Representation or Misrepresentation of Autistic Agency? Multimodal Literacy Analysis of *Makayla's Voice*

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Abstract: *While media portrayals of autism have been widely studied, limited research has examined how the agency of non-speaking autistic individuals is constructed through multimodal storytelling and mediated communication. This study examines how nonverbal autistic agency is portrayed in the Netflix documentary "Makayla's Voice: A Letter to the World." Grounded in multimodal literacy theory, the study employs qualitative methods and thematic analysis to examine how the film frames Makayla's communication and self-representation across text, audio, and visual modes. The analysis also draws on agency theory to examine how autistic agency is represented, and it applies the social model of disability to explore how the film challenges or reinforces societal discriminatory attitudes toward autism. Findings reveal a complex portrayal: the film affirms Makayla's agency through poetic narration, metaphor, and visual imagery, yet simultaneously mediates her voice through facilitator involvement and selective editing. These strategies contribute to a process of narrative idealization, in which a story is smoothed over to enhance a character's positive qualities. The study contributes to critical literacy by demonstrating how media can both empower and constrain the voices of non-speaking autistic individuals. It also calls for more nuanced and ethically grounded representations that recognize diverse communicative practices and multimodal literacies.*

Keywords: *agency; facilitated communication; media representation; multimodal literacy*

Abstrak: *Meskipun representasi autisme dalam media telah banyak dikaji, studi yang secara khusus menelaah agensi individu dengan autistik non-verbal melalui narasi multimodal masih relatif terbatas. Penelitian ini bertujuan untuk mengkaji bagaimana agensi autistik non-verbal direpresentasikan dalam film dokumenter Netflix Makayla's Voice: A Letter to the World. Dengan menggunakan teori literasi multimodal serta pendekatan kualitatif dan analisis tematik, penelitian ini menganalisis bagaimana film tersebut membingkai komunikasi dan representasi diri Makayla melalui perpaduan teks, audio, dan visual. Studi ini juga memanfaatkan teori agensi dan model disabilitas sosial untuk mengevaluasi bagaimana film tersebut menantang atau mendukung pandangan diskriminatif terhadap autisme. Hasil penelitian menunjukkan bahwa film ini mengafirmasi agensi Makayla melalui narasi puitis dan imaji visual yang kuat, namun juga memperlihatkan adanya keterlibatan fasilitator yang memediasi dan penyuntingan film yang selektif. Proses ini mengakibatkan terjadinya idealisasi naratif, di mana alur cerita cenderung diperhalus untuk menguatkan sisi positif karakter dalam cerita. Penelitian ini berkontribusi pada literasi kritis dengan menyoroti bagaimana media dapat sekaligus memberdayakan dan membatasi suara autistik non-verbal. Penelitian ini juga menekankan perlunya representasi yang lebih bernuansa dan etis melalui berbagai cara berkomunikasi dan literasi multimoda.*

Kata Kunci: *agensi; autisme; literasi multimoda; komunikasi multimoda; representasi media*

1. INTRODUCTION

Autism Spectrum Disorder (ASD) is characterized by some level of social-communicative difficulties and unusual activity and behavior patterns, such as trouble shifting between tasks, an intense focus on specific details, and atypical responses to sensory experiences (World Health Organization, 2023). Media—including film, television, and print journalism—often reinforce stigmatizing views of autism through stereotypical portrayals (Jones et al., 2023; Mittmann et al., 2024). Across both fictional and non-fictional formats, these depictions tend to oscillate between deficit-based narratives that emphasize overly heroic portrayals or impairments of autistic individuals. Indeed, although non-speaking or minimally speaking autistic individuals are sometimes represented positively in stories, they are still often depicted as deficit individuals who cannot function independently (Venker & Lorang, 2024). To challenge deficit-based portrayals of autism, the Netflix documentary *Makayla's Voice: A Letter to the World* (hereinafter *Makayla's Voice*) positions its central figure, Makayla Cain, as a non-speaking autistic child who exercises her agency. Venker & Lorang (2024) define authentic representations of agency as rooted in independence and self-determination, typically excluding reliance on external support. Their analysis explores how agency is both represented and misrepresented in children's picture books. Drawing from their study, the current research aims to answer the question: How is agency represented or potentially misrepresented in *Makayla's Voice*?

The film portrays Makayla's agency in overcoming her verbal deficit, utilizing a letterboard as an alternative medium of communication. Yet, the representation of agency within the film remains fraught with challenges of authenticity, narrative control, and mediation. For example, *Makayla's Voice is* framed by the filmmakers, narrated through voiceovers, and curated through selective editing. Moments of fluent, poetic expression are emphasized, while the relational labor of facilitated communication (i.e., the guiding hands of her father and facilitator) is subtly minimized. This portrayal invites closer examination of how Makayla's agency is constructed within the film.

A growing body of research has examined portrayals of autistic individuals in various types of non-fictional and fictional media (Dean & Nordahl-Hansen, 2022; Diaz et al., 2023; Jones et al., 2023; Mittmann et al., 2024; Venker & Lorang, 2024). However, there is still a notable lack of studies that scrutinize whether a character's agency is represented authentically in a documentary film. Additionally, research in multimodal literacy has emphasized the need to validate communication through multiple modes (e.g., visual, gestural, and technological), as those shown in films, rather than privileging speech (Kress & van Leeuwen, 2021). However, little scholarly attention has been paid to how constructions of non-speaking communication may inadvertently reinforce idealized understandings of agency. While existing studies have explored agency in fictional or child-oriented media, few have critically examined how a documentary film constructs or mediates non-

speaking autistic agency using multimodal resources.

2. RESEARCH METHODOLOGY

This study employs a qualitative method to examine how *Makayla's Voice: A Letter to the World* (Palacio & Cain, 2024) represents—or potentially misrepresents—the agency of a nonverbal autistic individual. Although this study examines a publicly available documentary, it acknowledges the ethical considerations involved in analyzing the mediated representation of a real individual without direct participation, particularly given the sensitivities surrounding disability and communication rights. The researcher remains critically aware of her positionality as an external observer and of the interpretive limitations involved in engaging with narratives shaped and presented through public media.

2.1 Theoretical Framework

Three interrelated frameworks are involved in this study: multimodal literacy, agency theory, and the social model of disability. Multimodal literacy provides tools for examining how visual, auditory, and textual elements interact to construct meaning across modes. Agency theory provides a lens for interpreting nonverbal communication as a valid expression of autonomy, intentionality, and self-determination. The social model of disability allows for a critical assessment of how the film challenges or reinforces dominant narratives surrounding autistic independence and communicative competence.

2.1.1 Media Representation of Autism and Multimodal Literacy

Media representations have a profound influence on societal attitudes and perceptions of autism (Dean & Nordahl-Hansen, 2022; Mittmann et al., 2024). Portrayals in popular media—whether in film, television, social media, or news outlets—often reflect and reproduce misconceptions, framing autism in restrictive, deficit-oriented, or simplistic ways (Diaz et al., 2023; Gauld et al., 2022; Karaminis et al., 2023). This framing contributes to the persistent social marginalization of autistic individuals, strengthening misconceptions and fueling stigma (Soffer & Argaman-Danos, 2021).

Recent scholarship emphasizes the necessity for media to enable self-representation by autistic individuals and their communities (Fontes & Pino-Juste, 2022; Kapp, 2019). Providing platforms for autistic people to tell their own stories, whether through film, social media, games, or literature, can foster greater authenticity and understanding. Importantly, many autistic individuals communicate through alternative or augmentative forms, employing multimodal expressions—such as gestures and digital messages—alongside or instead of traditional speech (Olli et al., 2021; Soffer & Argaman-Danos, 2021). This multimodal view resonates with Kress & van Leeuwen's (2021) framework, which emphasizes that meaning is constructed across multiple modes of expression, not just through words. Assistive technologies can aid the meaning-making process by reducing communication barriers and increasing opportunities for civic participation among

individuals with autism (Sousa, 2023), such as enabling them to express their agency.

2.1.2 Autistic Agency and Social Model of Disability

Agency is conceptualized as the degree to which an individual independently makes choices, takes initiative in their own lives, and influences their surroundings; thereby, autistic agency demonstrates autistic individuals' sense of empowerment and their ability to make independent choices (Venker & Lorang, 2024). Such a perspective on agency in autistic individuals has been represented in media, such as picture books for children (Cotterill, 2021; Pla, 2018). However, traditional approaches to disability have often failed to reflect this perspective. The medical model has typically focused on impairments as problems within the individual, rather than considering how the environment contributes to disabling experiences. Therefore, the social model is more appropriate for understanding people with disabilities (Oliver, 2023).

Nevertheless, while the social model successfully emphasizes the socio-political dimensions of disability, critics note that it sometimes disregards the complex, lived experiences of disabled individuals, especially those with intellectual disabilities and atypical communication (Goodley et al., 2021; Riddle, 2020). However, Riddle (2020) cautions against attempts to over-expand the social model, arguing that reforms should instead focus on conceptual clarity in the pursuit of justice and equality.

Autistic individuals often find themselves at the center of those debates, reflecting their longstanding marginalization in both clinical and educational conversations. Botha & Gillespie-Lynch (2022) found that autistic adults frequently view autism as a key aspect of their identity instead of framing it as a deficit. This perspective aligns with the neurodiversity movement, which advocates for understanding autism as a natural and valuable manifestation of human variation (Kapp, 2019).

While autistic individuals assert their agency and challenge deficit perspectives, the expression of that agency is deeply influenced by interpersonal and contextual factors. Emirbayer and Mische (1998) conceptualize agency as a process that evolves, comprising a repetitive dimension (drawing upon past routines), a projective dimension (imagining future possibilities), and a practical-evaluative dimension (making judgments in the moment). This framework resonates with the experiences of nonverbal individuals, such as Makayla, who assert their agency through facilitated and alternative forms of expression (Olli et al., 2021).

Additionally, Timmons et al. (2024) highlight that perceptions of disabled individuals are influenced by their context, gender, and the nature of their disability. Autism, when combined with intellectual disability, tends to elicit more unfavorable judgments, further impeding their ability to assert agency.

Collectively, this review of literature points to a significant gap in understanding: while there's growing acknowledgement of autistic agency and the validity of alternative communication methods, media and academic representations often fail to reflect the full complexity of these mediated, relational, and context-specific expressions of agency. This

study aimed to address that gap by examining how *Makayla's Voice* constructs, mediates, and at times idealizes non-speaking autistic agency, thereby providing a more accurate and comprehensive view of autism in media representation.

2.2 Data Collection and Analysis

A full transcript of the film was created, including spoken dialogue, voiceover narration, on-screen text, and relevant visual sequences. Particular attention was paid to scenes involving letterboard use, facilitator presence, metaphorical imagery, and poetic narration. These moments were selected for their potential to reveal how Makayla's agency is constructed, supported, or mediated. Data were analyzed using a two-cycle coding approach (Saldana, 2021). The first cycle used descriptive coding to identify recurring features related to modes of communication, narrative framing, and visual language. The second cycle focused on coding, generating thematic categories such as multimodal self-expression, mediated agency, and narrative idealization. For example, self-expression is evident in Makayla's statements, such as *"Portia is my voice"* and *"Silence is my cage, but it's my gift to the world to sing my silence out loud."* Mediated agency includes instances in which Makayla's facilitator and father assisted her in using the letterboard. Narrative idealization provides for the visualization of narrated texts. These themes were then interpreted through the study's theoretical lenses to evaluate how the film affirms, complicates, or distorts representations of autistic agency. To ensure analytic rigor, the researcher maintained reflexive memos throughout the analysis to maintain critical awareness of the researcher's interpretive role.

3. RESULTS

Makayla's Voice: A Letter to the World (Palacio & Cain, 2024) is a documentary film about Makayla Cain, a non-speaking autistic teenager who communicates through a letterboard. Makayla's life is supported by a close-knit circle that includes her parents, an older sister, an older brother, and a private teacher who also serves as her communication facilitator. The documentary is narrated through a combination of Makayla's typed messages, which are voiced by an actress, and visual storytelling that incorporates slow-motion sequences, metaphorical imagery, and reflective music. It weaves together scenes of daily life, poetic narration, and interviews with family members to portray Makayla as an articulate and emotionally rich individual. The film aims to challenge assumptions about silence and agency by giving voice to Makayla's inner world, highlighting both the expressive power and relational complexity of her nonverbal communication. However, while the documentary foregrounds her intelligence and creative insight, it also raises questions about mediation, idealization, and the authenticity of represented agency. Throughout the film, Makayla's communication through the letterboard is facilitated by her teacher. Furthermore, the film centers on Makayla's internal reflections, relationships, and expressive capacities, using poetic narration and symbolic visuals curated by the filmmakers.

The data were analyzed. Table 1 summarizes the main findings, with selected quotes and their relevance to the overarching research aim: to examine the representation or misrepresentation of autistic agency.

Table 1. Key Themes and Representative Data

Theme	Example of Data Excerpt	Interpretive Notes
Expressed Agency	"I dream of one day hearing my voice. I hope it's raspy, giving me a unique sound."	Reflects projective agency and self-authored identity.
Poetic Self-Representation	"Van Gogh used color to communicate, and I use letters on a board."	Draws a metaphor between artistic and nonverbal expression; affirms multimodal literacy.
Reframed Silence	"Silent is not us. We are the sound of hidden beauty."	Resists deficit views of silence; redefines silence as expressive.
Relational Agency	To her father: "You found my voice before anyone else did."	Acknowledges interpersonal support; aligns with the social model of disability.
Mediated Communication	The facilitator holds the letter board and assists with spelling: "I'm not silent."	Agency is co-constructed; authorship is ambiguous.
Ambivalence toward Normalcy	"I wish I could be more like my siblings."	Reflects internalized ableism or longing for inclusion; contrasts with empowerment messaging.
Narrative Idealization	Slow-motion visuals, metaphors, and selective fluency emphasize inspiration.	Suggests narrative smoothing; authentic struggles are minimized.

Table 1 presents seven themes that emerged from the data, arranged to reflect a continuum from expressed agency to more mediated or idealized portrayals. The first theme, Expressed Agency, captures moments when Makayla articulates desires and imagined futures, such as her aspiration to one day hear her voice and her preference for how it might sound. This quote reflects strong projective agency, where Makayla is portrayed as forward-thinking, self-aware, and intentional in her reflections—characteristics often denied to nonverbal autistic individuals.

Building on this, the second theme, Poetic Self-Representation, includes metaphoric comparisons that position Makayla's communication as artistically and emotionally rich. Her analogy to Van Gogh—using letters on a board as he used color—underscores her self-concept as an expressive individual who communicates creatively through alternative means. These moments reinforce the film's attempt to validate nonverbal expression through a multimodal lens.

The third theme, Reframed Silence, shows how Makayla challenges deficit-oriented interpretations of silence. Rather than viewing her lack of speech as an absence or limitation, she redefines it as a space of beauty and meaning. Her statement, *"Silent is not us. We are the sound of hidden beauty"* demonstrates narrative resistance and suggests that her silence carries depth and value. These early themes collectively portray

Makayla as an autonomous and thoughtful communicator whose nonverbal voice is both valid and profound.

The fourth theme, relational agency, adds nuance to this picture by acknowledging the role of others in enabling Makayla's voice. When she says, *"You found my voice before anyone else did,"* she credits her father or facilitator for supporting her ability to communicate. This reflects the social model of disability, which emphasizes that agency often depends on the accessibility of supportive environments. While her voice is presented as her own, it is also socially and relationally mediated.

This mediation becomes more visible in the fifth theme, Mediated Communication, where Makayla is seen using the letterboard with physical assistance. In scenes where facilitators guide her hand or spell out messages on her behalf, the clarity of authorship is less certain. Though the film presents these moments as collaborative, they introduce ambiguity about the extent to which Makayla's agency is autonomous or co-constructed—a critical point of tension in the representation.

The sixth theme, ambivalence toward normalcy, emerges in quotes where Makayla expresses a desire to be like her siblings. This statement introduces emotional complexity, suggesting internalized frustration or a longing for inclusion. Without further context, such expressions risk being misread as evidence of self-rejection rather than a critique of societal exclusion. These moments complicate the empowering narrative and underscore the need for a socially grounded interpretation of disability.

The final theme, Narrative Idealization, reflects the film's aesthetic choices, such as poetic narration, nature metaphors, and highly polished editing, that frame Makayla's story as emotionally uplifting. While these techniques enhance the film's impact, they also risk obscuring the labor and relational complexity of facilitated communication. By emphasizing inspiration and poetic clarity, the film may unintentionally contribute to a form of narrative smoothing that simplifies Makayla's lived experience for emotional effect.

Together, these themes reflect a rich yet uneven portrayal of autistic agency—one that oscillates between authentic representation, relational mediation, and narrative idealization.

The findings demonstrate a spectrum of agency as represented in *Makayla's Voice: A Letter to the World*, beginning with moments of powerful self-expression and extending into more ambiguous portrayals shaped by facilitation, mediation, and editorial choices. This progression reveals an ongoing tension between affirming autistic agency and constructing it through a curated, emotionally resonant narrative.

Makayla's self-authored statements reveal a strong sense of projective agency. Her reflection: *"I dream of one day hearing my voice. I hope it's raspy, giving me a unique sound,"* exemplifies what Emirbayer & Mische (1998) describe as the future-oriented capacity of individuals to imagine and shape their identities. By expressing a specific, aesthetic vision of her future self, Makayla counters dominant

assumptions that non-speaking autistic individuals lack intentionality or self-awareness.

Her use of metaphor—particularly in the comparison *"Van Gogh used color to communicate, and I use letters on a board"*—affirms a multimodal understanding of literacy (Kress & van Leeuwen, 2021). Here, Makayla equates her nonverbal expression with visual art, thereby reframing her communication not as compensatory, but as creatively and intellectually rich. This represents a powerful act of poetic self-representation, affirming that literacy and agency are not bound to speech. Such metaphors represent powerful acts of poetic self-representation that legitimize alternative forms of communication.

Similarly, her statement *"Silent is not us. We are the sound of hidden beauty"* resists traditional deficit frameworks. Rather than framing silence as a void, Makayla reclaims it as meaningful and expressive, aligning with the resistance of autistic individuals toward stereotypes (Botha et al., 2022). Her poetic reframing aligns with the broader aims of the neurodiversity movement, which challenges pathologizing discourses and emphasizes self-authored identity (Kapp, 2019).

Yet, Makayla's agency is not wholly autonomous; it emerges in relational contexts. Her acknowledgment—*"You found my voice before anyone else did"*—illustrates the enabling role of caregivers and facilitators. This relational dynamic aligns with the social model of disability (Oliver, 2023), which posits that accessible environments and social support shape agency. As Olli et al. (2021) argue, agency in nonverbal communication is co-constructed, underscoring the importance of understanding voice as emergent within networks of assistance and care.

However, the representation of this relational agency becomes more complex in mediated scenes. For instance, when Makayla's facilitator physically moves the letterboard while spelling statements like *"I'm not silent,"* the boundary between support and authorship becomes blurred. These scenes, though intended to amplify Makayla's voice, raise critical questions about whose voice is being represented. The presence of adult intermediaries, combined with selective editing, illustrates how media portrayals can both affirm and obscure autistic agency depending on framing choices.

Moments of emotional vulnerability also contribute to the film's layered portrayal. Makayla's reflection, *"I wish I could be more like my siblings,"* humanizes her experience but risks misinterpretation. Without critical context, this statement could be read as a desire to be "cured," inadvertently reinforcing ableist assumptions. A more nuanced framing could have situated this moment within a broader critique of structural exclusion, aligning more closely with the social model's emphasis on systemic barriers rather than individual deficits.

The film's aesthetic strategies—such as slow-motion forest scenes, poetic narration, and carefully curated moments of fluency—further complicate its representation of agency. These choices contribute to a form of narrative idealization. As Diaz et al., (2023) and Mittmann et al. (2024) caution, such inspirational framings, while well-intentioned, risk misrepresenting disabled individuals by emphasizing extraordinary talent while omitting the everyday

realities of communicative effort. In *Makayla's Voice*, the visible labor, pauses, and negotiations involved in using a letterboard are largely absent, replaced by a polished portrayal of eloquence and clarity.

In sum, *Makayla's Voice* presents a layered and often moving portrayal of nonverbal autistic agency. It succeeds in elevating multimodal forms of communication and resisting some deficit-based narratives. However, its tendency toward poetic abstraction and editorial smoothing complicates the authenticity of its representation. Makayla's voice is present, but it is also framed, mediated, and at times idealized in ways that warrant critical reflection.

The researcher argues that this tension reflects a central concern in critical literacy studies: not only what is represented, but how meaning is constructed, framed, and circulated through multimodal forms. From this perspective, portrayals of non-speaking autistic individuals must be interrogated for how they position agency within dominant discourses of fluency, coherence, and emotional appeal. When elements such as facilitated spelling, metaphor, and visual imagery are curated to generate affective impact, they may unintentionally obscure the relational and embodied labor that underpins alternative communication. A critical literacy lens demands attention to the power relations embedded in these representational choices, raising questions about who has the authority to speak, how voice is mediated, and which forms of literacy are legitimized or marginalized. Media portrayals that emphasize poetic fluency and an inspirational tone, even when affirming, risk reinforcing normative assumptions about what constitutes literacy or agency. Therefore, critical literacy must remain attuned to the intersection of aesthetics, access, and authorship in multimodal storytelling, particularly in representations of disability and communicative difference.

4. CONCLUSION

This study examined how *Makayla's Voice: A Letter to the World* portrays autistic agency, revealing a tension between authentic expression and narrative mediation. The film affirms Makayla's identity through poetic, multimodal storytelling, but also idealizes her voice and downplays the effort behind facilitated communication. Her agency is both self-expressed and co-constructed, shaped by editing and support. Theoretical frameworks have clarified this complexity: multimodal literacy affirms nonverbal modes as legitimate; agency theory reveals how voice evolves through context and collaboration; and the social model of disability reframes support as relational, rather than deficit-based. Limitations, particularly the lack of behind-the-scenes access and Makayla's direct input, underscore the need for ethical care in interpreting mediated voices. Still, this study points to the potential of inclusive storytelling that values alternative communication without oversimplifying it. Ultimately, media and educators must move beyond inspirational framings to embrace nuanced, ethical portrayals of neurodiversity—portrayals that recognize silence, support, and multimodality as central to autistic agency.

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