



## **The Hidden Health Cost of Neurodiverse Advocacy Parenting.**

### **Duality, Nervous System Load, and Intergenerational Neurodivergence**

For parents of children with additional needs, particularly mothers, the cost of caregiving extends far beyond time, energy or financial sacrifice. It is also physiological, relational and, in many cases, intergenerational. These parents are often required to occupy multiple roles simultaneously: organiser, advocate, researcher, emotional regulator, case-holder and protector, while remaining a secure base for their child. This creates a profound duality. Outwardly, the parent must present as calm, containing and emotionally available, while behind the scenes they may be engaged in ongoing negotiations with schools, CAMHS, GPs, local authorities, and, at times, legal systems.

Research consistently demonstrates that caregiving burden is associated with poorer mental and physical health outcomes. Parents of children with special educational needs report significantly higher levels of stress, influenced not only by the child's needs but by the availability, or absence, of professional and systemic support (Cheng et al., 2023). Where systems are delayed, adversarial or inaccessible, parental stress is amplified rather than reduced. This suggests that much of what is conceptualised as "caregiver burden" may, in fact, be a response to systemic insufficiency.

This is particularly relevant within the UK context. The National Audit Office (2024) reported that although funding for special educational needs and disabilities (SEND) has increased, the system is not delivering improved outcomes for children and young people. Similarly, the House of Commons Education Committee (2025) described parents as "exhausted" by the need to fight for even basic support. Tribunal data further reflects this adversarial landscape, with parents overwhelmingly successful in appeals relating to Education, Health and Care Plans (EHCPs), suggesting that many are required to challenge decisions in order to access appropriate provision (Browne Jacobson, 2025). These processes carry not only emotional strain but also financial implications, as families may seek private assessments, legal advice or representation.

Alongside this systemic pressure, parents often engage in invisible labour that remains largely unrecognised. This includes preparing documentation, attending meetings, researching rights, educating extended family members, monitoring bias within institutions, and anticipating potential breakdowns in support. Importantly, much of this labour occurs out of the child's view. The parent may actively shield the child from the complexity, conflict and uncertainty of these processes, maintaining an experience of safety and continuity.

From an attachment perspective, this represents a significant relational task. Bowlby (1969) described the caregiver as a secure base, offering safety from which the child can explore and to which they can return in times of distress. However, in advocacy parenting, the



caregiver is often required to provide this secure base while their own sense of safety is repeatedly challenged. The parent may be navigating rejection, delay, disbelief or systemic invalidation, while continuing to offer emotional attunement and co-regulation to the child. This creates a dual state in which the parent must hold both activation and regulation simultaneously.

A further lens through which to understand the relational dynamics within advocacy parenting is the Double Empathy Problem, first proposed by Damian Milton (2012). This theory challenges deficit-based models of neurodivergence by suggesting that communication difficulties between neurodivergent and neurotypical individuals arise from a mutual lack of shared understanding, rather than impairment located solely within the neurodivergent person. When integrated with attachment theory, this has important implications for how Inner Working Models are formed. John Bowlby (1969) proposed that children develop expectations of self and others through repeated experiences of attunement and responsiveness within relationships. In neurodivergent contexts, where mutual understanding may be reduced across neurotypes, repeated experiences of being misunderstood by caregivers, educators or professionals may occur despite the presence of care and intention. From the child's perspective, these moments can still register as misattunement. Over time, this may contribute to Inner Working Models organised around being unseen, misinterpreted or fundamentally different. This may manifest relationally as withdrawal, heightened vigilance, masking behaviours, or an increased reliance on the caregiver as the sole source of accurate understanding. In this sense, attachment insecurity may not arise solely from inconsistency or unavailability of care, but from a relational mismatch in understanding. For parents, particularly those engaged in advocacy roles, this dynamic often necessitates ongoing translation between their child and the systems around them. Where the parent is themselves neurodivergent, they may hold both an intuitive understanding of their child's internal world and a heightened difficulty navigating neurotypical systems, reinforcing their role as a bridge between worlds and adding further cognitive, emotional and relational load.

This relational mismatch can also be understood through the lens of attunement and mentalisation within attachment theory. The capacity of a caregiver to accurately perceive and reflect a child's internal state, often referred to as marked mirroring, is central to the development of a coherent sense of self (Fonagy et al., 2002). When a child's emotional or sensory experience is consistently recognised and reflected in a way that feels accurate and regulated, they are able to internalise this process, supporting emotional regulation and self-understanding. However, within neurodivergent contexts, where communication styles and expressions of distress may differ from neurotypical expectations, there is an increased risk of misattunement across wider relational systems. Even in the presence of a highly attuned caregiver, repeated experiences of being misunderstood within schools or professional environments may disrupt the child's developing sense of being accurately "held in mind." This may also impact the development of trust in others as reliable sources



of understanding and guidance (Fonagy and Allison, 2014). As a result, the child may become increasingly reliant on the primary caregiver as their sole source of accurate interpretation, while experiencing difficulty generalising trust and safety to broader relational contexts.

From a physiological perspective, this duality carries cost. Studies have shown that mothers of children with developmental conditions experience higher levels of anxiety, depression, fatigue and reduced quality of life compared to mothers of typically developing children (Soytaç et al., 2023). Sleep disruption is particularly prevalent, with research indicating that caregiver burden is strongly associated with poor sleep quality (Priya et al., 2025). Given the role of sleep in nervous system restoration, repeated disruption may prevent the body from adequately metabolising stress. Over time, this may contribute to chronic activation of the stress response, resulting in somatic symptoms such as fatigue, muscle tension, digestive disturbance and reduced resilience.

An additional dimension of this duality is the parent's requirement to rapidly shift between states of activation and regulation within short timeframes. Many parents describe needing to "turn on a sixpence," moving from managing acute emotional distress, such as a child's meltdown or dysregulation, into presenting as calm and socially appropriate within minutes, for example during school transitions or professional interactions. This pattern reflects a form of sustained hypervigilance, characterised by ongoing monitoring of the environment and anticipation of potential triggers. Trauma and stress research indicates that chronic activation of the nervous system can result in heightened alertness and difficulty accessing restorative states, akin to CPTSD, even when outward functioning appears intact (van der Kolk, 2014; Porges, 2011). Within caregiving contexts, this is further compounded by emotional labour, where individuals suppress or regulate their internal emotional states in order to meet external expectations (Hochschild, 1983). Over time, this repeated activation and rapid state-switching may contribute to physiological strain and reduced regulatory capacity, as the body remains oriented towards preparedness rather than recovery (Cheng et al., 2023; Hayes & Watson, 2013).

The health impact of unpaid care is also reflected in national data. Carers UK (2025) reports that women make up the majority of unpaid carers and are more likely to experience adverse health outcomes as a result of caregiving responsibilities. Nearly half of carers report at least one negative impact on their health. This suggests that caregiving, particularly when unsupported, is not a neutral role but one that carries measurable physiological consequences.

However, an additional and often underexplored layer is the likelihood that a proportion of these parents are themselves neurodivergent, sometimes undiagnosed. Neurodevelopmental conditions such as autism and ADHD demonstrate strong familial and genetic patterns. Autism, for example, is widely recognised as highly heritable, with estimates ranging between 60% and 90% (Genovese et al., 2023; Xie et al., 2020). Research



into the Broader Autism Phenotype (BAP) further suggests that many parents of autistic children may display subclinical traits, including differences in communication, sensory processing and behavioural patterns, without meeting full diagnostic criteria (Narzisi et al., 2025; Kazantzidou, 2025).

An additional consideration is the assumption, often implicit within both research and professional systems, that neurodivergence is contained within a single identified child. However, evidence suggests that neurodevelopmental conditions frequently occur within family systems rather than in isolation. Sibling studies indicate that the likelihood of autism in a younger sibling of a diagnosed child is significantly elevated, with recurrence rates estimated at around 20%, considerably higher than population averages (Ozonoff et al., 2011; Autism Science Foundation, 2023). Furthermore, siblings who do not meet diagnostic thresholds may still present with subclinical or overlapping traits, often referred to as the broader autism phenotype, including differences in communication, attention and sensory processing (Bolton et al., 1994; Losh et al., 2008). Research also demonstrates cross-aggregation between conditions such as autism and ADHD within families, suggesting shared genetic and developmental pathways (Rommelse et al., 2010; Ghirardi et al., 2018).

In practice, this means that households may include multiple children presenting with varying degrees of neurodivergent traits, each with uniquely differing needs, sensitivities and regulatory profiles. This can create environments that feel coherent and adaptive within the home context, where mutual understanding and flexible responses are possible, but appear inconsistent or problematic within structured institutional settings such as schools. Consequently, reports from educational environments may not accurately reflect the child's functioning within the home, but rather the degree of fit, or misfit, between the child's neurotype and the demands of the system. This further intensifies the parent's role as interpreter and advocate, as they are required to reconcile differing narratives of the child's behaviour while holding a more nuanced, context-dependent understanding of their needs.

This has significant implications when considered through an attachment and trauma-informed lens. Many neurodivergent adults, particularly women, have historically been underdiagnosed and may have grown up in environments that did not recognise or support their needs. Experiences of masking, misunderstanding or being perceived as "too much" or "not enough" may shape their Inner Working Models, influencing how they relate to themselves and others. When these individuals become parents to neurodivergent children, they may find themselves navigating systems that mirror the very environments that failed to support them.

This creates an intergenerational dynamic in which the parent is not only advocating for their child but also, implicitly, confronting aspects of their own developmental history. The child's experience may activate echoes of the parent's unmet needs, intensifying protective responses and reinforcing a sense of responsibility. The parent may internalise beliefs such



as “If I do not hold this, it will collapse,” reflecting adaptive responses to repeated systemic gaps. This may also shape the child’s expectations of relational safety, reinforcing reliance on the caregiver while limiting trust in wider systems.

In this context, the concept of caregiver burden may be insufficient. It risks locating the difficulty within the child or the caregiving role itself, rather than recognising the broader systemic and relational context. The burden is not solely the child’s needs, but the requirement for the parent to compensate for the absence of coordinated, accessible and responsive support systems. The body becomes the site where this compensation is held.

From a trauma-informed perspective, this can be understood as cumulative stress exposure. Rather than a single traumatic event, the parent may experience repeated cycles of activation, uncertainty, advocacy and limited resolution. This may lead to patterns of hypervigilance, sustained sympathetic activation and difficulty accessing restorative states. At the same time, the parent continues to function as a secure base, regulating the child’s emotional experience and facilitating their engagement with the world.

This is the central duality of advocacy parenting. The parent is both protector and container, activist and attachment figure, system challenger and source of safety. They operate within institutional spaces that may require assertiveness, persistence and confrontation, while simultaneously maintaining warmth, attunement and emotional availability within the parent-child relationship. The capacity to hold these opposing states is often framed as resilience. However, from a physiological perspective, it may be more accurately understood as sustained adaptation in the absence of adequate support.

Therefore, the health implications of advocacy parenting should not be individualised as a lack of coping or resilience. Instead, they should be understood as predictable responses to prolonged responsibility, systemic insufficiency and, in some cases, intergenerational patterns of unmet need. When parents, often mothers, are required to reduce employment, absorb financial costs, navigate complex systems and regulate both their child’s and their own emotional experiences, the impact is not only social or economic but embodied.

The question that emerges is not why these parents experience exhaustion, stress or burnout, but why systems continue to rely on their capacity to absorb these pressures. Until structural changes are made, the hidden cost of advocacy parenting will remain located not within policy or provision, but within the bodies and lives of those who hold the gap.

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