
Authenticity in Crisis: Maternal Advocacy and Existential Caregiving Across the Institutional Networks of Disability and Care

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Abstract

This article offers an existential-phenomenological, hermeneutically informed case study of Cecelia, a Latine immigrant mother raising an autistic child, interpreting how advocacy and caregiving are lived within the technocratic architectures of special education and social services. Treating Cecelia's narrative as a text of lived experience, I conduct an iterative reading of three interviews and reflexive memos to trace how institutional languages of "progress," compliance, and partnership meet the embodied rhythms of maternal care. Cecelia's account discloses caregiving as relational labor shaped by exclusion yet animated by meaning-making and resistance. Her experiences show how schools can mistake presence for partnership and inclusion for engagement, narrowing the space where maternal knowledge is recognized as knowledge. This idiographic interpretation clarifies how everyday maternal practices both confront and exceed constraint, and it invites attention to the interpretive conditions under which trust and collaboration become possible.

Keywords

Phenomenology, Existentialism, maternal identity, special education advocacy, autism spectrum disorder (ASD), parent–school collaboration

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Parents and caregivers have long been pivotal actors in disability rights movements, catalyzing legislative gains such as Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA, 2004). These frameworks aimed to secure equity and access through procedural safeguards and by positioning families as essential participants in educational decision-making. Yet procedural inclusion does not reliably yield interpretive inclusion. Families of disabled children, particularly those from historically marginalized communities, can remain disempowered within systems that are formally participatory but practically difficult to navigate and unevenly responsive (Barrera-Lansford & Sánchez, 2025; Cowhy et al., 2024; Voulgarides, 2024).¹

Special education policy continues to be shaped by epistemic habits that privilege normative developmental trajectories and technocratic demonstrations of “progress” (Connor, 2019; Connor & Valle, 2015). In practice, these habits can narrow what counts as credible knowledge, especially when families’ claims are conveyed through embodied, relational, and culturally situated ways of knowing. For Latine immigrant mothers, advocacy often unfolds amid layered pressures of language, institutional asymmetry, and racialized expectations of family competence (Barrera-Lansford & Sánchez, 2025; Rios et al., 2020). This is not only a question of access to procedures, but also of intelligibility: whether the textures of caregiving can be understood within the sanctioned vocabularies of compliance, service minutes, and measurable goals. In such moments, mistrust is frequently interpreted as resistance or noncooperation, rather than as a reasonable response to recurrent misrecognition. This dynamic can be read as a form of hermeneutic injustice, where interpretive resources are insufficient for making certain experiences fully legible within institutional life (Fricker, 2007).

This article offers an existential-phenomenological, hermeneutically informed case study of Cecelia, a Latine immigrant mother raising an autistic child, to interpret how maternal advocacy and caregiving unfold within and against the technocratic architectures of special education and social service systems. Treating Cecelia’s narrative as a text of lived experience, I engage an interpretive reading that moves between part and whole, attending to how meaning is shaped through language, relationship, and institutional encounter (Gadamer, 2004; Ricoeur, 1991). Cecelia’s account registers the existential weight of caregiving as embodied, relational labor shaped by systemic exclusion yet animated by meaning-making, resistance, and care. Her experiences suggest how schools can mistake presence for partnership and inclusion for engagement, leaving limited space for the emotional, bodily, and relational work that caregiving entails. Her story, drawn from in-depth interviews conducted over several months, offers an idiographic view of how everyday maternal practices both confront and exceed institutional constraint.

As a brief signpost, this reading is informed by critical disability scholarship and related traditions that foreground power and ableism, but the analytic engine of the essay is applied hermeneutics and existential phenomenology, with attention to the interpretive conditions under which trust and collaboration become possible.

¹ In this article, I use identity-first language (e.g., “disabled students”) to honor disability as a claimed identity and culture (Best et al., 2022). This choice also reflects Cecelia’s own language throughout the interviews.

Theoretical Orientation

Interpretive Conditions of Recognition and Care

This essay approaches Cecelia's account through applied hermeneutics, treating narrative as a text of lived experience situated within institutional worlds that organize meaning through sanctioned vocabularies. Gadamer (1960/2004) argues that understanding is not a technique applied to an object but a dialogical event in which meaning emerges through engagement, history, and language, moving between parts and whole through a fusion of horizons. Cecelia's narrative is therefore not only a report about events in special education, but a site where meanings are disclosed, contested, and at times foreclosed by institutional expectations about what counts as legitimate knowledge.

Ricoeur (1991) provides a further warrant for reading narrative as text and for treating temporality as central to meaning. Lived experience becomes intelligible through the interpretive labor of narration, where identity and purpose take shape across time rather than as static facts. This is especially salient in special education, where institutional time is organized through cycles, benchmarks, service minutes, and measurable objectives, while caregiving unfolds through recursive rhythms that resist linear progress narratives. Disability studies scholars have described this tension through the language of *crip time*, which names how disabled bodyminds often move according to rhythms that do not conform to normative schedules, developmental expectations, or clock-based demands (Kafer, 2013; Samuels, 2017). Used lightly here, crip time helps clarify why the temporal grammar of special education may misrecognize disabled life as delayed, resistant, or out of sync, rather than as organized by different embodied and relational rhythms. The interpretive problem therefore concerns both the events that occur within systems and the meanings those systems are able to receive.

These tensions have ethical consequences. Families' experiences can be disadvantaged not only by barriers to access, but by interpretive conditions that make some forms of experience difficult to articulate and harder to credit. Fricker (2007) describes hermeneutic injustice as a condition in which shared interpretive resources are insufficient for making certain experiences fully intelligible within public life. In special education, caregivers may be asked to translate their knowledge into categories that privilege what can be documented and audited; when these categories cannot name the textures of care, misunderstanding becomes structural rather than incidental. Mistrust, in such contexts, may be read as noncompliance, when it is more accurately understood as a response to recurrent misrecognition.

Care is therefore not an affective backdrop to advocacy but a moral and political practice that unfolds within institutional arrangements that allocate responsibility, demand proof, and set the terms of legitimacy. Tronto (1993) clarifies how institutions draw moral boundaries around whose needs are recognized and whose labor is presumed, often invisibly. Ruddick's (1989) account of maternal thinking further supports the claim that maternal knowledge is neither sentimental nor secondary, but a disciplined form of situated judgment shaped by responsibility, attention, and practical reasoning. Together, these resources keep power in view while grounding the analysis in hermeneutic and existential commitments.

Toward an Ontology of Maternal Becoming

Taken together, these philosophical commitments support a reframing of motherhood as existential and political becoming, not a fixed identity or normative role. Maternal advocacy is not simply procedural engagement with education systems but an act of asserting relational and embodied knowledge against bureaucratic abstraction. Caregiving is lived ambiguity: joyful, burdensome, mundane, and transcendent, often within the same day and sometimes within the same moment.

This is where existential phenomenology becomes analytically useful for this case. In existential scholarship on motherhood, maternal identity is understood as a process of becoming—one shaped through encounter, rupture, vulnerability, and the ongoing reorganization of self and world (Arnold-Baker, 2019; Prinds et al., 2014). Velasco (2022) sharpens this point by suggesting that existential parenthood involves remaining with ambiguity rather than resolving it prematurely. Read through this literature, Cecelia's advocacy is more than a strategy for navigating systems. It is a situated struggle over freedom, recognition, responsibility, and care within conditions she did not choose.

This essay therefore refuses reductive accounts of motherhood and disability, attending instead to how maternal care is lived at the intersection of existential freedom and structural constraint. In what follows, I situate this inquiry in the institutional terrain of special education, where care is routinely translated into procedural legitimacy and measurable progress, and where the interpretive conditions of trust and collaboration are often precarious.

Context and Hermeneutic Questions

The context for this interpretation is a special education landscape shaped by decades of legal reform and by persistent inequities in everyday institutional life. Laws such as IDEA (2004) formalize parental participation through procedural safeguards and individualized planning, yet the lived enactment of these commitments can remain uneven. For culturally and linguistically marginalized families, participation is often mediated by bureaucratic opacity, institutional asymmetry, and racialized assumptions about competence (Barrera-Lansford & Sánchez, 2025; Voulgarides, 2024). The problem is not only whether families are invited to meetings, but whether their meanings can be heard within the interpretive vocabularies that govern educational decision-making.

Guiding this interpretation is a single question: What happens when “progress” becomes the dominant moral and temporal grammar of special education, while a mother's lived time of care resists that grammar, and mistrust emerges where institutional languages cannot recognize maternal knowledge as knowledge?

The Paradox of Partnership in Special Education

Despite decades of legislative reform aimed at promoting equity and access for disabled students, special education systems continue to reproduce exclusionary practices through the very procedures meant to secure inclusion. While laws such as IDEA (2004) mandate individualized planning and parental involvement, operational frameworks often remain entrenched in

technocratic logics that privilege measurable outcomes, compliance checklists, and diagnostic categorization over relational, embodied, and temporal realities (Connor, 2019; Connor & Valle, 2015; Lewis & Mason, 2025; Parker-Katz & Passi, 2021). Within this paradigm, students risk becoming objects of intervention rather than subjects of experience, and families risk being recognized primarily through their ability to perform institutional fluency. Florian's (2014) caution is useful here because special education cannot be understood as an uncomplicated ally of inclusion when it remains organized around sorting and responding to those positioned outside education's normative center.

Structures intended to facilitate engagement can also function to exclude, particularly for culturally and linguistically marginalized families (Rios et al., 2020; Shapiro et al., 2004). Although mandates position parents as collaborators, language barriers, bureaucratic opacity, and racialized assumptions about competence can undermine meaningful participation. The result is a paradox: a system ostensibly grounded in inclusion can reproduce hermeneutic exclusion, where families' experiences are difficult to render intelligible within sanctioned vocabularies and therefore difficult to treat as credible (Fricker, 2007). The invitation to partnership can coexist with interpretive conditions that narrow what counts as knowledge, what counts as care, and what counts as reasonable advocacy.

This paradox is not merely procedural. It is also existential and hermeneutic. When maternal advocacy is filtered through institutional logics that devalue embodied knowledge and relational expertise, caregiving itself can be rendered invisible or suspect. Families may be compelled to translate their lives into a discourse that misfits the rhythms of care, thereby intensifying mistrust and widening the distance between procedural participation and relational collaboration.

Case Framing

This essay examines the case of Cecelia, a Mexican immigrant mother raising her four-year-old autistic son, Hector, within these intersecting conditions of constraint. As a Latine mother and non-native English speaker, Cecelia's experiences are shaped by institutional asymmetry, linguistic marginalization, and the recurring need to establish credibility in spaces that claim partnership. Her accent, bilingualism, and refusal to adopt technocratic discourse as her primary mode of communication often positioned her as difficult to read within institutional expectations of what a cooperative parent looks like. In hermeneutic terms, her advocacy repeatedly encountered a problem of intelligibility, as her meanings were not easily assimilated into the categories that structure meetings, documentation, and decisions.

Cecelia's narrative offers an idiographic view of maternal caregiving as an existential project, revealing how caregiving involves ongoing negotiations of freedom, responsibility, temporality, and embodiment within systems that can misrecognize both child and caregiver. Centering her account resists the impulse to generalize or to treat maternal advocacy as a set of strategies, and instead dwells with lived experience where mistrust, persistence, and meaning-making appear as responses to institutional languages that alternately invite and foreclose understanding.

Although the broader project involved seven participants, this article lingers with one narrative to clarify how existential meanings of care and advocacy take shape within specific structural

conditions. The aim is not statistical generalization but analytic depth. By rendering the textures of caregiving in context, the case invites readers to judge transferability in relation to their own settings and to the relational realities of family and school encounters (Lincoln & Guba, 1985).

Interpretive Process

Philosophical and Methodological Commitments

This study employs existential and phenomenological approaches to examine maternal caregiving as a lived, relational, and temporal project. As outlined in the theoretical orientation, these traditions center embodiment, temporality, and being-in-the-world as fundamental structures of experience. Rather than imposing categorical abstractions, the study orients to the ambiguities and transformative possibilities embedded in caregiving as it is lived.

This methodological choice aligns with epistemological commitments in critical disability studies that foreground relational, affective, and political dimensions of disability and caregiving (Goodley et al., 2018; Goodley et al., 2021). It also draws on feminist existential thought, particularly Beauvoir's (1949/2010) insistence on examining how gendered and embodied experiences shape subjectivity. Within this orientation, the study resists deficit framings of caregiving and attends to the complex, negotiated, and meaning-laden experiences of Latine mothers navigating care networks.

Reflexivity, Positionality, and Ethical Considerations

After Institutional Review Board (IRB) approval was obtained, Cecelia provided informed consent prior to the first interview, and participation remained voluntary and negotiable throughout the study, with attention to her comfort, agency, and understanding of the research process.

Recognizing the historical marginalization of disabled individuals and their families in research, I grounded this study in a reflexive ethic of inquiry. I identify as disabled, which offers one point of resonance with disability politics and the lived stakes of schooling. However, I do not identify as Latine nor as a mother, and I do not share Cecelia's linguistic, cultural, or immigration histories. These differences mattered in the interview space. I entered as a male, university-based researcher and special education scholar, situated within the very institutions Cecelia has learned to mistrust. For that reason, positionality functioned as an ongoing methodological practice rather than a brief disclosure. I approached the interviews as dialogical encounters rather than instruments of extraction, relied on open-ended invitations rather than leading prompts, and returned to Cecelia's language when composing analytic memos. Member checking and follow-up clarification calls provided additional safeguards against interpretive imposition. Reflexivity thus served as a way of noticing how my assumptions traveled through the analysis and of remaining accountable to Cecelia's situated knowledges.

Aligned with feminist and disability studies methodologies (Goodley et al., 2018; Cioè-Peña et al., 2024), the study positioned Cecelia not as a subject to be observed but as a co-constructor of meaning. Informed consent was obtained prior to participation, and confidentiality was maintained throughout. Cecelia selected the pseudonym used in all presentations of her narrative. The study adhered to university IRB protocols for research involving human participants, with heightened

attention to the emotional and ethical demands of narrating caregiving experiences in marginalized contexts.

Data Sources and Dialogical Engagement

This case study is drawn from a broader phenomenological inquiry involving seven Latine mothers of children with disabilities, focused on capturing the phenomenological dimensions of caregiving within systemic and sociocultural contexts (Passi, 2025). Cecelia was selected as a focal case based on her reflective engagement with the study's concerns and her capacity to articulate the temporal, relational, and affective textures of caregiving. At the time of the interviews, Cecelia was thirty years old and studying to become an occupational therapist, an ambition shaped by her experiences navigating special education and advocating for her son.

Data sources consisted of three one-hour, in-person interviews conducted over the course of a month, following Seidman's (2006) three-interview protocol: life history, present experiences as the mother of an autistic child, and reflection on the meaning of those experiences. Interviews were structured not as information-extraction tools but as dialogical spaces where Cecelia could narrate her experiences on her own terms, foregrounding affect, temporality, and relationality (Clandinin & Connelly, 1990).

Interviews were supplemented by field notes and "memory protocols" (Jovchelovitch & Bauer, 2000) composed immediately following each session, capturing relational dynamics, affective atmospheres, and emerging interpretations. Analytic memos were also composed throughout data collection and analysis, guided by van Manen's (1990) reflective phenomenology. Five memos were produced and discussed in peer debriefings to interrogate assumptions and attend to potential biases. Together, these materials supported a recursive engagement with the interview texts and sustained attention to existential motifs such as ambiguity, embodiment, freedom, and responsibility.

Interpretive Analysis

Analysis followed a phenomenological-hermeneutic approach consistent with the theoretical orientation. Interview transcripts, field notes, memory protocols, and analytic memos were read iteratively and dialogically to identify moments of existential intensity, those charged with paradox, ambiguity, or insight into being-in-the-world as a caregiving mother. Rather than coding for frequency or thematic saturation, meaning units were clustered through interpretive resonance with existential structures. Themes were not imposed in advance but allowed to surface through immersion and reflection. This posture was guided by van Manen's (1990) hermeneutic phenomenology, which emphasizes dwelling in lived experience, orienting to meaning, and maintaining openness to the textures of life as it is lived.

The analysis led to the articulation of existential motifs such as *Authenticity as Tension* and *The Fragile Architecture of Trust*, capturing Cecelia's navigation of caregiving within relational, temporal, and structural constraints. To support interpretive rigor, the case analysis built on the procedures of the larger project, including iterative analysis, reflexive memoing, and structured member checks. For this focal case, Cecelia was contacted by phone two weeks after the final

interview to review and clarify her responses, supporting co-constructed meaning and affirming interpretive resonance (Creswell & Poth, 2018; Seidman, 2006). The analysis remained anchored in thick description, participant-centered interpretation, and the ethical responsibility of honoring Cecelia's voice without reducing it to theme or typology.

Findings

Cecelia: A Life in Fragments

Cecelia left northern Mexico as a child, hidden in the back of a truck with her family. Her mother had left to escape Cecelia's father, a man whose cruelty saturated the household. That first crossing, then, was not just a migration story. It was an act of survival, an attempt to sever a cycle of harm. They crossed into the U.S. hoping for safety, but what followed was a betrayal that changed everything: Cecelia was sexually assaulted by her uncle, a wound that shaped her distrust of men and deepened her silence. "I don't talk about things," she said. "Especially not to men."

When I first invited Cecelia to participate, she hesitated. I am male, and she later admitted, "I almost didn't come. You just never know if they'll really listen." Eventually, she spoke carefully. Her story did not follow a neat arc of trauma and recovery. It emerged in fragments—crossing borders, being silenced, raising her autistic son in a system that often misunderstood her.

Cecelia's mistrust of educational institutions was seeded early. As a child, she was placed in a "special ed" classroom after teachers noted her quietness and social withdrawal. "They said 'LDs' or something like that," she recalled, referencing the label of learning disability. Despite having strong grades and perfect attendance, she was removed from the general classroom not for academic performance but for not engaging, for being silent. "It was more of my language than anything else," she said. She also remembered the racial dynamics of the placement, "they were all Black students," which deepened her sense of being educationally sidelined. She wanted to speak up, to advocate for herself, but could not: "I had to put a foot on the ground and woman up," she said, "but I was so shy." This early experience of being misunderstood and mislabeled would later inform her refusal to remain silent in advocating for her son.

Dwelling in Disruption: Time, Routine, and the Weight of Care

Time, for Cecelia, is lived through the body, shaped by routines that blur exhaustion and intention. "I wake up already tired," she said, "not just because of sleep, but because I know what the day will take from me." The fatigue was anticipatory. Hector's needs passed through her first, and only then into the world. Care became a form of buffering.

Her caregiving unfolded through micro-decisions with macro significance. Routine was not convenience or habit, but necessity, a choreography of accommodation and future-oriented fear. She described taking the bottle away, then giving it early: "Just give it to him at five in the morning," she said, because later he would want to bring it with him, and "it calms him down." What looks like "behavior management" from the outside read, in her account, as timing shaped by a knowledge of Hector's emotional thresholds and by her awareness of how others might interpret

him. “It’s like, I feel like I’m hurting him,” she said, “but at the same time, it’s good for himself,” so that “in the future, he doesn’t get bullied” for still needing comfort objects.

Cecelia’s caregiving stretched across temporalities, rooted in present demands but saturated with visions of the future. “With the IEP [Individualized Education Program], I learned that a routine has to be mandatory,” she explained. “It doesn’t matter his age. It just has to be consistent” to help him have “a well day.” Her phrase, “a well day,” offered an alternative metric for success: stability, emotional equilibrium, and a morning that does not unravel before it begins.

Speaking into Silence: Maternal Advocacy as Existential Resistance

For Cecelia, advocacy began not with confidence but with silence, an embodied response to being misheard or dismissed. When she re-entered special education as an adult, she found professionals speaking a language she was expected to understand but never invited to shape. IEP meetings were not experienced as spaces of inclusion, but as decisions delivered. “They didn’t ask me what I thought,” she said. “They just said, ‘This is what we’re doing.’” It was not that she lacked insight, but that her insight did not register as the right kind of knowledge.

That dissonance echoed her childhood. “Nobody stood up for me,” she said. “I was quiet.” Because she “didn’t speak up,” she was “always getting blamed,” especially by her brothers. That history sharpened her attunement to Hector’s vulnerability as a nonverbal child. When his brothers accused him, she felt the old scene return. “It relates to Hector because he’s nonverbal,” she explained, and when others said “Hector hit me,” it “makes me feel like when I was little.”

The recognition carried an internal conflict. Cecelia was caught between uncertainty and allegiance, trying to interpret what she could not fully access. “It’s kind of tricky,” she said, describing how she would ask Hector what happened and he would simply stand there. In her telling, his silence was not emptiness but distance, as if he were “talking to me” in a way she could not decode, “like it sounds like I need to learn Chinese or something.”

Yet this was not resignation. Cecelia responded to erasure with self-authoring. “I started taking classes,” she said. “I wanted to know what they knew.” The decision was practical, but it also marked a shift in how she understood herself: not as a passive recipient of institutional language, but as someone who could interrupt its authority.

Advocacy, however, did not always bring clarity. It often brought strain. Cecelia navigated unfamiliar discourse while managing doubt, relational tension, and exhaustion. Her caregiving knowledge, shaped by love and vigilance, was regularly subordinated to technical assessments and professional judgment. “I feel like I’m always trying to prove that I’m not crazy,” she said. “That I know what I’m talking about. That I’m not just being dramatic.” To advocate was not only to speak, but to defend one’s capacity to speak meaningfully at all.

Her motivation was layered. She fought not only for her son’s recognition, but against the ghost of her own misplacement. “They just assumed I didn’t know English,” she recalled, referring to her childhood placement. In fighting for Hector’s recognition, she resisted the earlier narrative that once defined her. Cecelia’s advocacy cannot be reduced to procedural participation. It was a refusal

to inhabit the role of deferent mother or passive client, and a reclamation of voice, not as volume but as presence.

The Fragile Architecture of Trust

Cecelia's story is shaped as much by care as by mistrust. Early betrayals left her wary of those who claimed authority or offered help. "I don't even trust my own parents," she said, as a summary of how fractured her relational world had become. Trust was not a default. It was earned through time, vulnerability, and consistency.

Her caregiving was carried out largely in solitude. Although married, Cecelia described feeling alone in her advocacy for Hector. "He doesn't always understand why I fight so hard," she said of her husband. "He says I'm too emotional, that I take things too personal with the school. But how can I not? They're talking about our son like he's a problem." Returning from IEP meetings to a household that did not reflect her urgency intensified isolation.

The weight of mistrust extended into professional settings. Many therapists and educators, she felt, were "just doing their job," performing efficiently without recognition of her emotional presence or Hector's unique way of being-in-the-world. Yet one therapist disrupted that pattern: "There was this one," she recalled, "she cried when I cried ... She wasn't just doing paperwork. She saw him." The moment was brief but clarifying. For Cecelia, trust was not built on credentials alone. It required reciprocity, an affective recognition that made her caregiving legible as caregiving rather than pathology.

Trust, then, was not procedural. It was fragile, affective, and rare. Cecelia's persistence was sustained less by policy than by intermittent moments of recognition and her refusal to abandon what she knew to be true.

Authenticity as Tension: Caring Between the Ideal and the Real

Cecelia's caregiving unfolded in a contested space between what felt right for her child and what others expected of her as a "good mother." The tension surfaced most clearly in family judgments. "They say I baby him," she said, describing critiques that framed responsiveness as indulgence and sensitivity as weakness. In choosing to care differently, Cecelia resisted not only systemic pressures but intimate norms.

This resistance did not offer certainty. Her decisions, what to withhold, when to soothe, how to discipline, were saturated with doubt. Weaning Hector from comfort objects was not narrated as a developmental milestone but as a moral dilemma. At stake was not only self-regulation in the present, but future safety in a world that punishes difference. Here, care appears as deliberation rather than instinct, a negotiation of freedom and responsibility (Merleau-Ponty, 1945/2012). Cecelia's caregiving balanced compassion now with protection later. To act authentically in such a context was not to act without contradiction, but to remain accountable to contradiction as it unfolded in lived time.

Rather than rejecting the “good mother” ideal entirely, Cecelia rewrote it. Her authenticity was less a matter of confidence than of staying with ambivalence, practicing care that was responsive, aware of its limits, and open to revision.

Hermeneutic Reflections

The Czech novelist Milan Kundera (1984) described modernity’s dilemma as one of repetition without clarity. He wrote, “We live everything as it comes, without warning, like an actor going on cold” (p. 5). Cecelia’s narrative reflects this burden. Her experiences as a mother, immigrant, trauma survivor, and caregiver unfold not in a linear arc, but in a series of existential interruptions, moments where decisions must be made without rehearsal and meaning must be forged amid ambiguity. Yet within this rhythm of vigilance and exhaustion, Cecelia also encountered moments of awe. Reflecting on her son’s way of being, she explained: “Their life is not as damaged as what we live. Their life is so innocent. Even though people judge them by their disability, I feel like they are way smarter than we are. I always treated my son like a regular child.” In this moment, Hector emerges not simply as one in need of advocacy but as someone who reorients Cecelia’s perception of the world. She did not romanticize autism, but she did locate within it a kind of lightness, a freedom from the oppressive social scripts that shaped her own life. This recognition, echoing Kundera’s existential metaphor, reframes caregiving as more than burden. It becomes an invitation to perceive differently.

Embodied Attunement and Revolt: Reclaiming Presence in Constraint

At the heart of this case lies a conflict between institutional logics and maternal attunement. Cecelia’s despair during IEP meetings, described as being at the “center of something” where others “just talk and talk,” captures the asymmetry of expertise embedded in special education. Although procedural safeguards nominally protect parent participation, the epistemic architecture of the IEP process often marginalizes the knowledge families bring. For Cecelia, institutional time felt recursive and unyielding, a “circle with no doors.” Her repeated presence at the table did not equate to relational inclusion. These bureaucratic rhythms of evaluation and compliance remained misaligned with the nonlinear and affective temporality of caregiving.

This misalignment is not only procedural but phenomenological. Merleau-Ponty’s (1945/2012) account of embodiment clarifies why Cecelia’s knowledge cannot be reduced to preference, emotion, or anecdote. The body is not simply an object that moves through institutional space; it is the medium through which the world becomes meaningful. Cecelia knows Hector through rhythms, thresholds, gestures, silences, and anticipatory adjustments. Her knowledge emerges in the lived interval between his distress and the world’s response to it. When institutional actors translate this attunement into categories of behavior, compliance, or parental concern, they risk stripping caregiving of the embodied conditions through which it becomes intelligible. This is the analytic value of phenomenology in this case, as it allows Cecelia’s caregiving knowledge to appear not as supplemental information about Hector, but as embodied perception formed through daily relational attunement.

Critical disability scholarship helps name how institutional norms of development and professionalism can pathologize difference and obscure the labor of care, particularly for mothers

whose racialized and linguistic positioning shapes how their speech is received (Annamma et al., 2016; Goodley et al., 2018, 2021). At the same time, Cecelia's account suggests that the practical force of these norms is hermeneutic as well as procedural: the system authorizes certain vocabularies of "progress" and narrows what can be recognized as credible parental knowledge. Within that narrowing, compliance can function as a survival strategy. Yet even within constraint, Cecelia enacts resistance through embodied forms of care that do not conform to diagnostic labels, institutional timelines, or measurable outcomes.

Cecelia's view of Hector further complicates deficit paradigms. Returning to the moment when she confided that Hector's "life is not as damaged," Cecelia resisted ableist projections by reframing autism not as lack, but as a mode of being less burdened by social artifice. Her awe at Hector's "lightness" gestures toward a revaluation of value itself. As Meekosha and Shuttleworth (2009) argue, honoring disabled ways of being requires not only dismantling barriers but also recognizing how disability unsettles what counts as knowledge, relation, and worth. What emerges here is not a simple story of resistance or victimhood, but an existential reckoning shaped by love, loss, and interdependence.

A gentle caution is necessary here. Kierkegaard (1844/1980) once described anxiety as "the dizziness of freedom" (p. 61), and Cecelia at times seemed to recognize and embody this tension. Yet the rhythms of her story do not narrate a singular experience of despair. Alienation and aloneness repeatedly opened onto moments of repair. Ernst Bloch (1954/1995) cautioned against being consumed by "the darkness of the just lived moment" (p. 193), when the present becomes opaque and uncertain, while still insisting that anticipatory consciousness can emerge from that darkness. This reframing allows us to dwell alongside Cecelia without collapsing into nihilism or hopelessness. Cecelia certainly did not. The freedom she exercised remained alongside trauma and pain, but within that tension her words pointed toward a future still unfolding. She spoke of ambitions, such as studying to become an occupational therapist, and joyful moments, like taking Hector to the park with other mothers of autistic children, where they would "just let them be on their own." In those moments of collective maternal care, she could even "just forget about the kids." Cecelia recognized that her life had been reshaped and enriched because of Hector, and in his future, as well as her own, she saw possibility.

Authenticity, Ambiguity, and the Myth of the Good Mother

Cecelia's caregiving is lived not only within structural constraint but also within social scripts of what a "good mother" should look like. From extended family accusing her of "babying" Hector to professionals treating her concern as emotional overreach, Cecelia repeatedly encounters maternal normativity. These interactions produce a double bind: to resist is to risk being labeled unstable or excessive; to comply is to betray her own embodied knowledge.

This tension is not merely social but existential. Sartre's (1943/1956) account of *bad faith* helps illuminate what is at stake in these encounters. Bad faith names the temptation to take refuge in socially prescribed roles in order to evade the burden of freedom. The "good mother" appears as one such role—coherent, recognizable, and institutionally legible. Yet to inhabit it fully would require Cecelia to disavow doubt, mute her attunement, and translate her care into acceptable forms of performance. She does not. She does not feign neutrality in IEP meetings or suppress emotional

presence. In refusing to collapse into the role of compliant parent, she confronts freedom under constraint, not as abstract choice, but as a lived and often costly responsibility.

Beauvoir's (1949/2010) feminist existentialism deepens this account by showing how such roles are not freely chosen but historically sedimented. Women are often confined to identities that appear virtuous—the nurturer, the selfless caregiver, the “good mother”—while being denied full subjectivity within them. Cecelia's experience reflects this paradox. Her care is demanded yet mistrusted, expected yet scrutinized. When she is told she is “too emotional” or overly protective, what is at issue is not simply behavior, but the boundaries of acceptable maternal subjectivity.

Cecelia's caregiving does not resolve this tension. It dwells within it. She second-guesses her decisions, weighs present comfort against future harm, and remains accountable to consequences she cannot fully predict. Rather than rejecting the “good mother” ideal outright, she reworks it from within. Her authenticity is not a stable achievement but an ongoing practice of negotiating competing demands, remaining responsive to her son while resisting reduction to role.

In this sense, Cecelia's caregiving aligns with Beauvoir's notion of ethical ambiguity. Freedom does not appear as control or certainty, but as the willingness to remain with contradiction and to act within it. Her authenticity is therefore not idealized or pure. It is weary, iterative, and relational. It resides in her continued effort to care without disavowing complexity, to speak even when recognition is uncertain, and to remain present within conditions that alternately invite and foreclose her voice. This is why existential phenomenology is especially useful for interpreting Cecelia's narrative: it does not treat maternal advocacy as a strategy, disposition, or competency, but as a situated struggle over freedom, recognition, embodiment, and responsibility within conditions she did not choose.

In Cecelia's world, meaning is not measured only by milestones or services secured, but by enduring presence in ambiguity. Her insistence that she does not seek certainty, only the dignity to be heard and held in struggle, returns the analysis to motherhood as lived philosophical inquiry rather than institutional role-performance.

Dwelling With Paradox: Reframing Maternal Agency

Cecelia's narrative reveals how disability is not merely a condition to be supported but a relational and epistemic world shaped by affect, routine, mistrust, and persistence (Passi & Parker-Katz, 2026). Her maternal knowledge is not incidental. Yet within special education systems, her ways of knowing are often positioned as excessive, unreliable, or merely anecdotal. Critical disability scholarship helps name how such misrecognition sustains hierarchies of expertise and legitimacy (Goodley et al., 2019; Meekosha & Shuttleworth, 2009). Connor and Valle (2015) describe related dynamics of epistemic exclusion, showing how medicalized and positivist framings of disability can diminish the knowledge of teachers, parents, and disabled people by privileging scientific and psychological language over lived, relational, and sociocultural understanding.

Cecelia is not only Hector's advocate. She is his translator, mediator, and interdependent partner in navigating a world that resists their intelligibility. Yet this agency must not be romanticized. To describe Cecelia's advocacy as existential freedom is not to suggest that freedom arrives without

cost, or that the burden of response should fall on the caregiver already carrying the greatest weight. In Cecelia's account, advocacy repeatedly requires additional cognitive and emotional labor, including learning institutional language, anticipating professional judgment, translating Hector's needs into acceptable terms, and managing the mistrust produced by prior misrecognition. Existential freedom, in this context, intensifies responsibility without necessarily redistributing support.

This is one reason Cecelia's story must be read as both an account of agency and an indictment of the institutional arrangements that require such agency to become necessary. The IEP process asks her to convert deeply embodied and culturally situated knowing into data points, goals, and scripted forms of participation. As Cioè-Peña (2024) observes, "the ideal of partnership collapses under the weight of systemic bias" (p. 117). When that collapse occurs, what is lost is not only procedural equity, but the epistemic integrity of those most impacted.

These dynamics also illuminate a normative ideal around which special education often orbits—rational, self-contained, developmentally linear. Cecelia's caregiving, and her refusal to be coerced into a compliant maternal role, subverts this ideal. Her agency emerges not through control or professionalized expertise, but through sustained relational labor that resists quantification (Goodley et al., 2018). McRuer's (2006) language of "crip refusal" helps name how such disruption can occur through lived difference, not as performative defiance but as insistence on another way of being.

An existential lens clarifies the stakes of this insistence. As Merleau-Ponty (1945/2012) argues, perception is never neutral but shaped by the body's relation to the world. Heidegger's (1927/1962) concept of *Geworfenheit*, or "thrownness," articulates the condition of being situated in structures not of one's choosing. For Cecelia, these include trauma and migration, but also the bureaucratic strictures of special education. And yet, like Camus' (1942/1991) rebel, she continues to act, not out of optimism, but out of refusal. Her revolt is quiet and maternal, persistent rather than theatrical.

DisCrit Mothering can be read here as one vocabulary for naming advocacy as counterhegemonic care, an embodied refusal of systems that misread difference as deficiency (Gomez & McKee, 2020; Saaltink, 2023). Cecelia's everyday decisions, what to say, what to hold back, how to reframe her son's needs, draw on experiential resources shaped by lived struggle, what Esteban-Guitart and Moll (2014) describe as "funds of identity." At the same time, I remain mindful of critiques that caution against privileging discursive analysis to the detriment of material realities and ethical deliberation (Vehmas & Watson, 2014). The existential-phenomenological orientation of this study aims to hold this tension, grounding structural critique in embodied, affective, and situated experience.

Limitations and Transferability

This paper offers an interpretive account of a single case and, as such, does not claim representativeness. Its contribution is idiographic and conceptual. The aim is to illuminate how caregiving, advocacy, and mistrust are lived and felt in a particular life, within particular institutional arrangements. Transferability depends on the reader's assessment of contextual

resonance (Lincoln & Guba, 1985). At the same time, the case is situated within a broader phenomenological project, and the analytic claims are grounded in iterative reading, memoing, and participant clarification.

Implications for Practice and Research

For practitioners, Cecelia's story underscores that trust is not a procedural outcome but a relational achievement that requires time, attention, and recognition of caregiver expertise. For schools, this means designing encounters that slow the tempo of meetings, make room for narrative and affect, and treat caregiving knowledge as epistemically credible rather than ancillary. For researchers, the case affirms the value of existential and phenomenological approaches for studying disability and family engagement, especially when technocratic measures of progress obscure what care costs and what it makes possible.

Conclusion

I close not with a call for more training or procedural refinement, but with a reminder that listening itself is a political and philosophical act. Sitting across from Cecelia as she shared her story, laced with pain, resilience, and an unexpected dark humor, became a site of existential reflection and reversal. My previous understandings of maternal care were rattled, and the fissure of awareness that emerged made space to witness a part of Cecelia rarely made visible. Like her, I came to understand that dwelling with paradox involves presence more than resolution. Her story does not fit comfortably within models of empowerment or victimhood. It asks something more difficult: that we acknowledge the limits of our frameworks and remain accountable to those whose truths exceed them, whose lives call us not just to theorize ethical care but to practice it.

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