

Listening to Parents, Listening to Myself: A Systemic Encounter with Autism, Emotion, and Family Legacy

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Abstract

This paper explores the complex emotional and cultural terrain navigated by 28 parents of children diagnosed with autism or ADHD, weaving their narratives with the author's lived experience as both a systemic practitioner and mother. Through reflective group sessions and therapeutic tools such as board games and genograms, parents found space to externalise blame, rediscover agency, and build supportive community. The research challenges conventional clinical models by centring parental emotion, trauma, and intergenerational legacy, offering a re-humanised lens for practitioners, educators, and policy makers. It calls for a shift from diagnosing dysfunction to understanding systemic patterns, advocating for empathy-led practice that listens not only to the child, but to the stories that surround them.

What does it mean to carry grief into pregnancy? To sense something different in your child and not be heard? This paper explores these deeply emotional spaces through the stories of 28 parents — and through my own story as a practitioner and mother.

I wish I could revisit the moment I was in the hospital and the doctor delayed my delivery. My child was distressed in the womb and came out not breathing. I felt I could have done more — but it was beyond me. I was in a country whose health system was unfamiliar: no midwife, only an obstetrician and a gynaecologist. He was ushered into the world without a sound.

That moment has stayed with me for 28 years. It shaped the way I looked at his every cry, his silence, his struggles, and his spirit. My journey as a mother has mirrored the experiences of the women I met in this research — from pregnancy through nurturing and containment, often while navigating abusive relationships and cultural misunderstanding. I kept asking: was it trauma, or was it labelling? Was the diagnosis an answer, or another layer of confusion?

Citation Link

This paper is not just a research report. It is an offering — a weaving together of professional knowledge and lived experience, of group stories and personal reckonings. I spoke with 28 parents who were navigating the terrain of autism and ADHD diagnosis in their children. They came from different cultures, classes, and family configurations — but what united them was a deep sense of wondering, worrying, waiting, and surviving.

We did not sit in clinical rooms. We sat in circles. Sometimes with board games in the middle, sometimes with silence. The tools we used were familiar — Ludo, Snakes and Ladders — not because they held answers, but because they opened doors. Through play, parents spoke. Through symbols, they remembered. And through one another, they found echoes of their own journey.

These parents shared frustration with the systems they found themselves in — systems that often left them feeling silenced, blamed, and bewildered. I remembered those same feelings from years back, but I had found ways to stand tall in my son's defence, refusing to be debased. Together in those sessions, we were able to build emotional containment without countertransference. No one was retraumatised, even though we were speaking of wounded children and heavy histories.

We were working with young people whose emotional age often lagged behind their biological age. Some parents struggled to love their children, not out of malice, but because they saw themselves as victims of a story they didn't choose. I began to externalise the problem — inviting them to see autism not as the child, but as a challenge that visited the family. I witnessed sudden empathy develop in that space. I was mindful not to turn insight into guilt — I feared retraumatizing them — but it went smoothly. They left with smiles, having entered burdened and unsure.

Women who walked in with weight on their shoulders left the room looking accomplished, holding answers that had previously eluded them. In the midst of stigma and stereotype, we were able to build a confident community of parent activists — full of love, resilience, and nurturing.

As a systemic practitioner, I was trained to look at patterns, at connections, at the wider system. But as a mother, I was feeling everything. I saw myself in their stories. I saw the shame of not knowing what to do. The fear of being blamed. The exhaustion. The moments of quiet joy when a child made eye contact, or when a sibling stood up for their brother. I saw faith, love, and loss tangled together.

The sections that follow will not read like a dissertation. I am deliberately allowing the messiness, the emotions, and the contradictions to stay. This is an attempt to re-humanise research. To let the reader feel what it means to parent in uncertainty, to be misunderstood by systems, to seek meaning when answers are scarce.

The story of autism is not only in the diagnosis. It is in the birth stories, in the family legends, in the cultural frames, and in the quiet inner dialogues parents carry. It is time we listened more carefully — not just to the children, but to those who are carrying their stories.

Before the Diagnosis: What We Were Carrying

Before we ever spoke about autism, before a word like “neurodivergent” was introduced, there were layers of emotion — grief, fear, trauma, and sometimes hope. The conversations in our sessions revealed how many parents entered pregnancy already carrying heavy emotional loads: the loss of a

parent, the breakdown of a marriage, a history of being unloved, or the haunting shadow of previous miscarriages.

One mother shared how her pregnancy followed a domestic abuse incident. Another described walking through her entire labour alone, misunderstood and misread by professionals. The silence around these early stories is deafening — yet it is in these silences that so much meaning lies.

Some spoke of being emotionally absent during pregnancy — not because they didn't care, but because they were numb with depression or overwhelmed by grief. One parent told me, "I didn't bond with him until he was three. I was afraid he'd die like the last one." In that moment, autism was not the concern — survival was.

Many of these parents felt unseen by health professionals. Their intuition about their child was dismissed. Their questions were met with condescension. For those from minoritised backgrounds, race and class complicated access to care. "If I were white and middle class," one mother said plainly, "they'd have listened the first time I spoke."

For me, these sessions unearthed my own suppressed memories: how I questioned myself endlessly after my son's birth, how I feared my grief might have changed him somehow. These parents reminded me that the diagnostic journey doesn't begin in a clinic. It begins in the body. In the womb. In the mother's loneliness. In the father's silence. In the community's gaze.

What we were carrying was more than children. We were carrying stories that hadn't been told, questions that hadn't been answered, and pain that hadn't been witnessed.

From Confusion to Connection: When Parents Begin to Name It

There is often a long, lonely space between noticing something and having it named.

Many of the parents I spoke with described this liminal period — when something in their child's behaviour felt different, but the systems around them offered no answers. Friends reassured them that "boys are just slower," or that "she'll grow out of it." Professionals brushed off early concerns, focusing on speech milestones or dismissing emotional distress as parenting problems.

In that gap, many parents began to blame themselves:

- "I thought I wasn't doing enough tummy time."
- "I wondered if it was because I shouted too much when I was pregnant."
- "I thought maybe I didn't pray enough. Maybe it was a punishment."

These are not just passing thoughts — they are inner indictments, shaped by histories of grief, shame, and silence. And yet, despite the weight of those internal voices, every parent in the group had kept going, kept seeking. Even when they were dismissed. Even when they were told, "It's nothing."

This part of the journey is hard to quantify in research — but it is here that the heart of the diagnostic experience lives. In the long hours of observing, wondering, Googling, praying, waiting. In the moments when a parent knows something but has no language, and everyone around them insists there is nothing to worry about.

When parents finally did hear the word *autism*, their reactions were complex and layered. Relief and heartbreak often coexisted. For some, it confirmed what they had sensed. For others, it shattered a hope they didn't realise they had been holding. And for many — especially those from communities where autism is misunderstood — it opened a new chapter of stigma and secrecy.

One mother whispered to me, "We don't say the word at home. My husband says I've cursed the child by speaking it."

Another father stood up in a session and said, "Now I understand. He's not being difficult. He's overwhelmed."

These were not just moments of cognitive understanding — they were moments of connection. When autism was externalised and spoken aloud, it lost its sting. It became something the family could talk about, navigate, even laugh about.

I was careful not to rush this process. Naming is powerful, but it must be held gently. For some, it was easier to describe behaviour first. For others, metaphor worked better — we talked about storms, wires crossed, signals missed. When the name *autism* arrived, it arrived into a space that had already been made safe.

As a practitioner, I found myself sitting in the sacred in-between: between confusion and clarity, between fear and understanding. And as a mother, I remembered that moment when I, too, first heard the word. I remembered crying. Not because it was a bad word, but because it made everything real.

In these group sessions, we gave each other the permission to feel all of it — the anger, the shame, the relief, the sorrow. There was no rush to "acceptance." Instead, we honoured the struggle to get there.

Because naming isn't just a clinical act — it is an emotional rite. It marks the start of a new relationship with the child, with the self, and with the systems around us.

How the Research Changed Me: What the Parents Taught Me

This research was meant to help parents — but it also changed me.

I entered the space with a trained eye. A systemic lens. Years of experience. But something shifted during those sessions. Sitting with those 28 parents, listening to stories that were raw, unfiltered, sometimes broken and often beautiful, I began to let go of the idea that I was there to lead. I became a listener first, a learner second, a witness always.

It wasn't that I didn't already know the theories — attachment, trauma, mentalisation, the Social GRACES. I had used them for years in practice. But this time, I *felt* them. I saw what it means for theory to breathe, to ache, to sit beside a mother whose child hasn't spoken in months, or a father who still doesn't know how to hold his son.

These stories stretched my thinking. They reminded me that progress doesn't always look like eye contact or speech. Sometimes it looks like a parent saying, "Today I didn't shout." Or, "I let him stim without stopping him." Or, "I danced with her for the first time."

They wanted me to tell *those* stories — the quiet, unnoticed victories. The day-to-day heroism. The patience it takes to love a child who doesn't show love in the usual ways. They didn't ask me to write a paper filled with statistics. They asked me to be honest. To show their tenderness. To tell how they arrived broken but left brave.

This research changed my practice in ways that no training could. I learned to sit with silence more. To hold emotional language gently. To remember that sometimes a parent's anger is a mask for grief, and that naming something too soon can shut the door to healing.

I also began to reflect more deeply on myself — not just as a practitioner, but as a mother. There were moments in those sessions where I felt tears rising — not just in response to their stories, but because they reminded me of my own. I had been that mother. I had also once believed it was my fault.

What the research gave me was not only insight, but a community. We became co-travellers. We held space for one another. And in doing so, I became a better practitioner — softer, slower, more curious.

If the parents could speak into this paper directly, I believe they would say:

“Don't make us sound like case studies. Let us be real. Let the world know we're trying. Let them see our strength. Our love. Our confusion. Our resilience. Tell them that we are not the problem — we are part of the solution.”

And so, I offer this work as a tribute to them. To their courage. Their vulnerability. Their faith in strangers. Their willingness to sit in a room and speak the unspeakable.

They changed me. And I will carry that change into every room I walk into.

Re-Humanising Practice: Naming Without Blame

One of the most powerful lessons from this work was this: naming is essential — but only when it comes without blame.

Too often, families arrive in services already carrying shame. Before we ask a single question, they have asked themselves a hundred.

What did I do wrong? Was it the birth? The bottle-feeding? The stress during pregnancy? These are not diagnostic questions. They are human questions — haunted questions.

In too many settings, the moment we introduce a name — autism, ADHD, sensory profile, neurodevelopmental difference — we unknowingly reinforce blame. The implication is: something is wrong with your child, and by extension, something may be wrong with you.

But what if naming could be liberating?

What if we could name without diagnosing dysfunction?

What if we could shift the gaze from “what's wrong” to “what's happened,” and even further to “what's needed now”?

In our sessions, I was determined to re-humanise the process of understanding a child's difference. That meant starting not with checklists, but with stories. Not with deficits, but with dynamics. We

didn't talk *about* children — we spoke about moments. Moments when something broke. Or bloomed. Or confused us all.

When one mother wept and said, *"He doesn't look at me. I don't think he loves me,"* I didn't reassure or redirect. I just asked her to tell me about a time he *did* look at her. She described a moment — brief, quiet, but electric. That moment became our starting point, not the symptom.

I saw how powerful it was to externalise the problem. To say to a parent, *"Your child is not the problem — the system around you is struggling to understand him."* It allowed empathy to enter the room. Self-compassion. Relief.

Naming without blame is not about avoiding truth. It's about honouring complexity. It's about refusing the binary — not autistic or neurotypical, not good or bad parenting, not trauma or genetics. It's *both/and*. And when we can sit in the *both/and*, we give families space to breathe.

Re-humanising practice means noticing tone. Pacing our questions. Watching the mother's body language. Listening to what is said in a sigh, or in what is *not* said at all.

It means accepting that a parent might take weeks to admit they're angry at their child. And when they do, holding it with care, not judgement. I reminded parents, gently, that the system is hard — and sometimes, parenting feels harder. They were allowed to feel that.

In this research, we didn't create miracles. But we did something quietly radical: we created safety. Safety to say *"I'm overwhelmed."* Safety to ask *"Am I a good mother?"* Safety to sit in uncertainty without being fixed or judged.

If we are to move toward compassionate, systemic work with families navigating autism, then we must bring the human back into the frame. The pain. The pride. The silence. The struggle. And above all — the story.

Because when people feel seen, they stop needing to shout. When they feel named — but not blamed — healing can begin.

Board Games and Broken Narratives: Playing Our Way to Truth

When you work with families navigating complex stories of diagnosis, trauma, and identity, sometimes words are not enough — or they come out too sharp, too guarded, too unsure. That's why, from the beginning, I brought in tools that felt familiar, playful, and symbolic.

Ludo. Snakes and Ladders. A genogram. A brain diagram.

At first glance, these look like simple resources — a child's pastime or a social worker's paperwork. But in our hands, they became portals. Invitations. Memory maps

We used board games to reflect on the ups and downs of parenting — the ladders that lifted us in joy, the snakes that pulled us into shame, the unpredictability of progress. These metaphors gave language to the emotional terrain of parenting neurodivergent children. It wasn't about diagnosing behaviour. It was about naming experience.

Then came the genograms.

When I asked parents to map out their families — across generations, across ruptures — many were shocked by what they saw. Patterns of abandonment. Repetition of maternal isolation. Cycles of emotional detachment, addiction, grief.

One parent whispered, “I never realised how much I was carrying from my mum, and she from hers.” Another said, “Now I see why I panic when he doesn’t talk. That was me.”

Using the child development chart and dipping in and out of attachment theory, we explored moments of connection and disconnection. We looked at how a child’s need for co-regulation might be misunderstood as clinginess, or how early trauma in the parent might make certain behaviours unbearable to witness.

I brought out a brain diagram, pointing gently to areas related to safety, overwhelm, and social connection. As we linked parental stress to the child’s emotional world, I heard again and again: “That’s me. That’s him. That’s our house.”

These tools didn’t just inform — they transformed. They brought confidence, vocabulary, and a glimmer of hope. They helped parents externalise what felt like chaos and reframe it as pattern. That alone created a shift.

At one point I asked, “What do we do with all of this now? These findings, these revelations?”

And that’s when something beautiful happened.

The group stopped being a “research setting” — and became a circle of wisdom. We began sharing interventions:

- “I use a visual timer now before transitions.”
- “Music calms him — not words.”
- “I learnt to pause before I answer. It helps.”

I was no longer the only facilitator. Everyone stood in their own power. Parents became podium speakers — delivering insight, honesty, and strategy with clarity and pride. We were not fixing children. We were reimagining relationships.

This work reminded me that healing doesn’t always come from answers — it comes from shared meaning. From playful tools that open deep dialogue. From looking at a genogram and finally understanding that your child’s meltdown isn’t a mystery — it’s part of a much older story, now being retold in a new key.

And once you see that, you can choose differently. You can parent differently. You can forgive yourself.

Conclusion: Drawing the Curtain Gently

As I draw the curtain on this story — which is not just mine, but shared across 28 families — I want to leave you with an invitation.

To my fellow practitioners: I urge you to adopt a more human approach. Come down from the tower

of theory and walk into the room with humility. Ask not just what's wrong, but what's happened, and what matters here? Let your practice be a place of warmth, not just structure. The parents we work with are not data points. They are storytellers, grief-carriers, decision-makers. Meet them as such.

To parents: Please, don't see yourselves as broken or to blame. You are not victims — you are containers. You hold emotion, confusion, courage, and hope. You are translators of your child's needs, even when you have no words. You are not failing. You are enduring.

To policy makers: I ask you to look again at the systems we've built around families. Are they rigid or responsive? Do they punish difference or embrace it? Reasonable adjustments are not luxuries — they are lifelines. Whether in schools, health services, or social care, families need systems that listen before they decide.

To spectators: Please don't rush to judge. Take a moment to observe with humanity, not ridicule. That child screaming in the supermarket may not need your advice — just your quiet understanding. That parent avoiding eye contact may not be rude — just exhausted.

To clinicians: I say gently — step into practice before you step into protocol. Be flexible with your models. Diagnosis is only one part of the picture. The rest is story, culture, silence, survival. When you make space for that, you help more than you measure.

And finally, to all who journey with families like these — may we all remember that healing starts not in correcting people, but in connecting with them.

Let us choose presence over perfection. Curiosity over certainty. And above all, let us never forget the power of listening — not just to the child, but to the heart that holds them.

References

About the author

Freda McEwen is a systemic family practitioner, researcher, and advocate with expertise in autism, ADHD, and trauma-informed care. She holds a Master's in Public Health (MPH), an LLB and LLM in Law, and a postgraduate qualification in systemic practice from Tavistock and Portman. Freda has been awarded an honorary PhD in Public Health in recognition of her published work and research contributions. She has served as a governor for Tavistock NHS Foundation Trust and has sat on several boards across public health, education, and social care, including the Citizen Council for NICE. Freda is the founder of the Inside Out Programme that supports parents of children with ASD and ADHD.

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