked to take work forward. The practical response appears to have been to invite mASCot into an engagement structure. Whatever the intention, that risks functioning as displacement: the system appears to have acted, while the harder work of properly reaching, understanding and responding to the wider cohort may remain undone.

6. Transitions are a particular area of concern

Transitions appear to be one of the clearest points at which responsibility becomes blurred.

Young people moving between different age-based service boundaries do not necessarily land safely anywhere clear, especially if they are neurodivergent, do not meet thresholds or cannot engage in standard ways.

Services may understand their own pathways as defined, but families often experience transitions as fragmented, uncertain & un-held.

This makes transition not just a pathway issue, but a holding issue.

The same concern applies not only to formal transitions between services, but also to the period after diagnosis, where support is often described but not experienced in practice.

7. Harm is being displaced, not resolved

In practice, harm is being displaced onto:

- families
- primary care
- the voluntary sector

Families continue to absorb the emotional, practical and financial consequences of service gaps.

Primary care, especially GPs, often becomes the default holding space when no other service is clearly leading, despite not being resourced to provide ongoing neurodevelopmental or complex mental health support.

Voluntary-sector organisations such as mASCot are often signposted to by services, but do not have equivalent authority to refer families back into services with urgency or accountability.

This creates an asymmetry: responsibility is transferred, but system accountability is not.

Families and voluntary-sector organisations become informal holding structures without the statutory backing, authority, supervision or resources required to do that safely.

8. The voluntary sector cannot be used as a substitute for system responsibility

mASCot recognises the value and importance of voluntary-sector organisations. These organisations provide essential support to families.

The concern is not the quality of voluntary-sector support. The concern is the increasing reliance on voluntary-sector organisations to carry levels of need that should be formally recognised, resourced and held within statutory systems.

Consultation does not discharge responsibility.

Engagement cannot substitute for a system-led response.

mASCot's presence in meetings or engagement spaces cannot be treated as evidence that the system has properly reached, understood or responded to the wider cohort affected.

There is a danger that unpaid or underfunded voluntary-sector input is used to fill evidence gaps in work the system itself should be undertaking, and that this is then presented as engagement, consultation or co-production without resolving the underlying issue of action and ownership.

This matters because mASCot is increasingly functioning as a lifeline for families in high-distress situations, despite not being resourced, commissioned or protected to act as a statutory holding structure.

We have often said that mASCot should be the icing on the cake. Its role should be to offer additional community groups, peer support and connection. It should not be functioning as a lifeline for families in acute distress or as an informal holding structure for needs that should be recognised and responded to elsewhere.

The fact that mASCot has become that kind of lifeline is not a marker of a healthy system. It reflects the scale of unmet need, displaced responsibility and the absence of adequate formal holding.

9. Voluntary-sector capacity is fragile

This issue is urgent because voluntary-sector capacity is itself fragile.

ASSERT has gone. Extra Time has gone. Healthwatch, in its current form, is being disbanded. [4]

mASCot is a not-for-profit CIC operating with minimal resources and is currently sustained by a very small team supporting around 2,500 families in a reduced and constrained post-COVID grant-funded environment.

There is a real risk that this capacity may not be there in future.

The question for the system is:

What is the statutory contingency plan for the neurodivergent population currently being held by mASCot if this capacity is no longer there?

This is not hypothetical for mASCot. It is a real and immediate concern.

If voluntary-sector holding disappears, the harm does not disappear with it. It is pushed back onto families, into primary care, into crisis services or simply left un-held.

A system under strain cannot safely depend on fragile, informal or shrinking arrangements to carry the consequences of unmet need.

This also sits within a wider context of system change beyond health. Forthcoming SEND reforms and potential tightening of access to statutory education support are likely to increase pressure on families and leave more children and young people without adequate support in school and community settings. Where this happens, need does not disappear. It is more likely to escalate and present later within health and mental health services.

This reinforces that the issue is not confined to one pathway or organisation. It reflects a wider system responsibility across education, health and social care.

10. Where we are now

mASCot is happy in principle to remain connected to relevant spaces, including the Experience Group, where useful.

But mASCot does not believe that participation in engagement structures, on its own, addresses the issue raised at APB.

The unresolved question remains:

Who is holding responsibility now, particularly for those outside thresholds, unable to engage in standard ways, or at transition points, and how is SPFT responding in practice to the evidence that already exists?

The concern raised at APB should not be allowed to drift into a participation route that makes it look as though the issue is being addressed while the more important question of responsibility remains unanswered.

This now requires attention above the level of incremental pathway refinement.

The unresolved issue is not simply whether services can improve communication, leaflets or process. It is whether there will be a system-level response proportionate to a public-health-level pattern of unmet need, distress and family strain.

Where needs consistently sit outside current commissioning arrangements, this should not be treated as a stopping point. It should be treated as a trigger for system leadership to ask how that gap is being addressed and by whom.

The absence of a commissioned response should not mean the need disappears. It should prompt escalation.

mASCot's position

mASCot will continue to ask how this issue is being taken forward in practice, and how any claimed improvements are actually being experienced by families.

mASCot has also developed ideas about how the situation could be addressed differently, including more responsive, preventative and community-linked approaches.

This paper is therefore not only setting out concern. It is also laying the groundwork for a more serious discussion about what a more coherent, effective and sustainable model might look like.

mASCot would welcome the opportunity to discuss:

- how current provision could be strengthened
- how services and mASCot can work together while this community capacity still exists
- how unmet need can be identified and held earlier
- how responsibility can be made clearer
- how voluntary-sector reliance can be made safer and more sustainable
- what a more preventative and community-linked model might look like

At this stage, mASCot's priority is to seek alignment on the nature and scale of the issue, and to ensure that it is addressed at the appropriate level, with clear ownership and accountability.

Conclusion

This is not a new issue and not an isolated pathway problem.

Waiting lists, referral problems and fragmented support routes point to a much wider pattern of unmet need affecting autistic children, young people, adults and families across the system.

The concern is no longer simply whether these experiences can be described. They have been described repeatedly.

The issue is whether there will now be a response proportionate to the seriousness, scale and duration of what families are living with.

This can no longer be approached as a pathway problem alone. It needs to be recognised and responded to as a wider system issue, requiring a step change in how neurodivergent need is understood, held and commissioned.

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References

[1] Autism Partnership Board meeting, December 2025 – barriers to support and recorded lived-experience action.

[2] CAMHS waiting-list presentation, 4 February 2026 – waiting-list impact, "how many people improve through CAMHS?", ND waiting-list figures, prevention/crisis concerns.

[3] LEAP minutes, 17 March 2026 – pathway refinement, communications, escalation processes, "12,000-person list", Right to Choose/private diagnosis concerns.

[4] SPFT Experience Group minutes, 1 April 2026 – Healthwatch disbanding and loss of independent patient/carer/family voice.

[5] Follow-up correspondence with Cara Loreilhe – SPFT responses on private/Right to Choose diagnosis and post-diagnostic follow-up.

[6] Local public health data cited in APB correspondence – 36% of neurodivergent adults reported suicide attempt, compared with 12% general population.

[7] Moseley et al., 2026, Bournemouth University / University of Cambridge – elevated suicide risk among autistic people and systemic factors.

[8] Brighton & Hove City Council Autism Scrutiny Process, 2014, and subsequent scoping work.

[9] Current lived-experience case reported to mASCot during drafting – example of wider family pattern.

[10] Wider parent-carer evidence from mASCot, PaCC, Healthwatch and related local reports; forthcoming JSNA referenced as context only.