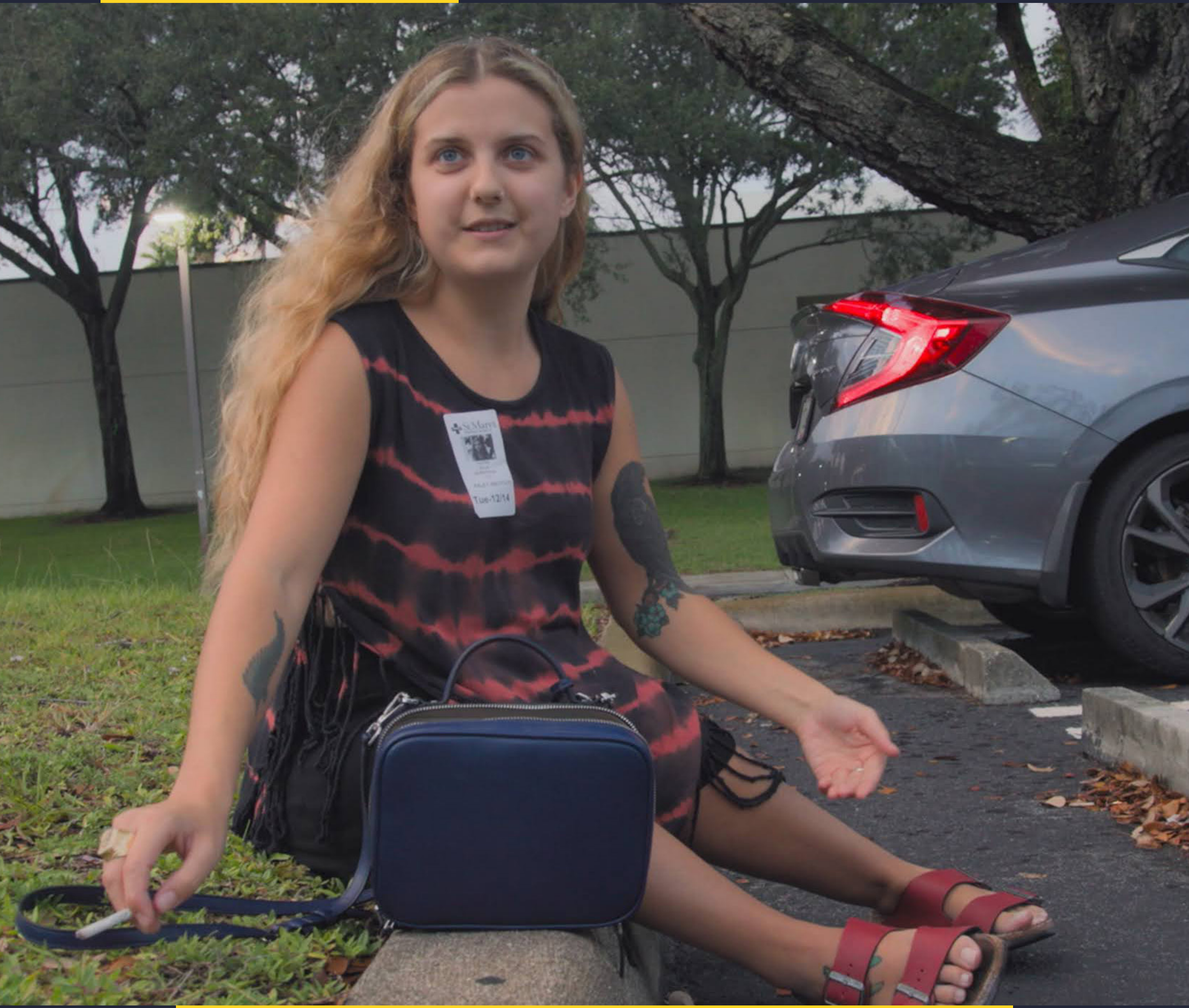
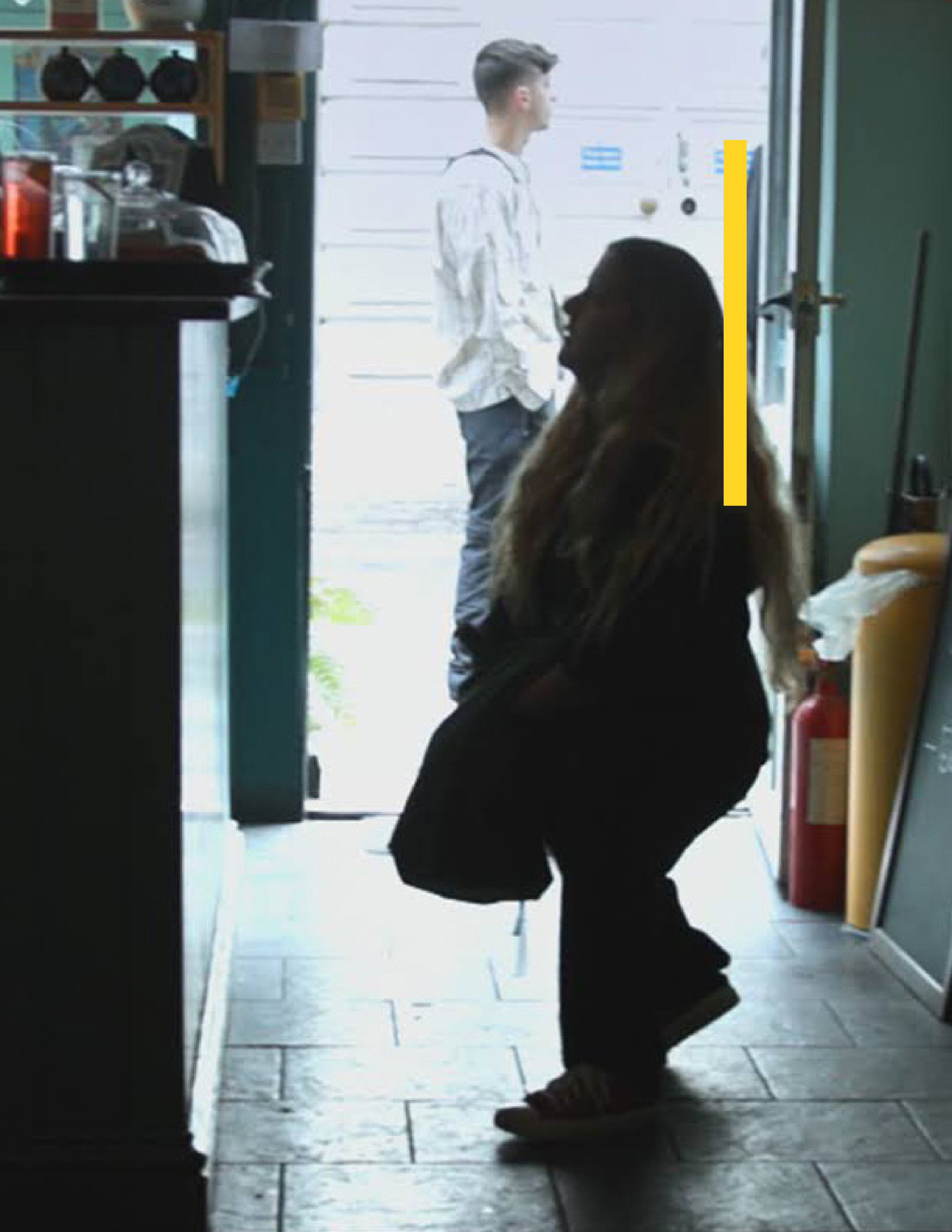
Is There Anybody Out There?

A FILM BY ELLA GLENDINING



POV

DISCUSSION GUIDE



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Film Summary

Born with a rare disability, filmmaker Ella Glendining wonders if there is anyone who can share the experience of living in a body like hers. This simple question–one which non-disabled people take for granted, leads to a journey to not only others who live like her–but to the realization that meeting them changes how she views herself in the world, as well as many surprises along the way.

Using This Guide

This guide is an invitation to dialogue. It is based on a belief in the power of human connection and designed for people who want to use *Is There Anybody Out There?* to engage family, friends, classmates, colleagues, and communities. In contrast to initiatives that foster debates in which participants try to convince others that they are right, this document envisions conversations undertaken in a spirit of openness in which people try to understand

The discussion prompts are intentionally crafted to help a wide range of audiences think more deeply about the issues in the film. Rather than attempting to address them all, choose one or two that best meet your needs and interests. And be sure to leave time to consider taking action. Planning next steps can help people leave the room feeling energized and optimistic, even in instances when conversations have been difficult.

For more detailed event planning and facilitation tips, visit https://communitynetwork.amdoc.org/.

A NOTE TO FACILITATORS

Dear POV Community,

We are so glad you have chosen to facilitate a discussion inspired by the film *Is There Anybody Out There?* Before you facilitate, please prepare yourself for the conversation, as this film invites you and your community to discuss experiences of ableism, intersectionality, activism, disabled parenthood (and parenting disabled children), and the International political landscape for disabled people. These conversations require learning truths about society, culture, looking within, and disability history that typically have not been taught in schools. We urge you, as a facilitator, to take the necessary steps to ensure that you are prepared to guide a conversation that prioritizes the well-being and safety of Disabled people, Black and Indigenous people of color, queer people, and youth in your community. Importantly, this film shares experiences through a lens of anti-ableist resilience, rather than focusing on trauma, and we hope this guide will aid you in conversations that expand understanding while maximizing care, critical curiosity, transformation, and connection.

Tips and Tools for Facilitators

Here are some supports to help you prepare for facilitating a conversation that inspires curiosity, connection, critical questions, recognition of difference, power, and possibility.

Share Community Agreements

Community Agreements: *What Are They? Why Are They Useful?*

Community agreements help provide a framework for engaging in dialogue that establishes a shared sense of intention ahead of participating in discussion. Community agreements can be co-constructed and created as an opening activity that your group completes collectively and collaboratively. **Here is a (working) model** of community agreements you can review. As the facilitator, you can gauge how long your group should take to form these agreements or whether participants would be amenable to using pre-established community agreements.

Opening Activity (Optional): Establishing Community Agreements for Discussion

Whether you are a group of people coming together once for this screening and discussion or a group whose members know each other well, creating a set of community agreements helps foster clear discussion in a manner that draws in and respects all participants, especially when tackling intimate or complex conversations around identity. These steps will help provide guidelines for the process:

- **Pass around** sample community agreements and take time to read aloud as a group to make sure all participants can both hear and read the text.
- **Allow time** for clarifying questions, make sure all participants understand the necessity for the agreements, and allow time to make sure everyone understands the agreements themselves.
- **Go around in a circle** and have every participant name an agreement they would like to include. Chart this in front of the room where all can see.
- **Go around two to three times** to give participants multiple chances to contribute and also to give a conclusive end to the process.
- **Read the list aloud**.
- **Invite** questions or revisions.
- **Ask** if all are satisfied with the list.

COMMON CONCEPTS & LANGUAGE

So many non-disabled people are concerned with 'getting it right' when it comes to language about disability. This guide encourages you to reassess the prevailing language in the United States when it comes to disability. Language is a reflection of our values, and how we value disabled people and what it means to be human needs to be radically reframed. This conversation centers on identity, community, and the barriers placed upon disabled people, rather than adhering to strict rules that categorize language as 'right' or 'wrong'.

In this guide, when we refer to a 'disability/disabled person', we are using the social model of disability, which encompasses d/Deaf, HOH (hard of hearing), chronically ill, and neurodiverse people, including anyone who wishes to self-identify under any additional term within this category.

The Social Model of Disability

A framework developed by Disabled people that describes people as being disabled by societal barriers rather than medical conditions or differences. This model acknowledges that we have built the world for particular types of bodies, and thereby we've privileged and disparaged certain types of bodies at all levels of society. It's the physical and attitudinal barriers in society – prejudice, lack of access adjustments, and systemic exclusion – that *disables* people.

The social model of disability identifies the barriers that make life harder for Disabled people. These barriers are identified as the physical environment; pervasive attitudes (specifically, ableism); the ways in which people communicate; the operational structures of institutions and organizations; and the broader discrimination against individuals who are *perceived* as 'different'.

The social model helps us to recognise what it is that can make life harder for disabled people, and it encourages us to consider how societies can change to better welcome and empower individuals, rather than assuming that an individual should 'fix' themselves to conform to an imposed standard of 'normality' and adapt to structures that exclude them. Removing these barriers creates equality and offers Disabled people more autonomy, societal acceptance, and ultimately, self-love.

The Medical Model

A concept rooted in the biomedical perception of disability, which focuses on the diagnosis of condition(s) or perceived 'problems' or 'deficits' within an individual. This model suggests that people are disabled by their conditions or so-called 'differences', and that these should be 'fixed' or changed through medical interventions and other treatments, even in cases that do not cause pain or illness. It prioritizes cure and charity, often conveying a sense of shame and implying that life with an 'impairment' is inherently limited, inferior, pitiable, or less valuable. Responsibility is placed on the individual, rather than on systemic or societal structures.

For example, if a wheelchair user is unable to get into a building due to the presence of steps, the medical model would suggest that the issue lies with the wheelchair rather than the steps' inaccessibility.

Who is disabled?

The term disabled has evolved over time and is influenced by social and cultural perceptions. For example, a century ago, someone needing glasses would have been labeled disabled, whereas today, that is often not the case. The UK's Equality Act 2010 defines a disabled person as someone with a physical or mental condition that has a 'substantial' and 'long-term' impact on daily life activities. Even though a person may fall under the definition of disabled, they may choose not to self-identify this way. Others may choose not to disclose their status, which is their choice.

Disabled person

Using the social model of disability promotes identity-first language, which prioritizes ‘disabled person’ over ‘person with disabilities’ (or any euphemistic language like ‘differently abled’ or ‘special needs’). Using the word‘disabled’ before ‘people’ recognizes that one’s identity is inextricably linked to their personhood. Additionally, ‘disabled’ functions as a verb indicating an action inflicted upon individuals. In the UK, the phrase‘disabled person’ is widely accepted, while in the US ‘person with a disability’--a form person-first language–is more commonly used.

Person-first language is designed to highlight the idea that the person should not be defined solely by their disability. However, many politically engaged disabled individuals, argue that their disability is an integral part of their identity and cannot be separated from any aspect of who they are. This perspective is why many prefer identity-first language, which places disability at the forefront of the terms we use. Examples of this include terms like “disabled people” or “Deaf person” rather than “person with a disability.”

Non-disabled

The term ‘able-bodied’ is often used to describe individuals that are not disabled, but this terminology is problematic for several reasons - especially as it’s solely focused on the body, and doesn’t acknowledge the social model of disability. A more appropriate and inclusive term, aligned with the social model of disability, is ‘non-disabled’.

Referring to someone as ‘able-bodied’ can also be misleading as there are varying degrees of physical ability. For example, an Olympic swimmer is more able than a novice swimmer. Furthermore, able-bodied fails to encompass the mental aspect of disability, disregarding those who are neurodivergent or experience mental health challenges. For these reasons, non-disabled is preferred.

Ableism

Similar to sexism, racism, and homophobia, ableism refers to the unfair preference for non-disabled people and the prejudice against disabled people. Ableism prioritizes the needs of non-disabled people, and in an ableist society assumes that the “normal” and preferred way to live is as a non-disabled person. For example, it is ableist to believe that non-disabled people hold more value in society than disabled people. Ableism is often a more insidious form of prejudice compared to sexism, racism and homophobia because there is generally less awareness of its existence and the way it permeates all societies. *Is There Anybody Out There?* is a personal film that resists the inherent ableism within society by depicting Ella’s journey of self-love in spite of the dominant cultural narrative telling her otherwise.

Internalised Ableism

Internalized ableism occurs when individuals, regardless of disability status, absorb the beliefs and moral judgments of the dominant ableist culture on a subconscious level. Society teaches us to judge and value people based on their perceived productivity, ‘ability’ and ‘normalcy’. These standards of wellness and productivity are unrealistic and unattainable–even for the dominant culture. For example, it is impossible for everyone to avoid illness or needing care at some point. However, disabled people who require care are often viewed as ‘abnormal’ and unfit for society. This dehumanization appears in daily life, where covert judgements, often disguised as preferences, are unconsciously directed inward for disabled folks as they judge themselves according to normative standards.

Participants

Dylan and Dylan's Mom

Young girl who has a similar condition as Ella and her mother who discusses her and Dylan's experiences with Ella.

Ella

Disabled filmmaker and director of *Is There Anybody Out There* who is searching to find someone with her same condition.

Ella's Mother

Ella's mother who shares her experiences of motherhood in the film.

Naomi

Ella's long-time friend who is autistic which allows her to partially relate to Ella's experience, though Naomi discusses the experiences of having an invisible disability.

Priscilla

A make-up artist in the US who has the same condition as Ella.

Scott

Ella's non-disabled partner at the time of filming and the father of her child.

Key Issues

Is There Anybody Out There? is an excellent tool for outreach and will be of special interest to people who want to explore the following topics:

- The definition and construction of Disability
- The social vs medical model of Disability
- Understanding internalized ableism
- Belonging as a Disabled person in society
- Disability identity and pride
- Disabled kinship and community
- Parental consent

Background Information

The Reinforcement of Normalcy

The fear of disabled individuals or becoming disabled is an ingrained perception passed down in an attempt to homogenize society and uphold the belief that “normalcy” not only exists but also is attainable and desirable. The concept of “The Other” shapes our self-perception as well as our view of other people, inevitably influencing our decision-making processes. The social model of disability is a relatively unknown concept. As society becomes increasingly medicalized and the notion of normalcy is further embedded in our consciousness, studies show that negative perceptions of disabled people start from as young as the age of five.

These negative perceptions, rooted in the distinction between those considered “normal” and “not normal” render those who are Othered into threats rather than people, and shape our treatment of disabled people often exacerbating their marginalization and predisposing individuals to systemic ableism from a young age. Furthermore, the classification of who is and isn’t disabled is constructed within social contexts and based upon the preferred (or normalized) traits and capabilities. One of the contributing factors to the definition of disability is that it is an ‘impairment’ that causes social exclusion, however, what are classified as ‘impairments’ vary significantly across times and cultures. For example, among the Tuareg people of the Sahara, excessive freckles and small buttocks are considered impairments, leading to social disapproval and barriers to marriage, thus full participation in community life. This demonstrates how disability is a manufactured set of cultural identifiers.

Culturally-established negative bias towards disabled people reinforces the mythological 'norm' of each social context. It is, therefore, unsurprising that people who are disabled and the parents of disabled children may resort to extreme measures to attain social acceptability. Such reinforcement of societal norms harms us all, turning us against ourselves and others– a dynamic that can be recognized - as internalized ableism. Ableism functions as a filter of unconscious bias that must be dismantled to allow us to truly act with free will, rather than perpetuating harmful behaviors with limited self-awareness.

Learning and Teaching Fear

Greater awareness of both the social and medical models of disability would allow more informed decision-making. Doctors and medical institutions in both the United States and the United Kingdom are often viewed as the primary authority when it comes to childbearing leading to diagnosis of disabilities as early as ten weeks in utero. Since medical professionals deliver these diagnoses to parents, the implicit biases, judgements and subjective understandings of disability held by these professionals are often conveyed as 'objective' medical advice. Due to the nature of medical systems, such advice is often communicated as necessary courses of action that are predominately rooted in the medical model of disability. For example, if someone is pregnant the doctor may tell the pregnant person that there is an "abnormality" with the pregnancy and encourage the pregnant person to take medical action to "fix" said abnormality.

Parents, as primary agents of a child's social integration, are thus positioned as the principal influence on future generations' understanding of disability and what it means to be categorized as disabled. Many parents are concerned about *'how'* disabled their children might appear, presuming that this will impact their child's quality of life in negative ways. This anxiety often centers on how easily their child will integrate into society based on their perceived 'difference'. Such learned fears and unconscious biases commonly govern decisions made by non-disabled parents without the child's consent. As the medical model frames disabled people as 'problems' requiring 'fixing', this cycle of bias is perpetuated from medical professional to parent, continuing across generations.

Challenging the Concept of the Other

In essence, society has been replicating a narrative surrounding disability that influences both self-perception and broader perceptions of future generations. Awareness and understanding of the social model in addition to the medical model allows more informed decision-making. Reevaluating and redefining what it means to be disabled can have a positive, inclusive impact on society at large. Often, medical advice is not only shaped by unconscious biases but can also be influenced by hierarchies, power dynamics, and internalized ableism; all of which play a role in what is deemed as 'necessary' treatment. Furthermore, medical classifications (like all normative frameworks in US society today) are rooted in long histories of supremacist ideas rooted in colonization where white men determined what was and was not acceptable, required, and "normal." Essentially, all of these categories require interrogation to fit today's needs.

Acknowledging disability as an intrinsic part of the human condition and as integral to a diverse, multifaceted society can cultivate greater self-acceptance and empathy. Rooted in common oppressive histories, anti-ableist initiatives often intersect with racial justice efforts as both resist the dominant, oppressive narratives ingrained in societal consciousness and institutional structures. These discourses encourage an examination of what we have learned, , internalized, and how these teachings and biases further alienate all of us from community, kinship, the environment, and healthy relationships with rest and productivity. Recognizing disability as an identity–and a part of each of us that should be embraced without fear– moves us closer to a world that values individuals as they are, beyond the confines of their capitalistic worth.

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DISCUSSION PROMPTS

Immediately after the film, you may want to give people a few quiet moments to reflect on what they have seen. You could pose a general question (examples below) and give people some time to themselves to jot down or think about their answers before opening the discussion. Alternatively, you could ask participants to share their thoughts with a partner before starting a group discussion.

1. How did this film leave you feeling? Where there any moments in the film that stick with you more profoundly than others? In what way(s) and how so?

2. What does community mean to you? What are some important communities you are a part of and how do you engage with those communities? Do some of those communities help you feel seen and understood more than others? In what way(s)? How so?

3. Does the world and built environment (i.e. your physical surroundings?) ever feel hostile to you? If so, in what ways?

4. Do you have any particular identities? How have these identities or intersecting identities shaped you?

    a. What are some ways of being treated that make you feel understood and valued in relation to these identities?

Surgery and Consent

When Ella discusses how minors are unable to consent to surgery with the doctor, he agrees that parents often feel conflicted; however, he adds that parents generally gain confidence in their decisions to proceed with surgeries after he meets with them.

1. Have you ever felt conflicted about making a medical decision? What factors contributed to that conflict?
    a. Were there any pressures that you grappled with and if so where were those pressures stemming from (society, family, personal ideas of “what is normal or usual”)?
2. Have you ever experienced a power imbalance when interacting with a medical practitioner? Why or why not?
    a. Have you experienced any medical practitioners who helped you feel empowered to make decisions that were best for you? How did they do that and how did it feel?
3. After watching the film, what do you feel doctors and surgeons should understand about disability and consent that would enhance their practice and their treatment of all patients?
4. Do you think parents should be able to give consent for their children to have life-changing surgeries? Why or why not?

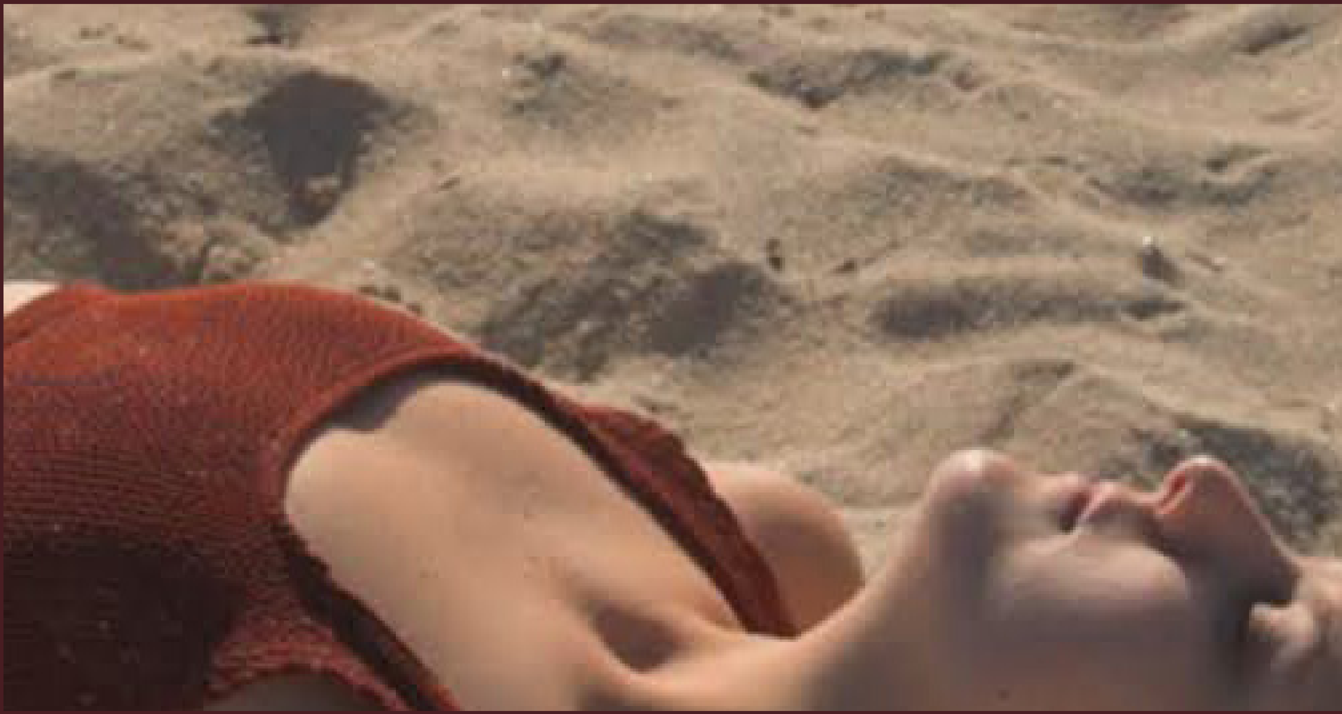
Disability and Community

In the film, two notable contributors are Naomi, Ella’s long-time friend who is also disabled, and Scott, Ella’s non-disabled partner at the time.

1. What other examples of disabled kinship and community have you seen in films? How do they compare and contrast to the friendship between Ella and Naomi?
2. What are your thoughts when Ella voices her concern about Scott being portrayed as a “non-disabled hero” and why do you think this is mentioned?

    a. How does Scott's limited screen time impact the film's narrative?

3. In what ways do Ricardo and Ella differ in their perspectives, and do you see similarities between their perspectives? If yes, what are the similarities?
4. Had you ever experienced and/or considered how physical surroundings can impact peoples' lives in different ways before seeing this film? How did this film help expand your understanding?
5. What are power structures that limit people's autonomy?
6. How have your understandings of disability been impacted by this film?



Resources

Autistic Women and Nonbinary Network offers community support and resources for autistic people across and beyond a gender spectrum.

GADIM The Global Alliance for Disability in Media and Entertainment was created to promote the inclusion of persons with disabilities in mass media.

Helping Educate to Advance the Rights of the Deaf (HEARD) is a cross-disability abolitionist organization to end ableism, oppression, and violence.

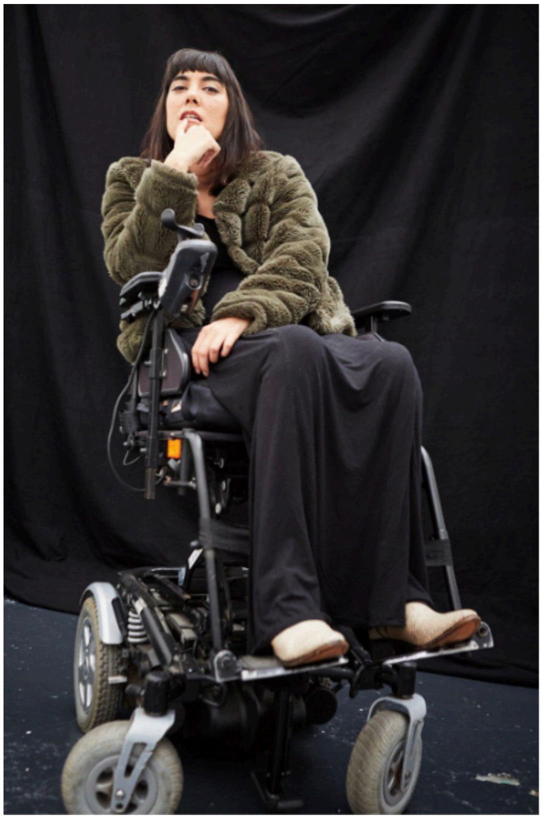
National Council on Independent Living is the longest running national cross-disability organization advocating for the rights of disabled communities and independent living.

Ramp Your Voice! is the brainchild movement of **Vilissa Thompson, LMSW,** a macro-minded social worker who is on a mission to educate and inform the public, political figures, and key stakeholders about the plight of people with disabilities, especially Black women/femmes with disabilities, in America.

Sins Invalid brought the disability justice framework to the public and offers a range of readings and performances to view and purchase.

Stella Young TED 2014. (watch) "I'm Not Your Inspiration Thank You Very Much."

Credits & Acknowledgments



Kyla Harris, Discussion Guide Author

Kyla Harris is a filmmaker, writer and activist who applies an intersectional approach to all of her work. She is a member of the Disability Screen Advisory Group for the British Film Institute (BFI) that advises and supports inclusivity in the industry, including the most recent British Film and Television Awards (BAFTA) Review. Kyla has been a panelist for a number of organisations including the BFI, Birds Eye View and Hot Docs Festival, often advocating for people who share her own identities as a queer, disabled women of colour. Along with Filmmakers With Disabilities (FWD-Doc) she co-wrote A Toolkit for Inclusion & Accessibility: Changing the Narrative of Disability in Documentary Film in association with Doc Society and Netflix as well as The FWD-Doc Engagement Pack in association with Doc Society and the BFI. Her short film It's Personal, that she co-directed and wrote, was commissioned by the Film Video Umbrella and is their most viewed film to date. She is currently co-writing a television series in development with Ash Atalla and Roughcut TV for Channel 4.

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