mASCot Position Statement

Risk, Responsibility & Hidden Need in Neurodivergent Pathways

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Introduction

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

This statement follows discussion at the December 2025 APB, where significant concerns were raised about access to Sussex Partnership NHS Foundation Trust (SPFT) support & related pathways, waiting times, pathway gaps & the lived experience of autistic people & families. While a formal action was agreed relating to lived-experience work, the issues raised in that discussion were broader & more structural.

This paper sets out mASCot's position on what was raised, what it reflects about current system functioning & why this now requires a clearer response at system level.

Summary

What this statement says

This statement argues that the issue raised at the December 2025 APB was not primarily about participation or further experience-gathering. It was about what is happening in practice for autistic children, young people & adults whose needs are not being clearly held across current pathways.

mASCot's position is that this is not a new issue & not an information gap. A substantial body of evidence already exists, locally & over many years, describing unmet need, long waits, exclusion from services, inconsistency after private & Right to Choose diagnosis, family strain & wider community impact.

The central question is no longer whether these experiences can be described, but what has changed in response & who is taking responsibility when need remains unmet.

Why it matters

Current system activity remains focused on pathway refinement, communications, engagement activity & incremental process change. The more important question is what has tangibly improved in the actual experience of children, young people, adults & families. In mASCot's view, this remains unclear.

The problem is not only one of waiting lists or pathway performance. Those on waiting lists are only the visible part of a wider pattern of unmet need. Beneath that sits a much larger population whose distress may never be fully captured by current structures, but whose lives are being affected across education, family life, employment, housing & health.

In that sense, this is not simply an operational issue. It is a public-health-level pattern of unmet need, distress & family strain across the wider population.

A further concern is that harm appears to be arising within current system conditions, while responsibility for that harm is not clearly owned. Neurodivergent communities are already known to face elevated levels of self-harm, suicidal distress & crisis. Yet families continue to experience fragmentation, repeated passing between services, unclear thresholds & an absence of clear accountability when need is acute.

A structural problem also remains: a significant cohort of autistic people may be insufficiently recognised or served within current pathways, especially where need is less visible to services, less likely to meet thresholds or less easily captured through standard engagement & feedback routes. This is not simply an engagement issue. It is a system-design issue.

What follows from that

Harm is being displaced rather than resolved. In practice, families, primary care & the voluntary sector are often left carrying the consequences of service gaps. For mASCot, this is especially serious because informal, unfunded reliance on voluntary-sector holding, in the absence of adequate statutory support, is now functioning at a level that is unsafe & unsustainable. Organisations such as mASCot have become lifelines for families in high-distress situations, despite lacking the authority, resources or statutory protection to function as system holding structures. This reflects the scale of unmet need & system dependence on voluntary-sector support, rather than any limitation in the value or quality of that support itself.

In this context, mASCot's core concern is that a wider APB question about current lived experience, process reality & where responsibility sits has been at risk of being absorbed into engagement structures, rather than being owned & addressed at the level required.

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

Purpose of this statement

Following the December 2025 APB discussion, subsequent meetings with SPFT & attendance at the SPFT Experience Group, we think it is important to set out clearly where we now stand.

From the outset, mASCot has worked from the position that transparency & accountability are essential if system activity is to translate into meaningful change in the lives of our community.

Our ethos has never been simply to raise issues. It has been to ensure that issues are not only heard but acted on. We have also consistently tried to bring solutions & to work collaboratively with services. It is in that spirit that we are writing this statement.

While mASCot's membership is concentrated in Brighton & Hove, the pathway & waiting-list issues discussed here extend across Sussex.

At the December 2025 APB, significant concerns were raised about long waits, exclusion from pathways, inconsistency after private & Right to Choose diagnosis, lack of clarity around NHS pathways & support, family strain & the wider impact on autistic people & those around them. [1]

Examples of reported improvements through the neurodevelopmental pathway were presented. Some were not reflected in the lived experience shared in the room. This mattered. The issue was not simply what services said they were doing, but whether that was being experienced as real in people's lives.

It was in this context that mASCot raised the question of impact on families & carers.

The formal action recorded in the minutes was:

"SPFT to consider commissioning a lived-experience study on the impact on family & carers." [1]

The wording of the action was clear. The concern for mASCot is how it appears to have been interpreted & taken forward in practice.

Our understanding of that discussion was that a wider structural concern had been raised. The issue was not simply whether more views could be gathered. It was what is happening in practice for a cohort of neurodivergent children, young people & adults whose needs & wellbeing are not clearly held when they do not fit thresholds, cannot access services in standard ways, are left waiting for long periods or sit between pathways & services.

Since then, mASCot has met with senior SPFT representatives, held a further follow-up meeting with relevant leads & attended the SPFT Experience Group.

Having followed this route through, it appears that the original APB action has been interpreted operationally as engagement activity rather than system-level work on accountability, responsibility & lived experience.

This risks a system-level concern about unmet need, harm & responsibility being reframed as a need for further engagement activity.

This statement is not intended as a comprehensive review of all system activity. It draws on recent meetings, presentation material, correspondence & lived system experience as a contemporaneous picture of what is currently being discussed & what families continue to experience in practice.

This is not a criticism of experience-gathering groups or of co-production itself. mASCot can see the value of participating in relevant spaces where appropriate. However, the issue raised at APB was not fundamentally a participation issue. It was a system issue.

From mASCot's point of view, the core points are these:

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1. This is not new

These issues have been raised repeatedly over many years, by mASCot & others. There is already a substantial body of evidence relating to:

- unmet need
- exclusion from services & pathways
- long waits
- inconsistency after private & Right to Choose diagnosis
- family trauma, exhaustion & financial burden
- wider community impact

mASCot has been raising these issues since it began in 2008, including repeatedly with the local authority & health services.

This is not a situation in which the system lacks information. The issue is what has been done with what is already known.

This is why scrutiny matters. Where concerns are raised repeatedly over many years, the question is no longer only whether they have been heard. The question is what has changed as a result, who has checked that change has happened in practice & how that has been evidenced.

This line of concern has been relevant to mASCot for many years, including since the 2014 Brighton & Hove City Council Autism Scrutiny Process. It sits within our longstanding focus on transparency, accountability & lived system reality.

Over recent months, mASCot has also pursued more specific questions, through APB-related routes, about suicide risk, neurodevelopmental waiting lists, commissioning & where responsibility sits when people fall between services. APB colleagues have been helpful in getting some of these questions taken forward.

However, the larger questions remain unresolved: when demand continues to grow, where do the consequences of unmet need go, who is expected to absorb them & who will now lead & take forward the response at system level?

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

mASCot has already contributed extensive evidence & lived system intelligence over many years. The central question is no longer whether parent-carer or neurodivergent voices can be invited into another room. The question is what SPFT is now doing in response to what has already been raised & how that is being acted on in practice.

What has changed for children, young people, adults & families in relation to assessment, post - assessment support & the wider experience of trying to access help through health pathways?

Across recent system discussions, the focus remains on development, review, redesign, communication & measurement. These may all be legitimate areas of work. But they also raise a simple question: what has tangibly improved for people & families in practice?

This concern is reinforced by material raised in a recent Child & Adolescent Mental Health Services (CAMHS) presentation, including the question: "How many people actually get better by accessing CAMHS?" [2]

That question matters because it goes to the heart of the issue. The concern is not whether activity is taking place, but whether that activity is producing meaningful improvement in people's lives & how that improvement is being understood & measured.

Current pathway & process work

Recent minutes from the Lived Experience Advisory Panel (LEAP) indicate that pathways are still being refined. Work continues on communications materials, patient leaflets, template letters, text message sequencing, contact details, a standard operating procedure for patients not accepted onto the pathway & processes for managing people who become unwell while on the pathway. Pilot work, review processes, communications exercises & other incremental pathway changes are also being described as part of current development. [3]

All of this may be necessary. But it also indicates that key operational elements are still being shaped while families continue to experience uncertainty, delay & unmet need.

The same pattern is visible in the Experience Group, where mASCot asked what action was being taken in response to the recent CAMHS presentation. The answer was not available within the meeting & follow-up was requested. That matters because it shows that the question is no longer simply what has been presented, but what is actually being done with it. [4]

Neurodevelopmental pathways have been subject to repeated review & redesign over many years, including since the 2014 autism scrutiny & subsequent scoping work. While increasing demand is recognised, a wider question remains: how core service functions, including identification of need, escalation & response, are being maintained while pathways remain in a continuing cycle of development.
[3][8]

Further engagement activity can create the appearance of movement without resolving the underlying gap.

Why this matters

What this points to is something larger than a pathways issue alone. Those on waiting lists, or trying to access neurodevelopmental or mental health pathways, are only the visible part of a much bigger picture.

Beneath that sits a wider population of autistic people & their families whose needs remain unmet, whose distress may never be fully captured by current pathways & whose lives are being affected across home, education, work, housing & health.

This cannot be understood as service-user dissatisfaction or isolated complaint. The consistency, scale & duration of the issues described, across multiple sources over many years, point to a systemic pattern of unmet need.

This wider pattern is also consistent with the direction of parent-carer evidence being brought together through the forthcoming Brighton & Hove Joint Strategic Needs Assessment (JSNA), even though that material is not yet being quoted here.

The CAMHS presentation also raises concern that "crisis services 'crowd out' prevention", pointing to a system increasingly shaped by reactive demand rather than early intervention. [2]

System attention may be directed towards small pieces of pathway work, limited engagement activity, pilot projects, website & communications exercises & incremental process changes. But the larger systemic picture may still go insufficiently confronted.

The issue is not simply that some groups are harder to reach. It is that current methods allow the system to focus on the part of reality that is most visible, most manageable or easiest to evidence, while the wider ecosystem of unmet need, distress & family strain remains insufficiently seen.

Services may then appear to be engaging, improving & co-producing within a narrowed field, while the much larger pattern of unmet need sits outside view.

In that sense, the problem is not only what is being missed, but what current structures make it possible not to see.

Nor is this simply a question of whether feedback exists. Community evidence has already been generated, at scale & over many years, including through mASCot's own reports & rapid-response evidence gathering. The more difficult question is what happens when that evidence is uncomfortable, systemic or points to failures that require more than incremental adjustment.

The concern is not that nothing is ever heard or that no change has ever occurred. In some areas, parent-carer evidence has contributed to important developments. The concern here is more specific: that in relation to neurodevelopmental pathways, mental health support, threshold-based exclusion, long waits, private & Right to Choose routes & the wider cohort whose needs are clear but not adequately held within existing structures, the more difficult systemic evidence still does not appear to be acted on at the level required.

Unmet need of this kind also has wider consequences for family health & wellbeing across the city. In that sense, the issue is not confined to pathway performance. It becomes a broader public-health question about the impact of sustained unmet need on households, carers & communities.

Repeated engagement without corresponding action ceases to function as meaningful involvement & instead functions as delay.

3. This is not a participation problem - it is a responsibility-for-risk problem

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

Known harm within current conditions

We know from local & national evidence & from repeated discussion across this work, that neurodivergent communities are at increased risk of self-harm, suicidal distress & crisis. That concern has sat behind many of the questions being raised, including questions about who is holding responsibility where need is clear, but pathways are fragmented, inaccessible or unavailable. [6][7]

Recent CAMHS material described waiting itself in stark terms: young people experience CAMHS waiting lists "not as a pause, but as a period of harm, uncertainty & deteriorating trust",

where lack of transparency, unrealistic thresholds & poor communication deepen distress & make them feel "forgotten, invalidated & forced to get worse before they can access help." The same material states that young people want "honesty, humanity & real early intervention." [2]

This sits within a wider context in which neurodivergent communities are already known to face elevated levels of self-harm, suicidal distress & crisis, as reflected in local data, research & recent system evidence.
[2][6][7]

Local public health data also indicates significantly elevated concern within neurodivergent populations, including findings that 36% of neurodivergent adults report having attempted suicide compared with 12% of the general population. [6] Alongside the CAMHS material, this highlights both a recognisable level of concern within this population & evidence of harm occurring within current system conditions.

Recent national research, including work led by Bournemouth University in collaboration with the University of Cambridge (Moseley et al., 2026), reinforces this picture. It identifies significantly elevated suicide risk among autistic people & highlights systemic factors, including delayed diagnosis, unmet need & negative service experiences, as contributing to that concern. [7]

This suggests that harm is arising within current system conditions & raises important questions about how responsibility for health & wellbeing is understood & held across pathways.

Who is holding responsibility?

This indicates that harm is present, recognised & evidenced, but not clearly owned by the system.

From our perspective as families, there appears to be no consistently clear mechanism for escalation, ownership or response when harm is identified within the system at a system level. While individuals may be advised to seek help through existing routes, for example via primary care or crisis services, this does not address the question of how harm is identified, owned or responded to when it arises from the way the system itself is operating.

Families may, in practice, be passed repeatedly between services, for example from GPs to mental health services, social care & neurodevelopmental pathways, without resolution, ownership or continuity. This creates a revolving-door experience in which responsibility is not held but displaced & in which accountability becomes increasingly unclear.

This is not experienced as support. It is experienced as fragmentation. Where this occurs, harm is not only unmet; it may be compounded by the very processes intended to respond to it.

The explicit reference in CAMHS material to young people wanting "humanity" also raises a further question about how care is currently being experienced & whether interactions within the system are consistently felt as compassionate, respectful & responsive to distress.

On the day this statement was being drafted, mASCot was made aware of a case in which a child with repeated suicide attempts & acute suicidal distress was reported to have been told by CAMHS that no support could be offered: "there is nothing we can do." [9]

We are not including this as an isolated anecdote, but as an example of a pattern that families describe repeatedly. It illustrates the point at which need is clearly present, but no service is able

or willing to take ownership. Families also describe situations in which children with an autism diagnosis are not offered meaningful help or intervention, with clear distress or unmet need instead being explained away as simply autistic behaviour.

For families, this is experienced not as a system under pressure, but as a system that may fail to respond even when need is acute, visible & clearly beyond any reasonable threshold for concern.

No urgency around prevention

The CAMHS presentation also raises concern that crisis demand is displacing prevention - that services are being pulled into reacting late rather than intervening early. [2]

If a population is known to be at increased risk & if current pathways are known to be producing delay, uncertainty & deterioration, then prevention cannot remain secondary to crisis response.

False economy

Where early support is not provided, costs are displaced & intensified elsewhere through crisis intervention, increased service use, reduced employment, family breakdown, educational disruption & wider long-term impacts across the system.

This creates a false economy. Short-term constraint does not remove need. It pushes the costs of unmet need into later crisis, more intensive intervention & wider harm.

System harm & family impact

While this paper focuses primarily on children, young people & families, it is also important to recognise that where needs go unmet & distress escalates without timely & appropriate support, the consequences may extend beyond the family into the wider community.

We raise this carefully. The issue is not any inherent risk within neurodivergent individuals, but the consequences of systemic failure to provide appropriate support when it is needed. It also includes the longstanding danger of blame & stigma being directed at individuals or families instead of at the absence of appropriate support structures.

Where that is the case, harm does not appear to be resolved. It remains, but without a clearly defined place where responsibility sits. Families experience this as harm being carried informally, often by parents, carers & the voluntary sector, rather than being explicitly held within services.

For families & voluntary-sector organisations working closely with them, the cumulative effect can be experienced as a profound mismatch between the severity of the distress being lived & the level at which the system responds.

Where the reality is acute distress, collapse, repeated crisis, school breakdown, loss of income, family strain & escalating safeguarding concern, a response framed primarily in terms of process, communications, engagement activity or incremental pathway refinement is not merely inadequate; it represents a failure of the system to respond at the level of seriousness required.

The system may, in that sense, be doing more than failing to resolve harm. It may also be contributing to its escalation.

We are raising this now not as a new issue, but from repeated experience of bringing these concerns into the system & continuing to see families requiring significant support without a clear accountable response pathway.

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

A significant concern is that there is a high-risk group of autistic people whose needs & wellbeing may remain insufficiently recognised within current pathways & service design.

Scale of the issue

Recent CAMHS material refers to over 11,200 young people waiting for neurodevelopmental (ND) assessment in Sussex. It also describes a current wait list of 5 years for ADHD & autism assessment, growing by 5 months per calendar month, with around 900 referrals per month. [2]

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

This is significant because it makes explicit the scale of the mismatch. The issue is not only that pathways are under pressure. It is that a substantial population is living with neurodivergent need that is not being meaningfully held through the pathway itself.

The CAMHS figure refers explicitly to young people waiting for ND assessment in Sussex. It may not capture the full all-age picture.

Who this group includes

That cohort includes autistic people both with & without a learning disability, who:

- are waiting for assessment
- are using Right to Choose & private routes
- do not meet thresholds
- have needs that are not being met through existing service pathways

The same LEAP minutes note that some people pursue Right to Choose & private diagnoses but remain unsupported, while follow-up APB correspondence & responses from SPFT indicate that the position on ongoing NHS support & medication review after those routes is still unclear. [3][5]

A further concern recorded in those minutes is that key operational questions were still being worked out for people not accepted onto the pathway & for those who become more unwell while on it, including how escalation & carer involvement would be handled, with some elements not yet finalised. [3]

These are not minor details. They suggest that key questions about what happens when people are not accepted, become more unwell or require escalation are still being operationally clarified.

Autistic people without a learning disability

There is then a distinct additional issue relating to autistic people without a learning disability.

While this group is increasingly recognised in principle within policy & strategy, in practice their needs are not consistently translated into accessible & effective support.

This group is especially vulnerable to being missed because their needs may be less visible to services, less likely to meet existing thresholds or less easily recognised within standard service models.

This includes people who cannot access services in a meaningful or workable way because provision is not adapted to their needs or who are left in unclear pathways that do not lead to meaningful support.

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

If some groups are less visible to services, whether because they cannot easily access support, are excluded by current thresholds or are not well served by standard pathways, there is a risk that services are being designed around only the part of need that is easiest to see.

This creates a situation in which services may be configured around the most visible need, rather than the full reality of the population.

Why this matters

This aligns with themes reflected across multiple local reports & evidence sources & with the wider body of parent-carer evidence currently being brought together through the forthcoming JSNA, without depending here on unpublished wording or findings.

There is also a large group of children, young people & adults experiencing significant distress who are not at crisis point but are also not able to access meaningful support. In practice, this results in a wide cohort whose needs are recognised but not responded to in a way that prevents deterioration.

This means the issue is not only whether people are heard, but whether the current system is configured to recognise, hold & respond to the full reality of need.

This has a further consequence: the same groups most likely to sit outside meaningful pathway holding may also be the least likely to be reached through standard engagement & co-production routes.

5. Who is not reached by engagement

There is therefore a broader structural question about who is being reached through engagement & co-production processes & who is not. This is not only about neurodivergence. It includes people whose needs sit at the intersection of multiple factors, including ethnicity, socio-economic position, communication differences & levels of distress, which can make need less visible & support less accessible.

A significant cohort of autistic people are not readily able to access, tolerate, or participate in standard consultation, involvement or feedback mechanisms.

In other words, some of the people least well held by the system may also be the least likely to appear within the routes through which that system tries to understand itself.

That matters because services may then be designed & evaluated based on feedback from the minority who can engage, while those who are least reached, least supported or most overwhelmed remain largely unseen.

This is especially important for those with high distress, communication differences, sensory overload, shutdown, burnout or fragmented access to support, because these are precisely the people whose experience may be least captured by formal engagement routes.

The issue here is not simply that some people are harder to involve. It is that standard engagement structures may produce an incomplete picture of need while still appearing to provide adequate visibility, reassurance or legitimacy.

Engagement cannot substitute for system reach. Nor can it substitute for the system's responsibility to identify, understand & respond to unmet need beyond those groups who are easiest to consult.

It also matters in relation to organisations such as mASCot. When a wider structural concern is routed into engagement spaces, there is a risk that the presence of organisations already holding distressed families begins to function as though the harder-to-reach reality is being adequately represented or covered. That would be a mistake.

mASCot's presence in such spaces cannot be treated as evidence that the system has properly reached, understood or responded to the wider cohort affected. Nor should the existence of participation or voluntary-sector routes be treated as equivalent to the system doing that work for itself.

In this case, that distinction matters particularly sharply. A wider APB concern was raised & SPFT was asked to take work forward. The practical response was to route that concern into an engagement structure by inviting mASCot into it.

Whatever the intention, that creates an ambiguity which risks functioning as displacement: the system appears to have acted on the issue, while the harder work of properly reaching, understanding & responding to the wider cohort may remain undone.

6. Transition points 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 the meantime, harm has not disappeared. It is being displaced onto:

- families
- primary care
- the voluntary sector

That is the real concern underneath all of this.

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

In practice, families & the voluntary sector become the de facto holding structures, acting as informal responses to harm without the statutory backing, authority or resources required to do so safely. Crisis services then become the point of escalation, rather than part of any meaningful preventative structure.

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

Services may also refer families to voluntary sector organisations such as mASCot, while no equivalent mechanism exists for those organisations to refer into services with authority or urgency.

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

Responsibility becomes diffused, while harm remains acute.

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

This is not a reflection on the quality or importance of voluntary-sector organisations, which provide essential & valued support to families. The concern is the increasing reliance on these organisations to carry levels of need that should be formally recognised, resourced & held within statutory systems.

What concerns us is the danger that unpaid voluntary-sector input is being used to fill evidence gaps in work the system itself should be undertaking & that this can then be presented as engagement, consultation or co-production, without resolving the underlying issue of action & ownership.

How responsibility is being displaced

Consultation does not discharge responsibility.

Engagement cannot be used as a substitute for a system-led response.

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

Nor should the existence of participation or voluntary-sector routes be treated as equivalent to the system doing that work for itself.

The concern here is that when a wider APB question was raised about current lived experience, process reality & where responsibility sits, the operational response was to route that concern into an engagement structure by inviting mASCot into it.

In practice, that creates an ambiguous but consequential shift. Attendance can begin to function as though the concern has been appropriately handled or as though mASCot's presence stands in for the wider population affected. That is precisely the inversion being questioned here.

If the system's response to a structural concern about unmet need is to rely on participation routes that only partially reach the population & then to treat involvement through those routes as sufficient, there is a danger that the larger problem is not being resolved but operationally displaced.

9. This matters even more because voluntary-sector capacity is fragile

This issue is not abstract. Voluntary-sector capacity is itself highly fragile.

Shrinking capacity

ASSERT has already gone.

Extra Time has also now gone.

Healthwatch, in its current form, is being disbanded.

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

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

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

Because that is not a hypothetical issue for us. It is a very real one.

Commissioned provision is not the same as informal holding

A great deal of practical, emotional & harm-related holding is currently being carried out informally by the voluntary sector.

If that disappears, the harm does not disappear with it. It is pushed back onto neurodivergent families, into primary care, into crisis services or simply left un-held, with the consequences absorbed elsewhere in the system.

The Experience Group identified the disbanding of Healthwatch in its current form & the resulting loss of an independent patient, carer & family voice, as a significant system risk. That matters. [4]

Much of the current local system appears to rely on an informal support layer whose contribution is real but insufficiently recognised.

It is important to distinguish here between commissioned voluntary-sector provision & the kind of informal, unfunded holding being carried by organisations such as mASCot. Some voluntary & community organisations are contracted to deliver engagement, consultation, support or facilitation functions within the wider system. That is not the same as an unfunded community organisation operating without statutory supervision, while informally holding families in situations involving acute distress, escalating safeguarding concern or near-crisis need.

An unsafe inversion of responsibility

What is being created is an untenable & high-risk inversion of responsibility, with increasing reliance on informal holding by those with the least authority, funding & protection.

This is not simply a shrinking voluntary sector. It is a system increasingly dependent on voluntary-sector support to carry need beyond what it is resourced or designed to hold, often without clear statutory ownership, supervision or contingency.

A system in which highly distressed families are repeatedly signposted around the ecosystem, only to circle back to the same unfunded community organisation, is not demonstrating joined-up support. It is demonstrating the absence of a sufficiently robust holding structure.

We have often said that mASCot should be the icing on the cake. The role of a small voluntary organisation should be to offer additional community groups, activities & peer support that statutory services may not be able to provide. 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 & responded to elsewhere in the system.

The fact that mASCot has, in practice, become that kind of lifeline is not a marker of a healthy system. It reflects the scale of unmet need, displaced responsibility & the absence of adequate formal holding, rather than any limitation of the voluntary sector itself.

Why this is now urgent

This is happening in a context of wider system pressure, organisational change & restructuring. That does not lessen the seriousness of what families are living with. If anything, it increases the urgency of having a more robust system than the one currently in place. A system under strain cannot safely depend on fragile, informal or shrinking arrangements to carry the consequences of unmet need.

The question is not simply how current pathways are being managed under pressure, but whether there is a sufficiently resilient system for recognising, holding & responding to need when both statutory & voluntary-sector capacity are under strain.

If the system has never properly quantified, recognised or contingency-planned for the role these organisations play, then it may also not have adequately assessed the consequences of their loss.

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

likely to escalate & present later within health & mental health services. This reinforces that the issues described here are not confined to a single pathway or organisation, but reflect a wider system responsibility across education, health & social care.

10. Where we are now

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

What remains unresolved

But we do not think that this route, on its own, addresses the issue that was raised at APB.

From our point of view, the unresolved question remains: Who is holding responsibility now - particularly for those outside thresholds, unable to engage in standard ways or at transition points - & 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 when 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 & family strain.

Across multiple discussions, a recurring position has been that certain needs sit outside current commissioning arrangements & therefore fall beyond the scope of existing services. From mASCot's perspective, this raises a system-level question. Where need is consistently identified, clearly evidenced & associated with risk, including through wider evidence now being brought together in the forthcoming JSNA, the issue cannot end at the point of service limitation. It requires escalation. The absence of a commissioned response should not function as a stopping point; it should function as a trigger for system leadership to ask how that gap is being addressed & by whom. Given the duration & consistency with which these issues have been raised, this question should already have been addressed at system level.

The question now is whether this will be taken forward through the right route & at the level the issue requires.

We are setting this out because it matters how this is understood & steered at APB level when SPFT next reports back.

mASCot's current position

We will continue to ask how this is being taken forward in practice & how any claimed improvements are actually being experienced by families, rather than relying on descriptions of what services say they are doing.

We have developed ideas about how this situation could be addressed differently, including more responsive, preventative & community-linked approaches.

We have never approached this work simply by identifying problems. In that sense, this paper is not only setting out concern. It is also laying the groundwork for a more serious discussion about what a more coherent, effective & sustainable model might look like.

What this opens up next

We would welcome the opportunity to discuss how current provision could be strengthened, how we can work together while this capacity still exists & how in time a wider vision for this might be taken forward.

At this stage, our priority is to seek alignment on the nature & scale of the issue & to ensure that it is being addressed at the appropriate level, with clear ownership & accountability. We would like this to be understood not only as a concern, but as an opportunity for a serious discussion about how things can be strengthened.

Conclusion

This is not a new issue & it is not an isolated pathways issue.

What is visible in waiting lists, referral problems & fragmented routes into support points to a much wider pattern of unmet need affecting autistic children, young people, adults & families across the system.

The concern is no longer simply whether this experience can be described. It has been described repeatedly. The issue is whether there will now be a response proportionate to the seriousness, scale & duration of what families are living with.

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

Paula Donovan & Sam Bayley
Directors, mASCot
On behalf of the mASCot community

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References

[1] Autism Partnership Board meeting, December 2025, including discussion of barriers to support & recorded action relating to lived experience.

[2] CAMHS waiting-list presentation, 4 February 2026, including lived-experience material describing the impact of waiting on young people, the question of how many people improve through CAMHS, figures on waiting lists & concerns regarding prevention, transparency & crisis-focused responses; subsequently referenced in Experience Group discussion, 1 April 2026.

[3] Minutes from LEAP, 17 March 2026, including discussion of ongoing pathway refinement, communications materials, operational processes for people not accepted onto the pathway or becoming unwell while on it, pilot & review work, reference to a "12,000-person list", the pathway targeting only a small portion of that population & noting that some people pursue Right to Choose or private diagnosis but remain unsupported.

[4] SPFT Experience Group minutes, 1 April 2026, including discussion of the disbanding of Healthwatch & concerns about loss of an independent patient, carer & family voice as a system risk.

[5] Follow-up correspondence with Cara Loreilhe following the APB discussion & SPFT responses regarding private & Right to Choose routes & post-diagnostic follow-up clarity.

[6] Local Public Health data cited in APB-related correspondence, including Brighton & Hove Health Counts figures indicating that 36% of neurodivergent adults, compared with 12% of the general population, reported having attempted suicide.

[7] Moseley RL et al. (2026), Bournemouth University / University of Cambridge, on elevated suicide risk among autistic people & systemic factors including delayed diagnosis, unmet need & negative service experiences.

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

[9] Current lived-experience case reported to mASCot during drafting, included here as an example of a pattern described by families.

[10] Wider contextual parent-carer evidence from mASCot, PaCC, Healthwatch & related local reports; forthcoming JSNA referenced as context only & not quoted.