**CONCEPTUALIZING DEMENTIA AS A DISABILITY: USING A DISABILITY STUDIES LENS TO EXPLORE INTERSECTIONS OF AGE AND DISABILITY**

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*This presentation includes unpublished ideas. I am open to people quoting and citing, but please ask me for permission first, particularly as I may be incorporating some of these ideas into future manuscripts. Also, feel free to check in with me if you have any questions. Thanks!*

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**INTRODUCTION**

Good morning. My name is Hailee Gibbons and my presentation is titled, “Conceptualizing Dementia as a Disability: Using a Disability Studies Lens to Explore Intersections of Age and Disability.” **[SLIDE]**

Older adults and people with disabilities are two groups that are increasingly intersecting in American society. Approximately 20% of the U.S. population is disabled, and about 33% of people who report having impairments are older adults (Moore, 2009). There are also growing numbers of people aging with disability, meaning that they have congenital or early-onset disabilities and are living into old age (Heller & van Huemen, 2013). Furthermore, older adults and people with disabilities share many of the same concerns, such as caregiving and family support, consumer-directed services, appropriate medical care, financial security, and physically and socially accessible communities (Bickenbach et al., 2012).

However, despite many intersections between older adults and people with disabilities, the interdisciplinary fields of gerontology and disability studies have remained, for the most part, disparate (Berger, 2013; Lightfoot, 2007). Collectively considering aging and disability is imperative; as Verbugge and Yang (2002) noted, “Disability and aging are processes that interweave throughout the life course” (p. 253). Furthermore, as our society ages and the disabled population “grays” (Kahuna, Kahuna, & Lovegreen, 2011), it will become progressively important for these two fields to communicate, inform one another, and partner. The Toronto Declaration on Bridging Knowledge, Policy, and Practice in Aging and Disability has called for these fields to collaborate in the areas of research, policy, and practice (Bickenbach et al., 2012).

One way to accomplish this goal is by connecting gerontology and disability studies through theory, which arguably influences research, policy, and practice. **[SLIDE]**

Gerontology has been criticized for being “data-rich but theory poor” (Birren, 1999). However, scholars have been increasingly stressing the importance of theory in gerontology. According to Bengston, Gans, Putney, and Silverstein (2009):

There has been a resurgence in the…use of theory to develop explanations and understandings of the aging process. More and more, investigators are choosing to grapple with the *why* and *how* questions of aging rather than simply describe the *what*. Among the most promising developments recently is the noticeable increase in efforts to advance interdisciplinary theories of aging. (p. 22)

These interdisciplinary theories of aging most frequently draw from traditional disciplines, such as biology, psychology, and the social sciences, but there has also been an increase in the use of critical theory, feminist perspectives, and postmodernism. However, disability studies is noticeably absent from gerontological theory.

Likewise, few disability studies theories consider old age, the process of aging, or life course perspectives. Much of the work in disability studies has been constructed within a “generational system” (Priestley, 2003, p. 156) that favors and emphasizes youth and middle-aged adulthood and the roles associated with these stages of life, such as education and employment. Thus, considering the experiences and lives of disabled older adults and incorporating gerontological perspectives would also benefit disability studies theory. **[SLIDE]**

I posit that dementia is an ideal way to explore ways to integrate gerontology and aging studies with disability studies. Dementia highlights the myriad ways old age and disability intersect. Furthermore, as previously mentioned, more people are aging with disabilities, and may acquire dementia in addition to their lifelong impairments. For example, research demonstrates that people with learning disabilities and intellectual disabilities have an increased likelihood of developing dementia in later life.

Scholars in gerontology and aging studies have largely led the way in studying dementia, and have been among the leaders who have called for society to change the way we view and act toward people with dementia. Conversely, disability studies has been essentially uninvolved in this scholarship. As Priestly (2003) observed, “Although…dementia is among the most common forms of impairment in older people, there has been relatively little research in this area from a disability studies or social model perspective” (p. 158). Exploring dementia through a disability studies lens bridges the two fields and opens up possibilities for both fields to build and expand on theory.  **[SLIDE]**

I will now examine dementia using four theories and frameworks in Disability Studies: the Social Model of Disability, the Political/Relational Model of Disability, crip time, and rhetoricity. In order to support the idea of theoretical integration, I support my analysis with gerontological theories, and also note when gerontological theories significantly differ from disability studies theories. Additionally, I intersperse my analysis with personal stories about dementia because I am indebted to the many people with dementia I have known who have influenced me in my thinking and I hope sharing these stories will better illustrate my points. **[SLIDE]**

**THE SOCIAL MODEL OF DISABILITY**

The Social Model of Disability is considered one of the founding theories of Disability Studies, and has been the most frequently cited model in dialogues about using Disability Studies to conceptualize dementia (Bartlett & O’Connor, 2010; Gilliard, Means, Beatie, & Daker-White, 2005). The Social Model “locates disability within society: in the *built environment* and the *values* and *social practices* which *discriminate* against people” (Marks, 2002, p. 52, italics in original). Crow (1996) defined disability under the Social Model as “the loss or limitation of opportunities resulting from direct and indirect discrimination” and stated that social change (or the removal of disabling barriers) was the solution to disadvantages rather than treating or curing disability (p. 2). The Social Model dictates that the problem is not the person, but society, which has been empowering for individuals with disabilities and has contributed significantly to the disability rights movement.

The Social Model of Disability may be perceived as similar to Lawton’s groundbreaking ecological model, which is a key framework in environmental gerontology. However, there are important differences between the ecological model and the social model. In the ecological model, the focus is on the individual in their specific environment, and changes to the environment and/or the individual may be proposed depending on the situation. In other words, the ecological model considers individual competencies in addition to environmental demands. In this context, dementia would be viewed as a deficit that decreases a person’s capacities. Under this model, if a person with dementia’s competencies had the potential of being improved, that would be recommended in addition to decreasing the environmental press, or demands. Thus, the suggestion to change the environment is not coming from a human rights and social justice perspective; rather, it is a practical decision. Conversely, in the social model, the fact that we cannot “fix” or “cure” dementia is irrelevant. Regardless of a person with dementia’s capacities or prognosis, the scenario does not change: the problem is the inaccessible environment and attitudinal barriers, and the solution is to alter the environment and address oppressive attitudes. **[SLIDE]**

Current dominant perspectives on dementia emphasize how the symptoms of dementia create challenges and problems for people with dementia. The Social Model offers a way to demonstrate how environmental and attitudinal barriers disable people with dementia. I will now share a story to further explain my point.

*I’m sitting at a table in the dining room in Assisted Living when I notice Maureen isn’t there. “Where’s Maureen, the Teenage Beauty Queen?” I ask, using Maureen’s favorite nickname. Edna looks down at her hands and does not respond. Angie quickly takes another bite of food. Muriel finally leans over and whispers, “She’s gone.” She then dramatically adds, “They put her in the Memory Unit.” Angie says in a matter of fact tone, “It’s about time.” Unsure of how to respond to Angie’s comment, I ask, “Has anyone gone to visit her since she moved?” “Heavens no, child!” Muriel looks at me as though I should be put in the Memory Unit too. “You only go there if you have to!”*

This story is interesting because one of the “symptoms” of dementia is withdrawing socially. However, examining this phenomenon through the Social Model illustrates how people do not withdraw simply due to their impairment. While the impairment may be a factor, many people with dementia, their partners, and their caregivers describe how friends and family actually withdraw from them or create unwelcoming spaces (Snyder, 2002). These spaces may be unwelcoming for people with dementia due to sensory reasons (e.g., large crowds, loud noises, over-stimulation) or due to prejudice and discrimination (e.g., judgment, lack of understanding, impatience, exclusion).

The Social Model can also help us reject the idea that people with dementia are “burdens” or “problems” by highlighting the lack of services and supports available to assist people with dementia living in the community. For example, there are many types of assistive technology that could allow a person with dementia to live in their own home for a longer period of time. These technologies range from low-tech (e.g., reminder devices, medication organizers) to high tech (e.g., a stove that turns off automatically after being left on for too long). However, many people are not educated about these options and some of the more high-tech technologies are often not readily available or affordable. Thus, the Social Model asks us to consider ways to change the environment and space in which a person with dementia lives.

Several scholars have advocated for using a Disability Studies lens to transform understandings of dementia, and have predominantly highlighted the Social Model as Disability Studies’ primary contribution (e.g., Bartlett & O’Connor, 2010; Gilliard, Means, Beatie, & Daker-White, 2005). The emphasis on how environmental and attitudinal barriers disable people with dementia is important. It can result in refocusing on exploring ways to adapt the environment to fit the unique needs of people with dementia and addressing prejudice and discrimination. However, as these scholars recognized, the Social Model has several limitations. For example, it denies individual voice, rejects medical ways of thinking, and ignores that impairment can cause issues, pain, and suffering. However, the Political/Relational Model of Disability advances ways to address some of these shortcomings. **[SLIDE]**

**THE POLITICAL/RELATIONAL MODEL OF DISABILITY**

Kafer (2013) advances the Political/Relational Model as a “hybrid” model, which “builds on social and minority model frameworks but reads them through feminist and queer critiques of identity” (p. 4). For instance, the Political/Relational Model views disability in a way that is similar to the Social Model, with a comparable focus on social change and political transformation. Unlike the Social Model, the Political/Relational Model recognizes that both impairment and disability are social constructions. In other words, the Political/Relational Model views impairment and disability as subject to the same social meanings, understandings, and contexts.

An important aspect of the Political/Relational Model for dementia is the focus on relationships, as “disability is experienced in and through relationships; it does not occur in isolation” (Kafer, 2013, p. 8). Dementia offers a unique way of illustrating this point. As previously mentioned, dementia is often depicted as a “living death” and “long goodbye.” Boss (2011) observes that caregivers frequently engage in “premature closure,” and often make claims such as “she is already dead to me” (p. 7). Reverend Pat Robertson, a high profile religious leader in the United States, proclaimed that divorcing a spouse with Alzheimer’s is acceptable because dementia itself is “a kind of death” (Moisse, 2011). On the dementia sub-group for the social news network site Reddit (2014), people post about “mourning a husband who has not yet passed,” “shaking hands with death,” and “watching [loved ones] slip away.”

In all of these cases, people with dementia are being described as “dead” when they are still alive because people are grieving the loss of how they viewed or conceptualized that person, and consequently also grieving the loss of how they made meaning of that specific relationship. A person with dementia forgetting someone whom they recently met would likely be viewed and reacted to differently than a person with dementia forgetting a loved one they have known for many years. In my own personal experience as a volunteer in dementia units of nursing homes, I met many people with dementia, none of whom remembered me, and it never bothered me – however, I would likely have felt differently if one of them was my family member or close friend. This phenomenon supports Kafer’s (2013) notion that disability is highly relational, rather than simply a characteristic of a person or a result of the environment. **[SLIDE]**

When we see disability as relational, we must also consider the “social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being” (Kafer, 2013, p. 5), and then, relatedly, how to overcome that exclusion and stigmatization. One way is to reexamine how we view change in our relationships. We change throughout our life course, but changes brought by dementia may be more difficult to accept due to their seemingly radical nature. Some people say that friends and partners either “grow together” or “grow apart.” How can we think of ways to grow together with our loved ones with dementia rather than growing apart due to the changes dementia may bring? How might we, in essence, perpetually build and rebuild our relationships, taking into account the short-term and long-term changes people experience as a result of dementia? Even if our relationship with a person with dementia has changed completely, how can we still maintain their personhood and value their feelings and thoughts? **[SLIDE]**

**CRIP TIME**

One possible way to reconceptualize our relationships with people with dementia is to focus on what that individual needs in that particular moment and time, and this is where crip time may inform our thinking. Crip time is a part of disability culture that challenges normative views and constructions of time. According to Kafer (2013), “Crip time is flex time not just expanded but exploded; it requires reimaging our notions of what can and should happen in time, or recognizing how expectations of ‘how long things take’ are based on very particular minds and bodies…Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (p. 27). For people with dementia, Kitwood, the famous psychogerontologist, (1997) names “five essential components to personal and social relationships: comfort, attachment, inclusion, occupation, and identity” (p. 80, as cited in Snyder, 2002, p. 130). However, these needs may be constantly changing from moment to moment. Kafer (2013) discusses the temporal nature of disability, and articulates that crip time is about, among other things, flexibility. Perhaps similarly, “dementia time” should be about focusing on that particular moment in time and place and remaining flexible as moments pass and needs change.

For example, I met many people with dementia in nursing homes who forgot who I was as soon as I left the room. However, as I got to know them better, I would often reconnect with them over similar topics. For example, some people love to talk about their careers, others like to talk about their families, and others like to talk about their interests and hobbies. As stories emerged (sometimes as unexpected times), I would remember them and use them to start conversations at later points in time. For example, Maureen loved talking about fashion. Every time I “met” her, I would talk to her about what she was wearing and her jewelry. Another woman, Rebecca, was a retired school teacher. I would often bring teaching up to her or talk about working with children. Even when Rebecca did not remember any stories about her days as a teacher, she would still express sentiments such as, “Children are wonderful,” and “I love children.” Doing this undoubtedly requires patience, as you may repeatedly engage in similar conversations. However, the important aspect of the interaction to focus on is the connection you are building in that moment in time, and the happiness it brings someone to talk about something they love. This is just one strategy for rebuilding relationships and living in dementia time. **[SLIDE]**

Another possibility is to consider alternate realities as a part of dementia time. What makes our reality “true” and “objective?” If we can acknowledge the possibility of multiple or alternate realities, we can understand that people with dementia may be operating within their own reality that is just as meaningful as ours is. I’d like to share another story to illustrate this point.

*As I walk down the dimly lit hall with buzzing fluorescent lights, nervousness creeps up on me. I have never been down this ward before – the nurses at Winchester Place Nursing Home claim it is for “the most severe cases.” A woman wearing a long, white nightgown is shuffling slowly toward me. I weakly smile at her, still feeling very unsure. Suddenly she hugs me, tightly wrapping her arms around me. She whispers in my ear, “You came, you came! You are finally here!” I realize she is crying tears of joy. I wonder who she thinks I am, and almost as if on cue, she tells me. “I told everyone my daughter would come, and here you are!” She is still holding me, and I, a teenager with an unloving and abusive parent, relish in how warm and tender it feels. She whispers to me, “I love you.” I look back at her and say, “I love you too.” Later, a friend chastises me for “lying” but I never saw it as a lie. In that moment, in that alternate reality, we both felt loved.*

Trying to understand their reality in that moment and time and thus valuing what they think and say as part of that reality is another way to perpetually rebuild connections. However, in order to value what people with dementia think and say, we must first understand why we fail to do that as a society. Using a Disability Studies lens demonstrates that one primary reason is because people with dementia lack rhetoricity (Price, 2011). **[SLIDE]**

**MENTAL DISABILITY AND RHETORICITY**

People with dementia are often dismissed, ignored, and avoided because they, like other people with mental disabilities, are denied rhetoricty. Price (2011) explains:

The failure to make sense, as measured against and by those with “normal” minds, means a loss of personhood…Prendergast (2003) marks this oppression with the term *rhetoricity* (p. 202): that is, the ability to be received as a valid human subject. People with mental disabilities lack rhetoricity; we are rhetorically disabled. To lack rhetoricity is to lack all basic freedoms and rights, including the freedom to express ourselves and the right to be listened to. (pp. 26-27)

People with dementia are primarily construed as severely lacking rhetoricity because of the defining characteristic of dementia – memory loss. The general view is that people who are unable to remember cannot provide a “reliable” or “accurate” account (Innes, 2009).

Furthermore, in addition to often having issues with memory, people with dementia are also frequently diagnosed with aphasia. Aphasia is classified as a communication disorder that impedes people’s ability to use or understand words. Typically, people with aphasia do not realize they are not “making sense” to others, which makes communication frustrating for them. Aphasia, in addition to memory loss, often furthers the perceived lack of rhetoricity. Being denied rhetoricity is not only isolating, but also dehumanizing. According to Price (2011), “We speak from positions that are assumed to be subhuman, even non-human; and therefore, when we speak, our words go unheeded. In concrete terms…people with mental disabilities are presumed not to be competent, nor understandable, nor valuable, nor whole” (p. 26).

Macdougall (2014) argues that conversations with people with dementia make more sense than we realize, particularly if we attend to the idea of alternate realities. The important aspect of dialogue with people with dementia is not logic or rationality, but rather listening, engaging, and establishing connectivity. To exemplify, here is another story.

*Bettie approaches me as soon as I enter the room and grabs my arm very tightly. Her eyes are wide and she looks very concerned. “Did you take the lamp to the doghouse?” she asks. I pause, trying to determine what she is feeling. She repeats the question, this time sounding even more anxious. “Did you take the lamp to the doghouse?” I do not know what she is attempting to communicate but I can tell from her tone and body language that it is really important to her and I feel it is wrong to ignore her question even though I cannot interpret her words. “Yes, I did,” I answer. Her eyes get even wider. “You did!” she cries. “No!” I quickly correct myself. “I did not take it.” She sighs with relief and smiles. “Oh good. Thank you so much dear.” She squeezes my hand and smiles up at me, and I smile back.*

It is essential to create moments and spaces in which the person with dementia’s rhetoricity is not denied. This act will not be simple, as it will call on us to suspend our judgment about what is “real,” “rational,” “logical,” and “correct.” But doing so will do more than allow us to connect on a deeper level with people with dementia, it will also help us remember that the voices, feelings, thoughts, and ideas of people with dementia are valid and meaningful. **[SLIDE]**

**CONCLUSION**

 In this presentation, I have analyzed dementia through four theories and frameworks in Disability Studies – the Social Model of Disability, the Political/Relational Model of Disability, crip time, and rhetoricity. **[SLIDE]** My goal in using a disability studies lens to analyze dementia is twofold. First, I want to consider ways to integrate gerontological theory and disability studies theory. Second, I want to explore new alternatives and build on existing alternatives for how we as a society conceptualize and treat people with dementia. Accordingly, in addition to providing an academic and intellectual critique of how we view dementia, I have also tried to offer up ways that we might enact theory in practice. There are also quite a few other Disability Studies theories that may help us reconceptualize the way we view and treat people with dementia, such as complex embodiment (Siebers, 2008), compulsory able-bodiedness (McRuer, 2006), and betweenity (Brueggeman, 2009). These warrant further exploration.

As many people in gerontology and aging studies are aware, dementia was not always subject to biomedical interpretations and understandings, as it was once considered a typical part of aging. Perhaps it is time for a new evolution in the history of dementia, in which it is not considered a tragic disease without a cure, but rather a disability, subject to societal meanings and cultural contexts. Doing so would certainly benefit the field of gerontology, which is currently limited in its analysis of disability by typologies of aging, such as normal aging, successful aging, and pathological aging. Furthermore, viewing dementia as a disability also opens up new possibilities for disability studies and the disability rights movement. The timing is ideal, as people with dementia are increasingly advocating for their rights (Bartlett & O’Connor, 2010; Basting, 2009). Additionally, involving people with dementia challenges disability studies to consider how we include or exclude people with “severe” mental and neurological impairments on a broader scale.

In conclusion, theoretical integration would benefit the fields of gerontology and disability studies, and hopefully ultimately enhance the lives of people who experience dementia and other impairments (whether recently acquired or lifelong) in later life. Thank you.