

**Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans***

**Duygu Beste Başer Özcan**

**Abstract**

Traditional family dramas have long relied on disability and queerness as metaphors to depict the dysfunctional states of American families. Although Stephen Karam's *The Humans* borrows elements from the canon with its portrayal of a family tested by secrets, resentments, and illnesses, it diverges significantly from the tradition. As this article demonstrates, the portrayal of disability and caretaking in *The Humans* is not stereotypical since it places access intimacy, a term disability activist Mia Mingus has coined, to the center as a trope that keeps the family together and gives them strength to be resilient in the face of drawbacks. In the presence of access intimacy and reciprocal care, the bond that connects family members to each other is strengthened. This article argues that although Stephen Karam is not a disability rights activist, his play *The Humans* contributes significantly to the disability justice movement with its focus on access intimacy within the family.

**Keywords:** American Theater, Stephen Karam, *The Humans*, Disability Studies, Mia Mingus

**Sahnedede Çağdaş Amerikan Ailesi:  
Stephen Karam'ın *The Humans* Adlı Eserinde Engellilik ve  
Erişilebilir Yakınlık**

**Öz**

Amerikan aile yapısını konu alan geleneksel Amerikan oyunları, engelli ve kuir karakterleri Amerikan ailelerinin işlevsizliğini vurgulamak için metafor olarak kullanmıştır. Birbirinden sır saklayan, birbirine kıزان ve hastalıklarla test edilen bir aileyi konu alması sebebiyle geleneksel Amerikan oyunlarıyla ortak unsurlar taşısa da Stephen Karam'ın *The Humans* eseri bu oyunlardan oldukça farklıdır. Bu makalede gösterildiği gibi, engellilik ve bakım verme *The Humans* eserinde klişe bir şekilde anlatılmamıştır. Aksine, engelli hakları savunucusu Mia Mingus'un "access intimacy" (erişilebilir yakınlık) kavramı oyuncunun ana temasıdır. Engelli bireylerin bakım ve erişim ihtiyaçlarını karşılayan diğer bireyler ile kurduğu yakınlığı tanımlamak için kullanılan "access intimacy" kavramı aile üyelerinin zorluklar karşısında güçlü ve metanetli kalmalarını sağlar. Bu oyun, "access intimacy" kavramını içselleştirmenin ve karşılıklı olarak birbirlerinin bakım ihtiyaçlarını karşılamanın aile bağlarını ne kadar güçlendirdiğini göstermektedir. Bu makalede de tartışıldığı üzere, Stephen Karam engelli hakları aktivisti olmasa bile, aile içinde erişilebilir yakınlığın (access intimacy) varlığının önemini merkeze alarak engelli hakları hareketine katkıda bulunmakta ve destek olmaktadır.

**Anahtar Kelimeler:** Amerikan Tiyatrosu, Stephen Karam, *The Humans*, Engellilik Çalışmaları, Mia Mingus

**Introduction**

In the twentieth century, the two-parent nuclear family, consisting of a white, middle-class, able-bodied heterosexual couple, and children, was glorified in American society. Conformity to normative standards was expected of families, and they were encouraged to follow the American Dream rather than their own desires and dreams. In contrast to American society's glorification of the perfect family, the playwrights of the era criticized this myth by portraying dysfunctional family dynamics in their works. Death, hypocrisy, incest, racial and

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

sexual violence, blame, guilt, and denial were the main themes. The most notable family plays of the first half of the era include but are not limited to Clifford Odets's *Awake and Sing* (1935), Tennessee Williams's *The Glass Menagerie* (1945), Arthur Miller's *Death of a Salesman* (1949), Eugene O'Neill's *Long Day's Journey into the Night* (1956), Edward Albee's *The American Dream* (1961) and *Who's Afraid of Virginia Woolf* (1962). Sam Shepard's family dramas dominated the second half of the twentieth century with plays such as *Curse of the Starving Class* (1976), *Buried Child* (1979), *True West* (1980), and *A Lie of the Mind* (1985). These works deconstruct the perfect family myth and challenge the idea of family as a monolith. While doing so, most rely on disability and queerness as metaphors to depict social problems that need to be fixed.

On the contemporary stage, however, the representations of the American family have notably transformed as playwrights began exploring diverse family structures marked by intersectionality. In other words, American families in the contemporary plays are not monolithic, but they are shaped by various forces such as the politics of race, body, gender, or class. Relying mainly on realism, contemporary playwrights have envisioned and promoted a theater that employs pressing concerns to expose problems lying at the center of the social politics in the United States. Such reevaluation prompted a critique of not only neoliberalism but also oppressive body and identity politics, resulting in the dehumanization and social stigmatization of minority groups.

Stephen Karam's *The Humans* is an example of such plays. The play had its premiere at the American Theater Company in Chicago in 2014. It opened off-Broadway in 2015 and had its Broadway premiere in 2016. The play was critically acclaimed. It won the Obie Award for Playwriting, the Tony Award for Best Play and the New York Drama Critics' Circle Award in 2016. It was also a finalist for the 2016 Pulitzer Prize for Drama.<sup>1</sup> In the play, Karam depicts the motivations, desires, and disappointments of an Irish American family, whose members are caregivers, disabled, and queer, in a post-9/11 setting. Although the play borrows elements from the canon with its portrayal of a family tested by secrets, resentments, and illnesses, it diverges significantly from the tradition. *The Humans* lacks the essentials of a traditional realist play that follows the pattern of a well-made play with a climax that eventually results in catharsis. Reflecting the atmosphere in the United

States after the 9/11 attacks and the economic crisis of 2008, the content is also unorthodox since neoliberal structures emerge as a problem that American families face now, while disability and queerness are essential parts of the family rather than metaphors. In other words, Karam dramatizes the Blake family's personal and familial crises while placing them in larger social, political, and economic contexts. In this vein, this article explores how Stephen Karam subverts and transforms the genre by focusing on disability and care work as experiences that keep the family together.

*The Humans* presents a family gathering at Thanksgiving in Brigid's new apartment where she lives with her boyfriend Richard. Brigid's parents, Erik and Deirdre, come from Scranton with Erik's mother, "Momo," who has dementia and uses a wheelchair. It is revealed that Erik and Deirdre cannot hire a professional caretaker for Momo because of their financial problems. The main reason for the financial crisis is that Erik lost his job after his affair with a colleague was revealed. As a result, the couple must sell the house they hope to live in after retirement. They are under considerable stress since taking care of Erik's mother is difficult while struggling with financial problems and trying to save their marriage.

Moreover, Erik and Deirdre's relationship with their daughters, Brigid and Aimee, is complicated despite their strong bond and deep affection. As traditional parents, the couple desperately wants Brigid to follow cultural norms and marry Richard. On the other hand, they accept their lesbian daughter, Aimee, supporting her relationship decisions and consoling her when she is heartbroken. Erik and Deirdre also resent their daughters for becoming non-religious and giving up on faith. They insistently remind Brigid and Aimee of the significance of faith, resulting in a chronic family conflict. Throughout the play, the audience/reader witnesses the family rekindling, evading, or tolerating these conflicts while also caring for one another and Momo. Meanwhile, Deirdre and Erik continuously exchange nervous looks as they wait for the right time for Erik to tell their daughters about his affair and financial problems. When he finally discloses his secret at the end of the play, Brigid and Aimee react strongly, feeling disappointed and frustrated. Everybody but Erik leaves the apartment, and he has an anxiety attack when all the lights go out. Finally, he also exists to calm down and meet the family outside, leaving the audience/reader uninformed about whether the conflict will be resolved or not.

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

In their correspondence regarding disability representation in canonical works and contemporary plays, disability studies scholars Ann M. Fox and Carrie Sandahl confirm the play's significant contribution to the field. Also, Carrie Sandahl notes in this discussion that in *The Humans*, "we see disability as it impacts a family across different generations" (Fox and Sandahl 148). All characters in the play are disabled on different levels, and the disability experience is presented with its complexities in real-life circumstances in a realist setting. Contrary to the tendency to narrow disability down to physical and mental impairment, Rosemarie Garland Thomson claims that disability is an umbrella term that includes "congenital and acquired physical differences, mental illness and retardation, chronic and acute illnesses, fatal and progressive diseases, temporary and permanent injuries, and a wide range of bodily characteristics considered disfiguring, such as scars, birthmarks, unusual proportions, or obesity" (13). Within this context, various disabilities exist on stage: Momo has dementia, Erik suffers from insomnia and chronic pain, Deirdre has arthritis, and she has developed an eating disorder as a coping mechanism. Aimee has broken up with her girlfriend and lost her job because of her severe intestinal problems, and now needs to undergo surgery. Brigid, on the other hand, struggles with depression since she cannot find a job and works at a bar to pay her student loans.

In this regard, the portrayal of disability and caretaking in *The Humans* is not stereotypical. Despite their disputes and problems, the family members always maintain an affective relationship, especially about care. All the while, "access intimacy," a term disability activist Mia Mingus has coined, keeps the family together, and it gives them strength to be resilient in the face of drawbacks. Within this context, this article argues that *The Humans* contributes significantly to the disability justice movement with its focus on "access intimacy" within the family as an enriching affective response to disability and care work.

### **Access Intimacy and Disability Justice**

Disability activism against stigmatization and discrimination in the United States gained momentum along with the Civil Rights Movement. Historian Kim Nielsen states that building on the arguments of feminist, African American, and queer activists, disabled people also claimed that "their bodies did not render them defective. Indeed,

their bodies could even be sources of political, sexual, and artistic strength” (160). In the following decades, disability activists fought against ableism in all areas of life, and claimed legal rights to protect them from discrimination, insisted on removing physical barriers, and they spoke against institutionalization. As a result, several laws passed to secure disability rights, including Americans with Disabilities Act (ADA) of 1990, which “prohibits employment, access, housing, and educational discrimination against people with disabilities” (Nielsen 181). The activism of disabled people resonated with artists, playwrights, artists and scholars who not only exposed discriminatory attitudes in art, literature, and academia, but they also advocated for justice for disabled individuals.

These discussions created a disability culture in the United States, and today, disability activists resist ableism, hierachal establishments, and the concept of normalcy that defines individuals through binary oppositions. Accepting that the Disability Rights Movement has brought crucial changes in terms of physical accessibility, disability activists claimed in the early 2000s that it is now time for a second wave to the movement, which must gravitate toward a justice-based activism rather than a rights-based one. They define disability in intersectional terms and claim that disability oppression is intertwined with racism, sexism, ageism, and classism. Within this context, disability activists, such as Mia Mingus, Eli Clare, Patty Berne, Leah Lakshmi Piepzna-Samarasinha, and Simi Linton, argue that all individuals are interconnected, and societies can achieve justice and equality through interdependence and close community relations.

Sins Invalid, a disability justice-based performance group that aims to expand disability justice, has published *Skin, Tooth, and Bone: The Basis of Movement is Our People* to provide a definition for disability justice and share their experiences in establishing this concept. They propose the following principles that disability justice should be based on: intersectionality, leadership of those most impacted, anti-capitalist politics, cross-movement solidarity, recognizing wholeness; sustainability, commitment to cross-disability solidarity, interdependence, collective access and collective liberation (23-26). Drawing on the principles of disability justice, Mia Mingus has contributed to the movement by coining the term “access intimacy.” In her renowned 2011 blog post entitled “Access Intimacy: The Missing Link,” Mingus introduces “access intimacy” to describe an “elusive,

hard to describe feeling when someone else ‘gets’ your access needs.” Differentiating access intimacy from physical, emotional, intellectual, political, familial, or sexual intimacies, Mingus defines it as “[t]he kind of eerie comfort that your disabled self feels with someone on a purely access level.” As Mingus argues, access intimacy is not for a specific group or community, and anyone has the potential to experience it. Instead, access intimacy is possible when individuals possess a similar emotional state in that both subjects share a needs/access-based intimacy.

Although Mingus does not claim it to be an affect, access intimacy can be characterized as a feeling evoked as a result of positive affective circulations. This change in affective registers regarding disability will help to develop other intimacies fundamental to human existence. In other words, it is a positively loaded emotive representation of the affect of disability; therefore, it is transformative. Mingus writes: “There have been relationships where access intimacy has helped to create the conditions out of which emotional, familial and political intimacy could grow” (“Access”). Then, access intimacy cultivates compassion, connection, and interdependence because it “invites attention to our fundamental intersubjectivity, our inherent vulnerability, and the asymmetries of power in any relationship” (Valentine 78). In this sense, what is fundamental to access intimacy is to understand disability as a “natural part of human experience” (Volion 87).

Since access is often associated with removing physical barriers, a disability justice based approach to disability broadens the definition of access. For instance, Piepzna-Samarasinha defines it as “a collective joy and offering we can give to each other” (17). Similarly, Desiree Valentine explains that defining “access” within a disability justice framework would force one to consider beyond physical accommodation. Emphasizing the significance of interdependence, access “demands attention to the wealth of social, emotional, and mental diversities of ways to inhabit the world” (80). The scholar also asserts that when access issues are discussed, “the cognitive and affective dimensions of (in)accessibility” should also be taken into account, and she states that attending to elements of access such as “everyday feeling, habits, values, and worldviews” will help social transformation (81).

When taken through this framework, access is inextricably intertwined with care since it is about access to one's physical, emotional, psychological, or social needs. As Peggy Phelan states, “[t]o take care of the body, to care for the body, and to care about bodies requires a specific ethics—one that takes touch as axiomatic, emotional attachment as a value, and interconnection as constant” (323). Therefore, access intimacy is not opening up a space for the disabled but creating a new social order with the disabled in every aspect of life. This is possible when a person has “crip knowledge” (Piepzna-Samarasingha 252). Such realization manifests itself when subjects open themselves up to one another, learn and value the knowledge embodied in all bodyminds.

Access intimacy breaks off the associations of access with logistics, and it moves the issue to the “realm of relationships” where interdependence and care become prominent (Mingus, “Access Intimacy, Interdependence”). Then, access intimacy promotes the “transformation of” the ableist society instead of “inclusion into” it (Valentine 84). As Mingus explains, “access for the sake of access is not necessarily liberatory, but access for the sake of connection, justice, community, love and liberation is” (“Access Intimacy, Interdependence”). In this regard, care relationships in *The Humans* demonstrate that the health of families, communities, and relationships depends significantly on transforming the affect of disability and care work. Access intimacy in *The Humans* results in a new kind of emotion as individuals’ affective states and affects circulating among them differ from the stereotypes.

### Care and Access Intimacy in *The Humans*

Before discussing the dramaturgical choices in *The Humans*, it is necessary to talk about the setting since it contributes significantly to the portrayal of family dynamics and access intimacy. The rundown, two-story apartment building in Chinatown requires a lot of maintenance. The family’s life is constantly interrupted by the strange—sometimes eerie—sounds coming from upstairs. Karam depicts the apartment as follows: “It’s big enough to not feel small. It’s just small enough to not feel big. . . . The rooms are worn, the floors are warped, but clean and well kept” (9). Just like the apartment, the

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

family has its cracks and each character struggles with their flaws and problems. Yet, they always take shelter in the family. Family members feel connected to one another in any case and never break the affective bond that keeps the family together.

Bess Rowen notes that, except for the inclusion of a lesbian daughter, the play does not challenge the conventions of realism or naturalism with its “standard cut-away house on stage” (338). This may be stylistically true; however, Karam’s dramaturgical choices when depicting the family and the house diverge from traditional family dramas. First, although the house’s physical condition is the symbol of the family’s current situation, the family members accept and support each other no matter what happens, and they enjoy one another’s company in all circumstances. Moreover, the family structure in the play subverts the traditional and normative representations of the American family. That is, neither the queer character nor the disabilities in the family lie at the core of the family’s dysfunctional state. They do not function as metaphors for the problems existing within the family, either. Karam rather points out that it is the current neoliberal politics that exacerbates stigmatization and frictions, pushing people to the edges of society. For instance, Brigid suffers from depression because she cannot find a job despite her degree, and she is forced to live a precarious life by working part time without health insurance and financial security. Similarly, Erik and Deirdre become disabled because of the physical labor, but they cannot afford to access decent healthcare, causing them to live with chronic pain. Aimee, on the other hand, is forced to resign because she uses her sick leave more than the company tolerates.

In such an oppressive environment, all characters are in a reciprocal care relationship, and the primary care work revolves around the grandmother, Momo, who has dementia. Janet Gibson points out that people with dementia are stereotypically labeled as the “living dead” because their cognitive and physical capabilities change to the point where they cannot function autonomously. Therefore, they are no longer seen or accepted as real people (4). *The Humans* challenges this perception by showing that the affective care network surrounding Momo continues incessantly from the beginning of the play to the end. In this regard, the focus of the play is not what the family and Momo have lost but how they have adjusted their lives according to Momo’s needs, and how they enjoy their time together. This does not mean that

Karam ignores the difficulties that come with the care work. While acknowledging the complexities, the play provides novel perspectives on creating access intimacy.

In the opening scene, the audience is introduced to Momo's wheelchair before Momo herself. The existence of a wheelchair—or a disabled character—on the stage per se does not make a play inclusive, yet it is a political expression when used to claim disability justice. Petra Kuppers points out the potential wheelchairs hold, claiming they can be “icons and communication symbols” (81). Then, the use of a wheelchair in *The Humans* draws attention to care and accessibility, thereby carrying political significance to transform affective responses to disability, care, and illness. Paul Longmore and Lauri Umansky note that disability in American society is associated with the loss of many things, such as independence, autonomy, or control (7). In *The Humans*, Momo experiences all of these, and to an ableist mind, Momo and her wheelchair bear the affect of loss. However, in Karam's world, the wheelchair becomes a signifier of care, interdependence, and access intimacy. Although it exists for Momo, she is not the one who uses the wheelchair. Everyone in the family is a wheelchair user since Momo's dementia is at a point where she does not have control over her body. Helping Momo with the wheelchair never poses a problem for anyone. On the contrary, they see it as an opportunity to connect and spend time with her. In this vein, dramatizing the real-life experiences of dementia as well as the portrayal of access intimacy both alter the perceptions of the nondisabled reader/audience and make people with dementia visible on stage not as passive stage props but as active participants.

At the beginning of the play, the only character on stage is Erik, standing next to the wheelchair. Deirdre and Momo exit the bathroom after a toilet flush is heard, an implication that Momo needs care for the basic daily tasks. Beginning a play with a toilet flush sound and showing two characters leaving the bathroom result in an immediate disaffection in the audience/reader since a bathroom's affect is associated with the emotions of disgust, filthiness, and privacy. The scene causes disaffection because Karam exposes a hidden, not publicly discussed aspect of caregiving. After Erik and Deirdre—together—help Momo to sit in the wheelchair, Momo begins mumbling words and sentences that do not make sense. It is understood that Momo does not recognize her environment and the people around her. Nevertheless, the family members try to listen to what she is articulating and communicate

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

with her. Erik explains to her that they are in Brigid's new apartment, where they will have a Thanksgiving dinner. However, Momo keeps repeating the phrase, "you can never come back," to which Brigid responds, "Momo, you can absolutely come back, any time you want" (13). As the quotation shows, the family members neither intimidate nor humiliate Momo. On the contrary, they attend to her well-being always in a loving manner and continue to communicate with her. Mingus states that access intimacy is "knowing that someone else is with me in this mess. It is knowing that someone else is willing to be with me in the never-ending and ever-changing daily obstacle course that is navigating an inaccessible world" ("Access"). In this sense, the characters make sure that Momo knows they are with her under all circumstances, so she never feels alone, desperate, or uncomfortable. In addition to the characters' positive affective states toward Momo and her current embodiment, they also consider her comfort. For instance, when Deirdre helps Momo lay down on the couch, Brigid, and even Richard, help to make her more comfortable by finding extra pillows and blankets, or by lifting and moving her feet to help her get situated. In this sense, affective immediacy of care coalesces into access intimacy in the family.

Karam does not narrow down Momo's individuality to her disability and shows that she is not just a body without agency. In this regard, not only does he dramatize how she is cared for, but he also conveys her story through other characters' anecdotes. As Gibson argues, in dramatizing dementia, it is necessary to offer "affordances for people with dementia" by depicting their "comprehension of reality" (197). This would help playwrights create "alternative narratives to dominant cultural ones" because they would be giving "voice to those who are usually silenced or thought not to be able to speak" (Gibson 197). In other words, Gibson insists on reimagining and dramatizing the subjectivity of people with dementia to achieve cultural change (197). Karam successfully creates an alternative narrative by completing her story and characterization through multiple perspectives. For instance, Deirdre tells Richard how she refused to quit driving when she was first diagnosed:

She was something, she refused to quit driving, Rich, refused, but . . . six years ago? Erik couldn't bring himself to take the keys from her, so he got her to take a driver's exam so the decision wouldn't be on him, and part of her test is—they show

her a picture of a “yield” sign, but without the word “yield” on it . . . well she can’t name it, but enough of her’s still there that she goes to the poor guy giving the test, really pissed off, she goes: “Trust me, I’d know what to do if I was driving.” And he’s like: “Then just tell me what you’d do if you were driving and pulled up to this sign.” And she goes: “I’d see what everyone else was doing, then I’d do that.” (67)

As the story reveals, adjusting to life with dementia is a multifaceted experience, and it is difficult not only for the person experiencing it but also for family members. Erik struggles to ask Momo to stop driving, whereas Momo refuses to accept that she is not capable of doing specific tasks anymore. Nevertheless, Momo gradually embraces her new bodymind and accepts it as a part of her selfhood. The family members also learn to adjust their lives according to Momo’s needs and her new embodiment.

In a later scene, when all family members say grace, Deirdre reads an e-mail from Momo, which has become a part of their Thanksgiving tradition. The use of the e-mail is dramaturgically significant regarding disability representation on stage because by giving Momo a voice, it upholds disability justice for people with dementia and refutes ableist notions that devalue their lives. It functions as a tool to give Momo agency and voice. Deirdre reads:

“Dear Aimee and Brigid, I was clumsy around you both today and felt confused. I couldn’t remember your names and felt bad about that. It’s strange slowly becoming someone I don’t know. But while I *am* still here, I want to say: don’t worry about me once I drift off for good. I’m not scared. If anything, I wish I could’ve known that most of the stuff I *did* spend my life worrying about wasn’t so bad. Maybe it’s because this disease has me forgetting the worst stuff, but right now I’m feeling nothing about this life was worth getting so worked up about. Not even dancing at weddings.” (*The Blakes smile. They have inside understanding of this remark*) “Dancing at weddings always scared the crap out of me, but now it doesn’t seem like such a big deal. This is taking me forever to type. Consider this my fond farewell. *Erin go bragh*. Dance more than I did. Drink less than I did. Go to church. Be good to everyone you love. I love you more than you’ll ever know.” (123)

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

Compared to the anecdote Deirdre shared, the e-mail showcases the transformation in Momo's understanding of dementia. As Susan Wendell suggests, living with disability or illness "creates valuable ways of being that give valuable perspectives on life and the world," ways of being that would be lost in case of the elimination of illness and disability (31). Within this context, Momo began living in crip time after dementia. In "Six Ways of Looking at Crip Time," where Ellen Samuels discusses the "less appealing aspects of crip time," she describes crip time as "broken time" and discusses that the disabled individuals must adjust their bodies and minds "to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to . . . It insists that we listen to our bodyminds so closely, so attentively in a culture that tells us to divide the two" (192). In this sense, Momo has learned to perceive the world from a different view and embraced crip time. Through the Thanksgiving letter, she passes her knowledge to her granddaughters, and crip time teaches her to accept the drawbacks of the illness as a natural course of human life.

It is not just Momo who develops a new perspective on life and the corporeality of dementia. Similarly, Erik's remarks, such as "[t]his is definitely not one of your better days Mom . . . oh man, we, uh . . . we'll all be there some day, right? . . . / we love you so much, Mom. . ." (95), show that he—and other family members—now see disability experience differently and they also embrace the crip time Momo lives in. This makes them commit to access intimacy rather than seeing care work as a burden or tragedy. In this regard, the family members never stigmatize Momo's disability and Erik's remarks evoke an acceptance of the disability activists' noteworthy claim that everybody will eventually be disabled if they live long enough.

Moreover, Marian Barnes posits that reciprocation cannot be expected when providing care for a family member with dementia. She notes, "[t]he changes in behaviors, activities, interactions and expectations resulting from dementia affect the individual concerned, their loved ones and close family members. They have significant impact on family dynamics, and on social networks" (55). In this regard, the Blake family also acknowledges the complexities of care and dementia, and they adjust themselves according to Momo's needs. Even though they are concerned about her health, they do not assign negative affects to her new corporeality. As Ashley Volion

argues, access intimacy requires acknowledging that every individual “navigates the world differently,” but this difference “does not mean lesser” (89). Therefore, none of the family members perceive Momo’s new bodymind as a lesser form of being. Also, Alison Kafer notes that “[t]o eliminate disability is to eliminate the possibility of discovering alternative ways of being in the world, to foreclose the possibility of recognizing and valuing our interdependence” (83). Within this context, incorporating Momo’s dementia into the play as an enriching rather than a degrading experience paves the way for the transmission of positive affects between the text and the reader or between the cast on stage and the audience.

Although a nondisabled actress plays Momo, the audience who has family members with dementia relates to the experience depicted on stage.<sup>2</sup> As Lauren Klein (Momo) explains in an interview, the characterization resonated with the audience, and she received positive feedback regarding her role. She states that the audience appreciated the way dementia was dramatized on stage, and they thanked her for giving voice to people with dementia. For instance, an audience member embraced Klein at the end of the performance and said, “You are playing the role that my wife recently played” (“Working in the Theater” 43:33 – 44:00). In this vein, dramatizing access intimacy and the real-life experiences of people with dementia alters the perceptions of the nondisabled reader/audience and it makes people with dementia visible on the stage, a place where they are traditionally rendered invisible.

As stated previously, Momo is not the only disabled character on the stage, and all characters are disabled on different levels. While the characters deal with their disabilities on their own terms, they also participate in a reciprocal care relationship based on access intimacy. Gibson suggests that “performance is always much more than text alone. It is, among many other factors, bodies, nonverbal language, gestures, lighting, and so on. . . . Bodies on stage are as responsible for creating stimulating theatre as are words” (115-116). Given Gibson’s argument, it can be suggested that *The Humans* makes use of nonverbal language and gestures in access intimacy representation, but the play’s real strength comes from the playwright’s dramaturgical choices. The continuous action, both on stage and the page, provided by “the doll house” view, allows a simultaneous portrayal of care, crises, and anxieties. In other words, each character gets their private moment,

either in another room or floor ("Theater Talk" 8:33 – 8:49). For instance, the audience watches Aimee, who is upstairs, nursing a cramp before she enters the bathroom while Deirdre wheels Momo downstairs to calm her down. Meanwhile, Brigid interrupts Erik's conversation to ask for his health and general well-being, and she questions why he cannot sleep (54). In another scene, Deirdre, Richard, and Brigid take care of Momo downstairs while Erik is upstairs and consoling Aimee, who breaks into tears after a phone conversation with her ex-girlfriend. As the examples demonstrate, the audience members sometimes watch manifestations of care on both floors, but other times they hear characters argue on one side of the stage while watching others engaging in care elsewhere. This simultaneity not only allows the audience to witness the access intimacy and the complexities within the family, but it also breaks the traditional linear structure of a regular realist play.

### **Family Conflicts, Neoliberalism, and Disability**

Although the relationship dynamics of the family are marked by access intimacy, the characters do not always grasp the concerns or problems of the other, mainly due to the generation gap. The affective responses of daughters and parents toward one another oscillate between care and resentfulness. On the one hand, characters are very attentive to the well-being of each family member; on the other hand, they are quick to criticize one another's decisions and actions. In this sense, Karam successfully grasps the tension between generations.

Deirdre and Erik have achieved middle-class status through hard work, hoping to provide their daughters with a better and more comfortable future. However, as Jayne Houdyshell (Deirdre) states, both Erik and Deirdre are "perplexed" by the idea of a "better life" because even though both girls are college graduates, their lives are as precarious as their parents' ("Theater Talk" 13:16 – 13:35). Moreover, neither Brigid nor Aimee shares Erik and Deirdre's devoted faith, from which they draw strength and resilience. Brigid and Aimee also find it difficult to fully understand Erik and Deirdre's motives and struggles. They can imagine how difficult it is for their parents to take care of Momo, both physically and mentally. However, they fail to see that the care work is only one aspect of the couple's struggles.

It can be suggested that Erik and Deirdre are the victims of what Lauren Berlant calls "cruel optimism." The scholar explains

that a desire for a good life, which has financial, intimate and moral aspects, lies at the center of cruel optimism because individuals drain themselves to satisfy this desire. According to Berlant, attachments to “upward mobility, job security, political and social equality, and lively, durable intimacy” result in cruel optimism (3). Within this context, both Erik and Deirdre are physically worn out because of hard work, yet still, they are not financially secure. As Erik tells Richard, “I’ll tell you Rich, save your money now . . . I thought I’d be settled by my age, you know, but man, it never ends . . . mortgage, car payments, internet, our dishwasher just gave out [ . . . ] don’ycha think it should cost less to be alive?” (40). The quote reveals that the promise of upward mobility does not apply to all citizens of the United States. On the contrary, it exhausts and oppresses them while shattering their hopes for a better life.

Erik also reveals that after twenty-eight years of labor, the school not only fired him but also took away his pension using the so-called “morality code” rule against him. With no savings and his retirement in danger, Erik now works part-time at Walmart, and the couple is planning to sell the house and rent an apartment instead because of the medical expenses. Similarly, Deirdre has been working for the same company for a long time. However, when Erik states that the company “would fall apart without her,” she says, “. . . yeah, well my *salary* doesn’t reflect that, and these new kids they hired, I’m working for two guys in their twenties, and just ‘cause they have a special degree they’re making five times what I make over forty years” (50). Deirdre’s statement exposes the contradictory consequences of the highly promoted values such as competitiveness, progress, and hard work since they apply only to a small group of citizens.

Erik and Deirdre’s situation indicates the precarious state of their social and financial positions, and it confirms that disability and class are closely interlaced in contemporary America. They seem to achieve the American dream, yet Karam shows that the dream is no more than an illusion, especially when disability is involved. They work hard all their lives to live a better life, but the gains of hard work can dissipate overnight, depending on their employers’ decisions. Moreover, Erik and Deirdre suffer from “neoliberal ableism,” defined as the intertwinement of neoliberalism and ableism since “neoliberalism provides an ecosystem for the nourishment of ableism” (Goodley et. al. 981). Victims of neoliberal ableism do not have access to affordable health care, and they experience “slow death” as they are “more

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

fatigued, in more pain, less capable of ordinary breathing and working, and die earlier than the average for higher-income workers" (Berlant 114). In this sense, after years of doing the same work, Deirdre has arthritis, and Erik suffers from chronic back pain. They have worked hard for a better life, including access to affordable healthcare and a financially comfortable life, yet—ironically—the money they make does not even cover the expenses of health problems caused by their labor.

The excessive pain they are living with cannot go unnoticed; therefore, Brigid and Aimee repeatedly inquire about their health, but the parents try to hide it, and both state they are doing okay. Brigid and Aimee's conversation shows the worrying state of Erik and Deirdre's health problems:

AIMEE: I'm more worried about—did you notice Mom's knees? . . . Going down / the stairs?

BRIGID: I saw, yeah . . . I'm afraid to ask how her arthritis is . . . or Dad's back . . . / I don't wanna know . . .

AIMEE: Well it's bothering him—can't you tell he's—

BRIGID: No, yeah, do you think it's because . . . he hasn't been sleeping, right? . . . (83).

The quote reveals that Aimee and Brigid pick up their parents' affective states, yet they ascribe the negative affectivity to the care work and health problems. Ignorant of the couple's other problems, the daughters either level fierce criticism at their parents, or they tease them cruelly. For instance, everybody in the family mocks Deirdre's overeating, disregarding the fact that it is her body's affective response to stress and pressure. The more Erik postpones disclosing "the secret" to Brigid and Aimee, the more Deirdre eats impulsively because she carries the affective burden of Erik's mistake. Therefore, her emotional state of nervous tension increases as the play progresses.

Erik, on the other hand, grapples with PTSD besides other health problems. Starting from the play's first scene, Erik seems uncomfortable and uneasy. He is already nervous about the announcement he needs to make, but his anxious state also reflects Erik's affective response to New York and the apartment. It is revealed that Erik and Aimee were

in New York City when the World Trade Center was hit by planes on 9/11. Erik was at Dunkin' Donuts waiting for the observation deck to open while Aimee was in a job interview. After the incident, Erik could not find Aimee for hours. He later recounts a scene which has become a recurring nightmare: “—this fireman was holding a body with your same suit on? [ . . . ] but with a coat of ash melted onto her?, like she got turned into a statue like [ . . . ] there was gray in her eyes and mouth even, it was . . . like her whole . . . (a discovery) [ . . . face was gone. . . ]” (140-141). Therefore, Erik associates New York City with the affect of horror, and being in the city and Brigid’s apartment that is close to World Trade Center aggravates his PTSD. For instance, when he sees falling ashes that “look like light flurries,” he feels “unsettled” and “steps away from the window, takes a few calming deep breaths” (61). His PTSD is also triggered by random thuds and rumbles coming from all directions in the apartment, which eventually induce a panic attack at the end of the play. Despite suffering from its consequences, Erik never sees PTSD as a serious condition, nor does he seek treatment to recover. As a traditional Catholic and a member of a generation that perceives mental problems as a weakness, he only talks to the priest about his dreams and uneasiness, which does not solve his problems.

In contrast to Erik, Aimee is not disturbed by New York City, nor does she accept having been influenced by the attack. It is not revealed in the play whether Aimee’s illness is actually related to PTSD or whether Aimee suffers from PTSD at all. However, she is obviously afflicted by cramps and pain, and she needs surgery because of cancer risk. Although she does not reveal this to her parents, Aimee is concerned about the stigma and marginalization that come with disability:

BRIGID: You’ll lose the whole intestine?

AIMEE: It cures the disease, though, so, . . . but . . . yeah . . .  
they make a hole in your abdomen so the waste can, you know  
...

BRIGID: Do Mom and Dad know?

AIMEE: No, I don’t want to discuss it at dinner and . . . I’m okay, I’m mostly just like . . . uhhhh, how am I gonna find another girl friend? . . . / I’m serious . . .

BRIGID: You’re a complete catch.

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

AIMEE: I'm gonna be pooing out of a hole in my abdomen.  
Who's gonna date me?

[. . .]

AIMEE: Uh-huh . . . when do I even—do I wait until the third date to be like: "Just FYI, I shit out of a hole in my belly." Is that a fifth date thing? (82)

Aimee's concern shows how important it is to have access intimacy and crip wealth/knowledge in relationships. Having crip knowledge would invalidate, in Piepzna-Samarasinha's words, the "ableist shame" and cultivate access intimacy. She states, "You can live in your sweatpants, you can change your ostomy bag in front of me, you can be really, really weird, the amount of time it takes for you to transfer to the toilet is normal. . . . some of our wealth is creating these small spaces away from shame, where it is okay to have a disabled bodymind" (252). In this regard, Karam attempts to demolish "disability shaming" through Aimee and Momo's bathroom scenes. Significantly, both Aimee and Momo (with Deirdre) visit the bathroom many times, and Aimee repeatedly reminds the family members that it smells bad after she leaves the bathroom. For instance, when Brigid asks if she needs anything, Aimee says, "An air freshener . . . ?" (58). Brigid ensures that Aimee understands that no one in the family cares about the smell and that her well-being is more important to them. In this sense, Brigid and other family members always focus on Aimee's access needs:

AIMEE: . . . okay, Mom, so . . . and I missed even more time right before they made their decision, I had another flare-up this month, so—

DEIRDRE: Why didn't you tell us?

ERIK: Oh babe, I'm sorry . . .

AIMEE: Because I don't want you to worry—

DEIRDRE: I would've sent you a care-package . . .

AIMEE: Yeah, and a bunch of text messages asking about my bowel movements.

DEIRDRE: I just wanna know what's / going on.

ERIK: You know we'd do anything for you, right?—[...] How about . . . financially, are you okay, or—?

[. . .]

DEIRDRE: But just—how are you feeling?

AIMEE: Just minor cramping, I'm good, I am . . .

RICHARD: How about food-wise, can we get you / something special—(44-45)

The scene is another moment that portrays access intimacy as the family members consider Aimee's needs in all aspects. As a result, Aimee is thankful to be in such a loving and connected family, especially at a time when she has lost her job, her girlfriend, and her health (122).

Contrary to the comfort of access intimacy within the family environment, Aimee faces neoliberal ableism at work. As David Mitchell argues, bodies are used and exploited by neoliberalist values (4). The ideal employee in a neoliberal structure is “healthy, rational, autonomous, educated, economically viable, self-governing and able” (Goodley and Lawthom 372). When employees do not fit into this definition and when they do not “adequately maintain their bodies,” they are blamed for their illnesses and impairments (Mitchell 4). Accordingly, Aimee is demoted because she “missed a lot of time” when she was sick, yet she is still expected to respond to e-mails even at Thanksgiving. In the corporate world, demotion means asking the employee to quit, so Aimee is at risk of unemployment and access to healthcare. In other words, she is held responsible for her health problems. When Deirdre states it is illegal to fire an employee because of a medical condition, Aimee summarizes the hypocrisy neoliberal values harbor: “Well they gave other reasons, obviously, but . . . yeah, you get the sense that they support your chronic illness as long as it doesn't affect your billable hours” (45). As the quote shows, Aimee's condition also demonstrates the significance of “crip time” in achieving disability justice. According to Kafer, ignoring people's needs, work schedules are strict and normative; therefore, crip time is necessary since it is “a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (27). In this regard, neoliberal work structures refuse to accept disability as a part of human condition. Forced to work beyond

her limits, Aimee is a victim of neoliberal ableism that is inflexible, insensitive, and inhumane.

The play ends after Erik discloses his affair and their financial problems to his daughters. Although such news is initially met with aggression, the family members calm down eventually, and all characters leave the stage one after the other—to unite again outside. In this regard, although the play does not offer a proper denouement, the audience knows that the family will overcome the problem together, as they always did. Once again, the play diverges from twentieth-century family dramas in which families do not survive the crisis after all secrets are revealed and collapse. In *The Humans*, however, the family does survive because the antidote to psychological turmoil and social stigmatization is prescribed as care that provides unity and connection. Therefore, the audience does not witness the traditional display of a dissolution of the family on stage but an act of rebuilding it over and over again.

## **Conclusion**

Karam transforms the stage by dramatizing a family that succeeds in forming an interdependent care relationship and enjoys access intimacy despite their differences, secrets, and resentments. While doing so, he refrains from glorifying the family as a socially constructed institution, but he also shows that the contemporary problems in the United States stem not from the dissolution of the perfect American family myth but from neoliberal oppression and ableism. As Mingus states, this provides an understanding of disability that “shifts from being silencing to freeing; from being isolating to connecting; from hidden and invisible to visible; from burdensome to valuable; from a resentful obligation to an opportunity; from shameful to powerful; from ridge to creative” (“Access Intimacy, Interdependence”). Portraying disability in Mingus’s terms, Karam expresses solidarity with the disability justice movement, and he shows that changing affects associated with disability will eventually bring social and political transformation. In other words, putting issues that are considered socially taboo on stage/page as a normal part of everyday disability experience compels the audience to reevaluate their perceptions of disability, access, justice, and normalcy. Moreover, it enriches disability representation in theater by incorporating disability not as a metaphor but as a real embodied experience.

## Notes

- <sup>1</sup> It was not only the play that received awards. Justin Townsend and Fitz Patton were awarded Drama Desk Awards, respectively, for Lighting Design for a Play and Sound Design in a Play. Also, Reed Birney (Erik) and Jayne Houdyshell (Deirdre) received Tony Awards for their performances in the Broadway production of the play.
- <sup>2</sup> Disability activists argue that it is necessary to cast disabled people for disabled characters. However, in her article “Why Disability Identity Matters: From Dramaturgy to Casting in John Belluso’s Pyretown,” Carrie Sandahl highlights the complexities of casting, and her analysis shows that each case should be evaluated separately. In *The Humans*, for instance, Momo’s dementia has progressed to the point where she does not recognize her environment. Casting an actress with dementia at that level would not be easy, and it would raise ethical questions. In this sense, issues regarding casting remain out of the scope of this article since it requires a more in-depth discussion and analysis.

## Works Cited

- Barnes, Marian. *Care in Everyday Life: An Ethics of Care in Practice*. Bristol UP, 2012.
- Berlant, Lauren. *Cruel Optimism*. Duke UP, 2011.
- Fox, Ann M. and Carrie Sandahl. “‘Frenemies’ of the Canon: Our Two Decades of Studying and Teaching Disability in Drama and Performance.” *Troubling Traditions: Canonicity, Theatre, and Performance in the US*, edited by Lindsey Mantoan, Matthew Moore and Angela Farr Schiller, Routledge, 2022, pp. 147-160.
- Garland Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia UP, 1997.
- Gibson, Janet. *Dementia, Narrative and Performance: Staging Reality, Reimagining Identities*, Palgrave Macmillan, 2020.
- Goodley, Dan, et al. “Dis/ability and Austerity: Beyond Work and Slow

Contemporary American Family on Stage:  
Disability Justice and Access Intimacy in Stephen Karam's *The Humans*

- Death." *Disability & Society*, vol. 29, no. 6, 2014, pp. 980-984, DOI: <https://doi.org/10.1080/09687599.2014.920125>.
- . Goodley, Dan and Rebecca Lawthom. "Hardt and Negri and the Geo-Political Imagination: Empire, Multitude and Critical Disability Studies." *Critical Sociology*, vol. 39, no. 3, 2011, pp. 369-384, DOI: 10.1177/0896920511431500.
- Kafer, Alison. *Feminist, Queer, Crip*. Indiana UP, 2013.
- Karam, Stephen. *The Humans*. Theatre Communications Group, 2016.
- Kuppers, Petra. "The Wheelchair's Rhetoric: The Performance of Disability." *TDR* (1988-), vol. 52, no. 4, *The MIT Press*, 2007, pp.80-88, <http://www.jstor.org/stable/25145469>.
- Longmore, Paul and Lauri Umansky. "Disability History: From Margins to the Mainstream." *The New Disability History: American Perspectives*, edited by Paul Longmore and Lauri Umansky, New York UP, 2001, pp. 1-29.
- Mingus, Mia. "Access Intimacy: The Missing Link." *Leavingevidence*, 12 April 2017, <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/>. Accessed 20 January 2023.
- . "Access Intimacy, Interdependence and Disability Justice." *Leavingevidence*, 5 May 2011, <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/>. Accessed 20 January 2023.
- Mitchell, David. "Gay Pasts and Disability Future(s) Tense Heteronormative Trauma and Parasitism in *Midnight Cowboy*." *Journal of Literary & Cultural Disability Studies*, vol. 8, no. 1, 2014, pp. 1-16. *Project Muse*, <https://muse.jhu.edu/article/541082>.
- Nielsen, Kim E. *A Disability History of the United States*. Beacon Press, 2012.
- Phelan, Peggy. "Reconsidering Identity Politics, Essentialism, & Dismodernism: An Afterward." *Bodies in Commotion: Disability and Performance*, edited by Carrie Sandahl and Philip Auslander, University of Michigan Press, 2005, pp. 319-326.

Piepzna-Samarasinha, Leah Lakshmi. *Care Work: Dreaming Disability Justice*. Arsenal Pulp Press, 2018.

Rowen, Bess. “Ruhls of the House: Surreal Spaces for Queer Homes in the Plays of Sarah Ruhl.” *Modern Drama*, vol. 63, no. 3, 2020, pp. 330-353, <https://doi.org/10.3138/md.63.3.1012>.

Samuels, Ellen. “Six Ways of Looking at Crip Time.” *Disability Visibility: First-Person Stories from the Twenty-First Century*, edited by Alice Wong, Vintage Books, 2020, pp. 189-196.

Sandahl, Carrie. “Why Disability Identity Matters: From Dramaturgy to Casting in John Belluso’s Pyretown.” *Understanding Disability Studies and Performance Studies*, edited by Bruce Henderson and Noam Ostrander, Routledge, 2010, pp.225-241.

Sins Invalid. *Skin, Tooth, and Bone: The Basis of Movement is Our People. A Disability Justice Primer*, 2<sup>nd</sup> ed, 2019.

“Theater Talk: ‘The Humans.’” *Youtube*, interview by Michael Riedel and Susan Haskins, uploaded by Cuny TV, 2 May 2016, [youtu.be/w5zpkZxZLVY](https://www.youtube.com/watch?v=w5zpkZxZLVY). Accessed 24 January. 2023.

Valentine, Desiree. “Shifting the Weight of Inaccessibility: Access Intimacy as a Critical Phenomenological Ethos.” *Puncta. Journal of Criminal Phenomenology*, vol. 3, no.2, 2020, pp. 76-94, <https://journals.oregondigital.org/index.php/pjcp/article/view/4781>.

Volion, Ashley. *Access Intimacy: The Missing Piece*. 2020. University of Illinois at Chicago, PhD Dissertation. *ProQuest Dissertations and Theses*.

Wendell, Susan. “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities.” *Hypatia*, vol. 16, no. 4, 2001, pp. 17–33. *JSTOR*, <http://www.jstor.org/stable/3810781>.

“Working in the Theatre Live: The Humans.” *Youtube*, interview by Frank Rich, uploaded by American Theatre Wing, 18 May 2016, <https://www.youtube.com/watch?v=L82zzciWiNE>. Accessed 20 January. 2023.