

What Can Be Learned From Relationships Between People With and Without Disabilities: Inter-abled Relationships

By Sierra Weiss, Tara Olayeye, and Jit Tan

According to the United States (US) Census Bureau, approximately 20% of the US population has a disability—people with vision and hearing deficits, wheelchair users, those with depression and anxiety that affect everyday life, among others—making them one of the largest minority groups in the nation.¹ With 1 in 5 people being disabled and a growing push for equal opportunity and inclusion, it is likely that many Americans without a disability may interact with people with a disability on a regular basis. Interactions with people who have disabilities can feel uncomfortable to the non-disabled, due to invisible, interpersonal barriers caused by preconceived notions of what people with disabilities require. This is especially true when a person has had no previous experience interacting with people with disabilities.²

Disability is often defined by a disruption in the ability to live what is considered to be a “normal” life, ie, the life experience of people without disabilities. That being said, there is an opportunity in modern society, as people with disabilities are becoming increasingly more included in everyday life, to accept what has historically been considered life outside the norm, and

embrace it to move toward a new normal. According to Rebecca Garden (associate professor, Center for Bioethics and Humanities, Upstate Medical University, Syracuse, NY), “Disability Studies not only deconstructs the norms of mainstream moral philosophy but also has challenged the very conception of the norm and thus the ... many ethical analyses of goodness in life...”³ The field of Disability Studies has made impressive strides over the past 50 years to change the discourse surrounding people with disabilities, their rights, and their equal access to society. Linguistic innovations such as the use of person-first language, and legislation such as the Americans with Disabilities Act, have made a significant difference in the way people with disabilities are viewed and treated. However, people with disabilities are often still considered to be outside the norm.

INTER-ABLED RELATIONSHIPS: THREE EXAMPLES

To create a more hands-on and intimate understanding of the range of possible relationships between those

with and without disabilities, we interviewed three diverse pairs of people who depict what is described as an “inter-abled relationship.”⁴ Our interview-based video aims to challenge the stereotypical notion of the caregiver and patient role, showing the depth and diversity that these relationships can entail. Sharing disability narratives and experiences between professionals and patients going through rehabilitative care can have a positive impact on that care, and on the consideration of individuals with disabilities.

We chose to interview individuals in three unique relationships—an engaged couple, a mother and daughter, and two colleagues—to shed light on the diverse impacts disability has on differently-abled people within such relationships. While much of rehabilitative medicine and patient-centered care has recently focused on considering the voices of the Disability Studies community,⁵ the analysis of the themes portrayed in our video offers a compelling format through which a wider range of healthcare professionals, families and friends, and those new to encountering disability, can consider building an inter-abled relationship. Disability is something that anyone may experience at some point in life. Direct and indirect perspectives observable in the videos we recorded provide a more nuanced understanding of the role of dynamic relationships in these unique circumstances. We found that these relationships had a keen sense of mutual understanding and respect. Although all successful relationships rely on a strong sense of partnership, each of these relationships showed a heightened sensitivity to the experiences of each person. Further, the videos offer insight into the more profound closeness, shared motivation, and overall benefits of a shared disability experience. This insight serves as a potential springboard for healthcare providers in rehabilitation settings to improve care—focused not just on medical or functional recovery, but

also on the lived social environment of the individual. Care provision can thus be more encompassing and sensitive to the diverse experiences of care recipients.

The video relates the experiences of: Morgan Leahy, a senior at Emory University who recently became deaf, and her able-bodied fiancé, William Baker; Rao Olayeye, a mother with sickle-cell anemia, and Mimi, her able-bodied daughter; and Dr. Rosemarie Garland-Thomson, professor of English at Emory University with a focus on Disability Studies, who has a congenital disability, and Dr. Jennifer Sarrett, lecturer for the study of Human Health on topics including Disability Studies and Bioethics.

Inter-Abled Relationships:

<https://vimeo.com/165050050>

INTERVIEW NARRATIVES

During the interviews, the three pairs revealed very different relationship dynamics and experiences, as well as diverse relationships with disability itself. The fiancés, Morgan and William, showed how their relationship grew and adapted as Morgan became increasingly deaf, such that their individual growth added to the maturation and resilience of the relationship. Although individual growth sometimes causes people in relationships to drift apart, Morgan and William consciously shared a goal of maintaining the integrity of their relationship and helping each other live their best lives through thick and thin. Rao and Mimi shared a close relationship and a strong bond. However, unique to their mother-daughter relationship was the able-bodied-versus-disabled construct that became a defining feature. Rao’s disability—which put Mimi in the caregiver position—

has made their bond even stronger. Dr. Garland-Thomson and Dr. Sarrett are disability scholars; Dr. Garland-Thomson has a congenital disability and Dr. Sarrett is able-bodied. The influence of Dr. Garland-Thomson's disability on their relationship has centered around academic discussions of disability.

For each of these relationships, we observed varying forms of adaptation to the disability experience.

Morgan and William

Despite the unexpected onset of Morgan's hearing loss, the security she and William found in their relationship gave them both a source of assurance and comfort. Morgan mentioned that their relationship "kind of just molded along with the deafness," suggesting that they found new ways to communicate and made new memories surrounding their challenges. Family caregiving has been consistently shown to have several benefits, some of which are resilience, personal growth, and greater intimacy.⁶ Similarly, Morgan and William's relationship adapted according to the needs of Morgan's disability while simultaneously strengthening their bond. Both mentioned maturing and "overcome[ing] mountains" through their respective experiences with Morgan's increasing disability because of the need to take on the responsibility of a new lifestyle—adding an additional positive dimension to their inter-abled relationship.

Disability was more of a constant feature in the relationships between Rao and Mimi, and between Dr. Garland-Thomson and Dr. Sarrett.

Rao and Mimi

Rao and Mimi's relationship developed around Rao's disability throughout their time as mother and daughter. Rao adjusted, albeit with difficulties and

struggles, to the role of a mother while being constantly aware of her higher risk of mortality. She had to learn to balance between the fear of dying early and not being able to care for her children, and the desire to be a "normal" and present mother. Conversely, Mimi grew over time to become both a daughter and a caregiver, as she came to understand more about her mother's disability.

Dr. Garland and Dr. Sarrett

Adaptation was not a prolonged process for colleagues Dr. Garland-Thomson and Dr. Sarrett. When asked if she had any initial reaction to Dr. Garland-Thomson's disability, Dr. Sarrett responded that it was "not a problem." Instead, she stated, "learning about Disability Studies from Rosemarie made me go back and ... reframe a lot of the things I had been doing." In their professional relationship, disability facilitated self-reflection and learning.

THE CAREGIVER ROLE

Through conducting these interviews, we found that the role of caregiver is often different than what might be expected. The stereotypical role of the caregiver and the patient evokes ideas of a medical setting; these three relationships challenge that notion. Typically, the mother is the caretaker and the daughter is the recipient, as a child matures. However, in their relationship Mimi sometimes had to play the role of caregiver when her mom Rao was particularly sick. Grue and Lærum state that mothers with disabilities typically "go to great lengths to 'present' themselves and their children as managing 'normally' in order to be accepted as 'ordinary' mothers."⁷ Although Mimi did have to take on a caregiver role at times, Rao also tried to conform to the general roles of a mother to the best of her ability. Recognizing the reversing of roles in her relationship with her children, Rao tried to show

her love and appreciation for them in ways other than taking care of them, such as spending quality time with them. We can see an intersection of roles and identity, in which there is no definite determination of who bears more responsibility or power. This intersection of roles also reveals how the dynamics in caregiving relationships are never fixed.

This theme of shifting dynamics in the caregiving relationship also surfaced in the other two relationships. As Morgan's disability increased, William took on added responsibilities, such as making sure she went to her doctor appointments. In return, Morgan's trust in William grew. Their relationship is an example of how both caregiver and care-recipient play equally important and mutually reinforcing roles, shaped by the disability experience.

Dr. Garland-Thomson was, in a sense, Dr. Sarrett's caretaker, as she was her supervisor. The topic of disability was a factor in their collegial relationship, as Dr. Garland-Thomson furthered Dr. Sarrett's understanding of Disability Studies. Working with Dr. Garland-Thomson on Disability Studies helped Dr. Sarrett to "confront [her] own ableism and confront [her] own issues with the subject." This exemplifies the notion of how the privileged position of the able-bodied is challenged when they are openly introduced to the disabled community.⁸ Challenging the status quo allows room for further conversation and mutual understanding. Dr. Garland-Thomson and Dr. Sarrett's relationship had progressed to a point where they were closer to being equal partners in caregiving, similar to Morgan and William. However, unlike Morgan and William, the type of mutual caregiving that Dr. Garland-Thomson and Dr. Sarrett provided was directed more toward the field of Disability Studies and is expressed through academic facilitation and research.

GREATER AWARENESS AND INCLUSION

In addition to the themes of adaptation and shifting caregiving roles, we also found that the three inter-abled relationships we encountered promoted a greater awareness of disability and inclusion. William shared that being with Morgan as she experienced the onset of a disability helped him create a personal relationship with the disabled community, by meeting with doctors, meeting others in the deaf community, and attending advocacy-related programs. Further, he was able to vicariously experience Morgan's disability by witnessing her transition, and being an active participant in helping her adapt to a new way of life, which gave him greater insight into the disabled and deaf communities. Mimi also expressed that her relationship with her mom and her mom's disability gave her a deeper understanding of what life with a disability is like. Considering that Mimi sometimes had to take on a caregiver role, her intimate experience with disability paralleled research showing that caregiving makes caregivers more compassionate and accepting.⁹ Although Dr. Garland-Thomson and Dr. Sarrett already had a strong awareness of the disability community, they learned from each other that language and awareness is a "constantly evolving process," which "involve[s] lots of feedback."

DISCUSSION/CONCLUSION

In our interviews, we identified the common themes of: the dynamic role of caregivers, the ongoing adaptation of relationships to address disability, and the way these experiences can bring greater awareness of and sensitivity to others' disability experiences. We also saw how these themes manifested themselves differently in each relationship. Moreover, each relationship prioritized different issues; these diverse

priorities were shaped by both the type of disability and the type of relationship shared. One of the greatest takeaways was the recognition that both the person with the disability and the person without played equally important roles in developing and maintaining the relationship. One was never necessarily weaker or inferior to the other. Instead, each individual complemented the other so as to fill in any gaps in knowledge and ability. Essentially, every person's experience was unique, important, and could not be dismissed simply because he or she might be labeled "disabled" or "able-bodied."

Such richness of information corroborates C.J. O' Toole's proposal that being more public about our relationship to disability can enrich discussion and understanding of the disability experience.¹⁰ We hope this will encourage greater efforts to seek first-hand, holistic accounts of disability. As mentioned in the introduction, we also hope that such shared disability experiences can help counter traditionally narrow conceptions of inter-abled relationships.

Dr. Garland-Thomson makes a compelling statement that sums up our key learnings from the interviews:

"All of us, whether we identify as disabled or not, count ourselves as people first, so that the salience of our disability in the world and in social relations varies."

Her words remind us that people occupy multiple roles in life that may at some point include disability. Importantly, this statement stresses that the individual with disability should not be solely identified by his or her disability. Her statement also explains how we need to allow for variance in the disability experience. This perspective can and should be considered in rehabilitation; therapists should always attempt to have

an empathetic and encompassing view of each patient's experience of disability.

In a meta-analytic review of studies that included patient-centered goal-setting in stroke rehabilitation processes, Rosewilliam and colleagues found that there exists a perceptual practice gap between therapists and patients; while therapists felt that their practice was patient-centered and followed the goals of the patient, patients themselves often felt they lacked control in the goal-setting process, and that their social and occupational needs were neglected.¹⁰ This finding suggests that improvements could be made within the rehabilitation field to move away from standardized, pathology-focused prescriptions toward a rehabilitation process that aligns with the goals of both patient and therapist. Consider that patients are people first: people who have many other roles and responsibilities, and will naturally encounter disability with very different attitudes. We saw this in Morgan Leahy, a woman grappling with her newly acquired disability while still trying to graduate from college and be a loving fiancée. We also saw Rao Olayeye, a responsible mother who has lived with disability her entire life.

Healthcare professionals need to make room for the different ways patients may wish to address their disabilities, both conversationally and experientially. Rehabilitation therapists might consider an explicit process of outlining the important values and needs of patients during both the initial goal-setting phase as well as throughout the rehabilitation process.¹⁰ The literature also recommends educating patients and family members not just about the patient's condition and potential treatments, but also about the process and aims of patient-centered goal-setting.¹⁰ All parties can then collaboratively determine the desired and appropriate degree of patient engagement in the

rehabilitation decision-making process. Our study focused on inter-abled relationships, highlighting the importance of the disabled person's network of relationships, be they family members, close friends, or colleagues. Taking this idea one step further, the strategies mentioned above reiterate the importance of engaging close relatives in the patient's rehabilitation process. Creating an optimal rehabilitation environment should not solely be a medical process of dispensing treatment, but should be an all-inclusive process that involves and empowers both the patient and his or her close relations.

VIDEO OUTREACH

The video created as a part of this research can be used in physical therapy classes and clinical training sessions to help students and practicing professionals develop a greater understanding of the importance and diversity of inter-abled relationships. We hope that encouraging greater shared disability narratives and experiences will provide a springboard for professionals and lay persons alike, from which greater care and consideration of individuals with a relationship to disability can be developed.

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About the Authors



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Tara Olayeye is a content creator, filmmaker, and video editor who recently graduated from Emory University in May 2017. During Tara Olayeye's senior year, she was chosen to represent Emory's Film Department in the Stipe Society for Creative Scholars. In Spring 2017 she co-founded Emory's first and only female production group, FemmeFilms, whose first film, [Petals](#), won a Jury Award and Silver Tripod Award at Campus Movie Fest 2017. [Petals](#) was also selected to screen on [Virgin America Flights](#) from June to July 2017.



Jit Hui Tan is a recent Psychology and Anthropology graduate from Emory University Class of 2017. She has a passion for community mental health and is currently working as a researcher at a mental health hospital in Singapore with goals of becoming a clinical psychologist. She believes that it is increasingly important to share the stories and perspectives of individuals as we become more embroiled in a highly technical and individualized world. She hopes that through the humanities, she can both learn and share the complex and intimate experiences of individuals all around her, thus creating a holistic understanding of our larger community.



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