

## The Formidable Double D: Analysis of Desire and Disability

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Représentations sociales et handicap : regards croisés sur le sens commun du handicap  
Social Representations and Disability: Perspectives on the Common Sense Notions of Disability

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Résumé de l'article

Cet article aborde l'enchevêtrement des représentations sociales concernant les personnes ayant des incapacités intellectuelles à travers une histoire émergente de recoins sombres des journaux américains. Ces articles trouvés sur internet ne sont pas des présentations statiques de faits, mais plutôt des interactions dynamiques puisées à des sites où des gens se répondent, se disputent et élaborent sur le sujet. Ce travail cherche les origines et les lieux de connaissances quotidiennes à partir des travaux de Serge Moscovici sur les représentations sociales pour qui les connaissances sont le résultat de processus communément partagé, fondées sur la socialisation, et continues. Une analyse du discours des journalistes et des répondants des articles publiés montre que les gens opprimés par l'étiquette de « handicapé intellectuel » se voient souvent empêchés de se définir; cette tâche reviendrait plutôt aux professionnels ou aux membres de la famille. Quand une relation est établie, elle est souvent présumée d'ordre clinique. Des caractéristiques telles que l'inaccessibilité à la communication verbale mènent souvent à de l'infantilisation, ce qui rend le consentement inconcevable. Finalement, en arrière-plan, on retrouve l'idée que les gens avec une étiquette de « handicap intellectuel » sont moins humains et n'ont donc pas les mêmes droits inaliénables, comme celui de ressentir du désir.

## The Formidable Double D: Analysis of Desire and Disability

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### Abstract

This article untangles the social representation of people with intellectual disabilities by calling attention to a recent story tucked in the shadowy crevices of American newspapers. These articles found on the Internet are not static presentations of facts, but rather dynamic sites of interactions where people respond, dispute, and elaborate on the content. This work traces the social origins and locations of everyday knowledge, drawing on Serge Moscovici's social representation theory that considers knowledge to be a process that is communally enacted, socially embedded, and ongoing. An analysis of the language used by journalists and commentators on published internet articles related to the case found that individuals oppressed by the label of intellectually disabled are often prevented from defining themselves, this task is deferred to professionals and families. When a relationship is established with someone else, it is therefore assumed to be a clinical relationship. Characteristics such as inaccessibility to verbal communication lead to infantilization, which makes consent inconceivable. Finally, lurking behind these themes is the implication that people who are oppressed by the label of intellectually disabled are less than human and therefore do not have the privilege of inalienable human rights, such as the right to feel desire.

**Keywords:** intellectual disability, social representation theory, sexuality, moral exclusion

### Résumé

Cet article aborde l'enchevêtrement des représentations sociales concernant les personnes ayant des incapacités intellectuelles à travers une histoire émergeant de recoins sombres des journaux américains. Ces articles trouvés sur internet ne sont pas des présentations statiques de faits, mais plutôt des interactions dynamiques puisées à des sites où des gens se répondent, se disputent et élaborent sur le sujet. Ce travail cherche les origines et les lieux de connaissances quotidiennes à partir des travaux de Serge Moscovici sur les représentations sociales pour qui les connaissances sont le résultat de processus communément partagé, fondées sur la socialisation, et continues. Une analyse du discours des journalistes et des répondants des articles publiés montre que les gens opprimés par l'étiquette de « handicapé intellectuel » se voient souvent empêchés de se définir; cette tâche reviendrait plutôt aux professionnels ou aux membres de la famille. Quand une relation est établie, elle est souvent présumée d'ordre clinique. Des caractéristiques telles que l'inaccessibilité à la communication verbale mènent souvent à de l'infantilisation, ce qui rend le consentement inconcevable. Finalement, en arrière-plan, on retrouve l'idée que les gens avec une étiquette de « handicap intellectuel » sont moins humains et n'ont donc pas les mêmes droits inaliénables, comme celui de ressentir du désir.

**Mots-clés :** handicap intellectuel, théorie des représentations sociales, sexualité, exclusion morale



A state judge Thursday cast doubt on the centerpiece of [University] professor [name omitted]'s defense of allegations she repeatedly sexually assaulted a 33-year-old man doctors say has the mental capacity of an 18-month-old.

[The professor]'s lawyer, James Patton, claims the man, known as [name omitted], may be physically impaired but has the mental capacity to understand questions and give his consent.

But during a hearing Thursday in Superior Court in Newark, Judge Siobhan Teare told Patton two decades' worth of psychological testing have concluded [name omitted] is severely mentally disabled and, thus, incapable of giving consent.

"Even if you found [name omitted], has the ability to communicate, you can't overturn 20 years of his being determined to be incompetent," Teare said during the hearing to gauge [name omitted]'s ability to communicate. "He does not have the ability to give consent. (Zambito, 2014)

In the excerpt above, the voices that are heard and therefore the voices that direct the unfolding of a story and the course of this particular piece of history are those of a judge, a journalist, and the implied claims of a defendant (a professor). The words, the story itself, rests silently but heavily on the body of a man at the center of the case. What is not said, who is not given the opportunity to be heard defines a society as much as that which is stated. This makes missing perspectives as vital, if not more so, to the meaning at the heart of a story as those that are included. Marginalization and neglect of voices by those in power comes as no surprise to social justice advocates and much effort and energy has gone toward advocacy and interrogation of once accepted exclusionary practices. Today, while many marginalized groups have made some strides toward equity, majority of the people who are oppressed by the label of intellectually disabled exist in a space of social invisibility and fear. People oppressed by the label of intellectual disabilities<sup>1</sup> are perhaps the most

<sup>1</sup> The alarming comfort the clinical environment has in its use, contributes to my discomfort of the label of intellectual disability. Smith (2006) surveyed the term *mental retardation*, an older rendition of the same construct, and found it is used to describe over 350 conditions asserting that the only certain commonality among all of them is society's discomfort and stigmatization of them. I share this discomfort for this and for how I have seen the category used within institutions to justify mistreatment. I continue to use the label, preceded awkwardly

stigmatized group of society (Thomas, 2000). This stigmatization and moral exclusion is evident in how people are represented in media while simultaneously are prevented from representing themselves.

I will start untangling the social representation of people oppressed by the label of intellectually disabled by calling attention to a recent story tucked in the shadowy crevices of American newspapers. These articles found on the Internet are not static presentations of facts, but rather dynamic sites of interactions where people respond, dispute, and elaborate on the content provided by the various authors. These comments allow me to begin tracing the social origins and locations of everyday knowledge. Serge Moscovici's social representation theory considers knowledge to be a process that is communally enacted, socially embedded, and ongoing (Moscovici, 1988, 1998). By examining the language referencing a man oppressed by the label of intellectually disabled, I aim to illuminate the intersubjective spaces where knowledge is produced in a dialogic fashion among individuals, communities, and broader social, cultural, and historical contexts. These social representations do not simply explain the communal world, but are the very building blocks of

by the words "oppressed by the label of", in order to connect this work with relevant literature.



this shared reality (Jovchelovitch, 2007). By beginning to deconstruct these representations, by beginning to trouble the silences enacted, the voices and lived experiences that are denied, we can also begin to collectively imagine the construction of a more just world.

The socially represented information that I will detail about the individuals involved and the relationship are all found within the published articles. However, the story in the published articles, and as a result in my summary, is missing crucial demographic information. Within the articles the race and the socioeconomic statuses are not explicitly named, though it might be read between the lines, and though they have significant meaning within the glue that binds us together. This incomplete telling is a meaningful problem as ableism is integrally linked to racism, classism, and sexism (Fritsch, 2009). While I have been in contact with someone near the case, I will remain committed to only sharing information that was publicly available at the time of this analysis.

### **Abuse or Desire: Background on the Story**

In an east coast US newspaper, a complicated story unfolds, one that is drastically different depending on the perspective. In these articles we learn about two people who might be prevented from engaging in a loving and supportive relationship or we are reading about one person who is abused and taken advantage of by another (Flaherty). These two possibilities exist within all of the articles in which a prominent professor of philosophy and disability rights advocate was introduced to a man. The man's brother (the professor's student) had connected the two of them with the hopes that the professor could teach him a communication method called *facilitated communication*. The man, whose level of disability is one of the contested issues in the case, lives with cerebral palsy. Within a year, the man and the professor find themselves working closely on a regular basis as the man was reportedly expressing himself successfully through this controversial communication method (I will briefly address facilitated communication below but the reader is referred to Biklen & Cardinal,

1997 for more on this method). Together the professor and the man wrote articles and presented at conferences. This intimate collaboration blossomed into a relationship. Two and a half years after being introduced, the couple met with the man's family to share their intention to spend their lives together. Through facilitated communication, the man communicated this desire, while the professor communicated her love with her voice.

Since that day when the man and the professor met with his family, the couple has been kept apart. The family went to the professor's school and brought legal action. Courts cleared the university, as the activities were not academically related to her role as professor of philosophy, but the case continues. Experts brought in by the family use mainstream assessments to repeatedly declare the man "profoundly mentally disabled". While the defendant, the professor's lawyer, brought in other experts to explore the man's ability to give consent. Absent from every article published up to the point of my writing is the voice, experiences, thoughts, contributions of the man. Depending on who is narrating, this is a story of either sexual abuse or a tale of misunderstood love but in all cases the story exclusively privileges the perspectives of those who are not oppressed by the label of intellectual disability.

As a critical social psychologist, I am interested in troubling the visible and invisible forces acting on the *scientific* and social representations of this man in the story and considering the complicating role of desire itself. The language used by the authors of the articles as well as the language used by the commentators reflect the continual construction of everyday knowledge that is socially embedded, looping back to shape reality itself (Moscovici 1988, 1998). In addition, by excavating the dominant psychological languages used to characterize, understand, and represent people with intellectual disabilities within academic literature I will allude to the direct relationships between scientific representations and the unfurled assumptions hidden in the public and media's perception of this story. Social representations, cultural and psychological, emerge through and

link with how individuals express knowledge. This cycle is crucial for psychologists to recognize and be accountable to.

### **A note on facilitated communication**

A significant piece of this story revolves around the highly controversial method of communication referred to as Facilitation Communication or FC. I will briefly outline this technique in this section. FC was introduced to the United States as an augmented communication for individuals for whom verbal communication was not accessible. Biklen, an early advocate of FC, believed the method to challenge prevailing assumptions about intelligence and those who are oppressed by the label of intellectual disability (Biklen, 1990). A major strength emphasized by Biklen was that it did not presume incompetence in those that were not able to verbally communicate (Moster, 2001). FC means that a facilitator works with someone to offer physical pressure that helps counteract movements that are otherwise preventing the individual from controlled action, such as pointing to letters on a board. Since its introduction to the United States, controversy has been strongly associated with FC on the matter of authorship. The controversy continues to the present with studies claiming physical control from the facilitator while on the other side of the debate, individuals find a way to communicate independently after many years of working with a facilitator (Biklen & Burke, 2006).

In the current case, the method was considered inadmissible in court rendering the man without a way to share his story. People in the margins of power, such as those placed low on the hierarchy of class, race, and ability, are often silenced by those with power. This includes the legal system and the press. Denying the opportunity to include the perspectives of individuals on the margins reifies society's oppressive structures. In order to no longer silence the man in question and to invite him to take this "border crossing" journey with me in this analysis, the provocative issue of facilitated communication would have to be addressed and deemed legally acceptable so that his sto-

ry can be reflected in the documents that are produced for publication (Biklen & Cardinal, 1997; Giroux, 1992). Without the ability to make way for his perspective to be represented, he is defined strictly through professional and familial reflections. Many individuals who are defined by assessments, such as the man in this case, have social circles that are limited to family and professional caretakers and doctors. These members of their communities are given full power including the power to define him. Judgments of his likes, desires, thoughts, and life are deferred to his family and the doctors. A practice implicitly encouraged by the discipline of psychology.

### **My positionality: Background on my Story**

Before entering into an exploration of psychology's complicated lineage, I would like to share a bit of mine. In a hermeneutic fashion, I would like to acknowledge the texture of my positionality and how this influences my location on the horizon of possibilities (Gadamer, 2008). Positionality reflects on where the researcher stands within a discourse and how the perspective on the topic at hand may be influenced by this position (Dobbins, 2007). My history as a collaborator at a social justice project seeking to disrupt institutions from within and to offer an alternative to the segregated sheltered workshop model of "vocational" support for people oppressed by the label of intellectual disability provides a meaningful backdrop to my value system from which I understand these issues from. Through this experience I was exposed to the institutions, both housing and vocational, that claim to support individuals society categorizes as intellectually disabled. In these settings from within the institutions, I came to understand the pervasive oppression, injustices, and abuse experienced by those who are inflicted with the violent label of intellectual disability. I was a witness to systemic torture as people I worked with, victims of sexual abuse, were forced to take part in outdated and dehumanizing aversion therapies to stifle any feelings of desire. I was a witness to erasure as all significant decisions related to lives were made by staff, whether about the grocery list or about someone's ability to en-



gage in friendship with others. I was a witness to pervasive, deep dehumanization. In short, I was a witness to the mechanics of moral exclusion (Opatow, 1990). According to Susan Opatow (1990), when groups are morally excluded, they are positioned outside of the scope of justice, making mistreatment, dehumanization, and erasure possible. Due to my experiences within institutions, I perceive the label and the structures that claim to protect the individuals affixed with this label as violent, deeply unjust and complicit in moral exclusion.

My aim with this text is not to speak for anyone, as that may reinforce the abuse that exists within academia and media. Rather, inspired by Ruthellen Josselson, I would like to analyze newspaper articles, commentary on the articles, and online blog posts on the court case described above from the position of the hermeneutics of demystification (Josselson, 2004). With this approach I will try to identify what is unsaid and what is unsayable in the articles through the analysis of the content, particularly content that is related to the man in the case. I contend that the unsaid and the unsayable expose the unwillingness of society to acknowledge people oppressed with the label of intellectual disabilities as fully human with rights to love, affection, and equality (Carey, 2009). Through the hermeneutics of demystification I would like to provoke attention focused on the intersubjective spaces that communally construct social knowledge and integrate psychology's history and practices.

### **An unfairly brief but vital history**

Before I explore the scientific literature's shaping of the social representation of the intersection of desire and intellectual disability, it is worth slipping back in time to reflect on this topic's history. The networks of social representations which are reflected by and shape today's discourse comes from a lineage of eugenics inspired atrocities and should be considered as relevant to a discussion about the present as the influence of these policies continues to reverberate today.

Among the many social changes during the 19<sup>th</sup> century, a growing specialization in psychology of the term *idiotcy* and the new challenges facing families brought on by industrialization inspired the formation of large congregate care facilities, with the first asylum opening in 1848 (Ferguson, 2013). These rehabilitative spaces demonstrated science's hopes of curing the community from "the most fearful of the host of maladies" (Brady, 1867 in Ferguson, 2013). A study of superintendents books and journals of the 19<sup>th</sup> century, chronicles the initial hopes of rehabilitating the feebleminded waning and developing a more pessimistic outlook. At the turn of the century, the asylums once created for rehabilitation advocated for mass institutionalization for the sake of the hopelessly disabled individual and the society (Ferguson, 2013).

Eugenics, coined by Sir Francis Galton, means good birth in Greek. At the time of his death in 1911, his science of improving the quality of the human race was only beginning to flourish in the United States. The psychologists working within the framework of 19<sup>th</sup> century institutions concluded by the 20<sup>th</sup> century the heritable nature of intellectual disabilities (Wehmeyer, Noll, & Smith, 2013). It was customary for institutions to publish pamphlets, books, detailing the lives of specific families that had demonstrated the threat the feebleminded imposed on "racial hygiene". These large eugenic family studies were immensely popular, frequently becoming best sellers. Eugenic family studies influenced the public's understanding of intellectual disability and the public's vehement support of sterilization (Smith & Wehmeyer, 2012). One such publication in 1912, by psychologist Henry Herbert Goddard introduced a woman, who he assigned the pseudonym of Deborah Kallikak, whose degeneracy is demonstrated by her performance on the Binet test for intelligence. These degenerates are described by Goddard as "wayward, they get into all sorts of trouble and difficulties, sexually and otherwise" (Goddard quoted by Smith & Wehmeyer, p. 123, 2012). He explains that her situation is hopeless and if she should ever leave the institution she would immediately become prey to evil men and women and fall into

a vicious, criminal life herself. In this treatise, he traces the girl's hopeless and dangerous lineage, declaring that an appalling amount of defectiveness was everywhere to be found.

This pro-eugenics document was remarkably popular and reprinted as late as 1939. Biology test books and politicians all cited Goddard's work. The infamous *Buck v Bell* Supreme Court case that declared involuntary sterilization of intellectually disabled citizens constitutional cited this text as did the German government in an act that would sterilize 150,000 people with disabilities between 1934 and 1939. This act was replaced by extermination in the beginning of winter of 1939. In the US, the Kallikak family represented a new fervor for eugenics and a threat of "race suicide", as described by then president Theodore Roosevelt (Dyer, 1992).

Goddard's suggestions for solutions to the problem posed by people with disabilities to the purity of society were two fold and both aggressively implemented in the US: segregation and sterilization.

**Scientific social representations of desire and intellectual disability today**

Goddard, Galton, Binet, and other men of science of the 19<sup>th</sup> and early 20<sup>th</sup> century, impris-

oned people with intellectual disabilities within the labels of *idiot*, *feebleminded*, and *moron*. Sexuality was mentioned as a point of vulnerability whereby people would be abused or as an aspect of danger to the good society. At the historic intersection of desire and disability, the involuntary sterilization of often involuntarily institutionalized individuals flourished.

In 2002, Government Mark Warner of Virginia, issued a formal apology for the forced sterilization of thousands of its citizens, including Carrie Buck, the woman at the center of the *Buck v Bell* case in 1930 ("Virginia governor apologizes for eugenics law"). While no longer defined by involuntary sterilization, desire and disability still occupy a passionately contested but paradoxically invisible space. Performing a search of English language academic journals within the popular database PsychInfo for the keywords of sexuality and intellectual disability brings to the surface a disturbingly stable representation. Similarly, this stability holds up when searching City University of New York's academic library's database (see Figure 1). Academic knowledge production continues to imprison people with intellectual disabilities in representations that imply that all are either inevitably victims or perpetrators of crimes regarding sexual abuse.

**FIGURE 1. RESULTS IN AN ACADEMIC LIBRARY'S DATABASE USING THE WORDS "SEXUALITY" AND "INTELLECTUALLY DISABLED"**

The screenshot shows a library search interface. At the top, there are three input fields: "Select search type:" with a dropdown menu set to "All Fields"; "Search for:" with the text "sexuality intellectually disabled" and a "Search" button; and "Select library:" with a dropdown menu set to "All CUNY Libraries". Below these fields is a "Browse List: Subjects" section with "Previous Page" and "Next Page" buttons. The main area is a table with two columns: "No. of Records" and "Brief Records".

No. of Records	Brief Records
1	<a href="#">Sexuality Information and Education Council of the United States -- Periodicals</a> [sexuality intellectually disabled] would have appeared here
1	<a href="#">Sexuality on television</a>
2	<a href="#">Sexually abused boys - [LC Authority Record]</a>
1	<a href="#">Sexually abused boys -- United States -- Case studies</a>
63	<a href="#">Sexually abused children - [LC Authority Record]</a>
1	<a href="#">Sexually abused children -- Abstracts</a>
2	<a href="#">Sexually abused children -- Alaska</a>
1	<a href="#">Sexually abused children -- Asia, Southeastern</a>
1	<a href="#">Sexually abused children -- Atlases</a>
1	<a href="#">Sexually abused children -- Attitudes</a>

At the bottom right of the table area, there are "Previous Page" and "Next Page" buttons.

The civil rights movements and the disability rights movements bolstered the rights of those with intellectual disabilities as well. Today, discrimination exists in blatant and more subtle ways, but continues to be pervasive. Perhaps the area where the violence of negated rights is greatest is when it comes to sexual rights. Past research has noted examples of people in sheltered workshops holding hands or kissing suffering punishment such as isolation and removal of privileges (Kulick & Rydstrom, 2015). In residential facilities and in family homes, individuals are equally likely to face discrimination and repercussion for expressing their sexual desires. Residential staff are warned of expulsion from their care positions if anyone engages in sexual acts while they are working (Winges-Yanez, 2014). If sexuality is expressed under these restrictive and unlikely conditions, it is likely to label the persons as deviant and dangerous (McRuer & Mallow, 2012).

Beneath the fragile surface of the intersection of desire and intellectual disability in psychological literature lurks the unfounded and ancient fear of this label harboring ignorant sexual deviants. Studies claim that there is an increase in incidents of sexual crimes among populations with intellectual disabilities (Lindsay, 2002). Some authors have claimed as much as a doubling of incidents between the years of 1973 and 1983 (Lund, 1990). In light of deinstitutionalization, whereby these individuals are incorporated into the larger community, the question of the prevalence of proper assessment and treatments of sexual deviance in intellectual disabilities has led to an increase in research on these topics in psychology (Lindsay, 2002). Among a slew of characteristics of offenders with intellectual disabilities found within research, including neglect and parental separation, sexual naiveté stands out (Day, 1993). According to the article, the inability to understand sexual relationships and poor impulse control, explains not only why people with intellectual disabilities are more likely to be perpetrators of sexual crimes but also more likely to be victims. Compounding the threat of people with intellectual disabilities as sexual deviants, researchers claim that they are more

likely to offend against younger children (Blanchard et al., 1999) and more likely to reoffend (Lindsay et al., 2001). A great amount of the little research occupying this hardly treaded space at the intersection intellectual disabilities and sexuality seeks to understand the behavior of individuals who have committed sexual offenses. Veiled as scientific inquiry, this work has reinvigorated historically rooted stigma.

The remaining space at the crossroads of disability and desire in psychological literature includes advocates seeking to understand the attitudes of the caretakers, the community, and the desires of the individuals taken care of. This research illuminates the relationship between a lack of knowledge or contact and the belief that people with intellectual disabilities are sexually deviant (Toomey, 1993). Those in contact, such as family and caretakers, adopt a protectionist perspective believing that people should be discouraged from having sexual relationships (Trudel & Desjardins, 1992) and preferring to avoid the subject altogether (Alcorn, 1974; Brantlinger, 1985). Disturbingly, a more recent study surveying teachers and administrators found that 100% would support sterilization (now illegal) when the intellectual disability was perceived as severe (Wolfe, 1997). Policies reaching back well over a hundred years continue to impact attitudes and lived experiences.

Admittedly, this all too brief survey of academic representations of intellectual disability in psychology and is in no way intended to fully describe the field. It does, however, help shed light on the darker influences that shape the media and popular representations of the intersection of intellectual disability and desire. I would like to make explicit the relationship between the meanings created within academic documents and the social representations circulating in everyday life utilizing Thomas Teo's concept of epistemological violence. Teo (2010) writes of interpretations in psychological papers as a form of action. These interpretations produce meaning, choosing specific ones from a multitude of various alternative meanings. If these actions have negative conse-



quences – ranging from misrepresentations to the neglect of the voices of those it claims to study – Teo considers them to be a form of violence. Under the authority of social science and knowledge, violence and damage has been inflicted upon individuals oppressed by the label of intellectually disabled. The violence descends from the academic pages and is enacted in the vulnerable underbelly of everyday life.

### **Social representations of intellectual disability through the lens of one case**

Returning to the case we started the article with, I will sift through the everyday language enacted by journalistic representations as well as the language of the broader public engaging with the content to better understand social representations of people oppressed by the label of intellectually disabled. At the time of this article's inception, the case involving this professor has not yet stimulated the advances of the popular media: an Internet search revealed only thirteen articles mentioning the scenario. Using a systematic search of the professor's name and news within the most prominent electronic search tool available, Google, I collected all articles and blogs related to the case that were published prior to January 1, 2015. A deep analysis of these published articles allowed me to highlight representations, metaphors, and absences referencing the precarious space where desire and disability intersect. In my textual analysis, I am only focusing on the representation of the man, not the legal aspects in general or the representations of the female professor.

This issue is deeply complicated and multiple identities and factors intersect in numerous places. Admittedly, elevating representations of only the man in question from the rest of the details robs the conversation from its true richness and complexity. This case is about far more than the accusation of sexual assault, a misunderstood relationship or the validity of the type of communication used by the man. To unravel this court case fully, this discussion

should be about far more than the social representations of desire and disability; it is about history, about the meaning of care, about race, class, privilege, and power, among other considerably influential issues. This full characterization will not be possible for some time as the case is currently in progress at the time of analysis. My interest here is to focus in on the way the man (often referred to as the victim by the sources) is described by journalists and readers of the news who have a superficial understanding of the situation. By artificially separating the social representation of intellectual disability and sexuality from other identity markers, I am interested in identifying the kinds of socially shared explanations people evoke to make sense of this particular and disputed topic.

In Table 1 below, I have elevated the phrases that accompany descriptions of the man found in the articles published in newspapers and online forums related to the case prior to January 2015. Often they were the only descriptions of him. I have made an effort to include descriptions that are value based as well as neutral statements.

A striking pattern in the comments and articles (see Table 1) written about the relationship is the consistent reliance on doctors and the family to provide the standing definition of the man. His voice has a glaring absence but the task of defining him as a person is assigned to psychologists and assessors as well as his family. Even a stranger that has never had any contact with the man has more power to define him than he has to define himself. It is repeated in almost every reference that decades of psychological tests have indisputably established his potential for consent and communication, which now fully define him. That professional declaration found equally in the words of journalists as well as readers responding, coupled with the family's claim that he is totally unable to communicate, are treated as an indisputable claim of not just his mental capacity but his identity.



TABLE 1. A SELECTION OF COMMENTS RELATING TO THE MAN INVOLVED IN THE CASE, INCLUDING THE SOURCE OF COMMENT

Description of man	Source of quote
alleged <b>victim... mental capacity of an 18<sup>th</sup> month old</b>	Journalist
<b>severely disabled-incapable of giving consent</b>	Journalist
<b>using him, for all intensive purposes to be rape apologists</b>	Commenter
<b>rape apology</b>	Commenter
If this guy <b>can really communicate</b> , let's hear his take	Commenter
<b>Young man's</b> self determination	Commenter
they are sexually <b>exploiting the boys</b> in their charge	Commenter
<b>doctors have declared</b> severely mentally disabled	Journalist
mental capacity of an 18 month old and could <b>not even effectively communicate</b> with his family	Journalist
<b>guinea pig</b>	Lawyer
<b>more tests</b> need to be done to determine the extent of DJ's ability to communicate and comprehend	Journalist
<b>vulnerable class of people</b> who are handicapped so that they cannot communicate	Journalist
severely disabled <b>brother</b>	Journalist
the mental capacity of an 18 month old <b>infant</b>	Journalist
mental equivalence of a <b>toddler</b> is capable of being seduced and subsequently <b>alienated</b> from his family	Journalist
capacity to be seduced and alienated ...then he was a <b>willful active participant</b> in the sexual acts	Journalist
<b>puppet</b>	Commenter
the mind of an <b>18<sup>th</sup> month old toddler</b>	Blogger
unable to communicate ... beyond the most <b>primitive</b> means	Blogger
<b>incapable of meaningful consent</b>	Blogger
heck of a lot more difficult <b>for a person with CP to find love</b> than it is for the rest of us lucky bastards	Commenter
under her "care"... he has the mind of an <b>18 month old infant</b> .	Commenter
a man who <b>is physically unable to resist advances</b> and may have the <b>mental capacity of a small child</b>	Commenter
<b>mind of an infant</b> . This is <b>what the family says. This is what the doctors say</b> .	Commenter
<b>akin to a doctor patient relationship</b>	Commenter
DJ is <b>obviously not functioning as a fully abled adult</b>	Commenter
his family and doctors are invested in him being a <b>vegetable</b>	Commenter
a person who is not a <b>fully</b> functioning adult	Commenter
<b>This is a painful manifestation of a larger struggle for human rights for disabled</b>	Commenter

<i>people.</i>	
male <b>victims</b> of sexual molestation are unable to suppress an erection	Commenter
conflate the presence of <i>sexual</i> desires in the disabled with the appropriateness of such relations between a <b>professional and client</b> . She had no business having sex with him, even if he did want it.	Commenter
We have a <b>young man here</b> who despite the instructor's claims, cannot speak for himself. I'm with his family. There has to be proof here that he was molested, and his family would be the best judge of that, and this jerk took advantage of the <b>poor kid...</b>	Commenter
took advantage of her <b>client</b> , sexually... <i>mercy</i> of others, and he or she needs to be <b>protected</b> from abuse.	Commenter
her victim isn't <b>physically appealing</b> .	Commenter

### Only a patient, never a friend

Perceived as someone who requires support, the man's relationship to the woman in the case is described as a *patient* and a *client* by those who respond to the story in the newspaper. Stark within the comments are the assumption that if someone benefits from care then all relationships outside of the family can only be medical and professional. Several comments indicate that only the doctors and the family can accurately represent him. Outside of the family, medical relationships are implied as the only feasible ones for someone who fits the description of the man involved in the case and these medical relationships are also privileged above all other perspectives.

In order to receive funding from the government in the US, people must demonstrate a need for supports for daily living activities. Providing proof of need creates an environment in which one is always a client or patient, unless defined by blood family to be a son or brother. All possible relationships are filtered through this lens of support, rendering appropriate non-family and non-professional relationships virtually impossible through this framework. Care takes on an insidious tone in this ideological landscape. This artificial barrier, if trespassed, is legally precarious.

### Infantilizing

The man, who is in fact 33 years old, is constantly referred to as an *infant*, *young man*,

*poor kid*, *boy*, and *toddler*. Bloggers, self-identified disability rights advocates, commentators, and professional journalists alike access these labels. The man, unable to communicate verbally and requiring physical supports is denoted to the status of an *infant* and at best a *young man*; all of his possibilities appear filtered through this infantilizing framework. This patronizing phenomenon is well documented in social sciences (Biklen & Burke, 2006).

However, social science not only documents the phenomenon underlying attitudes and behavior, but also constructs it. Intelligence testing has been used to identify and justify the mistreatment of certain categories defined by race and class (Danziger, 1997) since its inception in the early 20<sup>th</sup> century. IQ testing and other assessments in school create the labels that are then used to oppress individuals (Biklen & Burke, 2006). This label, arrived at through the use of psychological assessment, instructs legal entities on the matter of consent.

### Inconceivability of consent

As a consequence the judgments of doctors and other professionals, the question of consent is not something that is sought to be answered through investigation relating to this relationship, but is assumed to be inconceivable by those who engaged with the story. Referring to the infantilizing characterization of the man as a *toddler*, *infant*, *18<sup>th</sup> month old*, and *boy*, the response to the idea of a sexual relationship is in outrage. The inconceivability of



consent due to his characteristics as someone who does not communicate verbally reframes all possible sexual experiences as rape. Asexualized through infantilization, the possibility of a sexual relationship is met with anger, outrage, pity, and the call for protection.

### Vegetable and guinea pig

More extreme than even infantilizing the man in the case, several commentators, including journalists and the lawyer that is quoted by a journalist, dehumanize him completely. Equating him with non-humans his involvement in a meaningful relationship becomes impossible. This denigration makes conversations around human rights inappropriate as those rights apply to those who are fully human. With these verdicts, not only is his imposed asexualization complete but so is his dehumanization.

### Conclusion

In hermeneutics of demystification, Josselson (2004) illuminates the significance of that which is not explicitly said. Rather than using this method on the narratives of individuals in order to understand their lived experience, I am using this method to interrogate social representation of an oppressed category as presented in published articles and in comments from readers which follow them. Serge Moscovici's (1988) social representation theory is a useful tool to better understand the processes of human understanding as they occur within everyday lives, in this case to better understand the mechanics of moral exclusion as it relates to people oppressed by the label of intellectually disabled. Using hermeneutics of demystification I wanted to understand the significance of what crept behind the words of journalists, bloggers, and those who engaged with the case about a man with cerebral palsy in a relationships with a female professor. By better understanding these shared meanings I hope to better bring attention to the assumptions that binds us together as a community and directly impact the scope of justice.

The themes I elevated are at once shocking and not surprising given the history. To sum-

marize, I have found in the texts that individuals oppressed by the label of intellectually disabled are often prevented from defining themselves; this task is deferred to professionals and families. Relationships are often unlikely to be forged outside of family and professionals (such as doctors) due to the segregated lives many lead. When a relationship is established with someone else it is therefore assumed to be a *patient* relationship. Characteristics such as inaccessibility to verbal communication lead to infantilization that makes consent inconceivable. Finally, lurking behind these themes is the implication that people who are oppressed by the label of intellectually disabled are less than human and therefore do not have the privilege of unalienable human rights.

With this outward motion from the neglected perspectives, I hope to move beyond documenting the silencing to "investigating the varied strategies by which desires are buried, forming and yet emergent; spoken, embodied, performed, and/or enacted" (McClelland & Fine, 2008, p. 233). History, psychological claims, and policies of the past contribute to today's climate of extreme moral exclusion (Opatow, 1990). Based on the representation of the person involved in the case it is possible to conclude that individuals oppressed by the label of intellectually disabled may be perceived as undeserving of the right to desire, love, and the right to be loved, therefore infantilization, protectionist segregation, and dehumanization that is found in the social representation of the case is accepted by society. While *Buck v Bell* is no longer related to current law, its influence, as well as other eugenic related policies, reach into the present. To develop the example of *Buck v Bell* further, this period in history and this case was not about the right to procreate but the power of the state to prohibit possibilities of procreation. Hence, this law instigated segregated spaces and services that impose asexuality on individuals (Carey, 2009). These are the institutions, practices, and legal frameworks which support people oppressed by the label of intellectual disability. Though the governor of Virginia has offered an apology for the mandated sterilization of the past, its effects are far from over.

## Desire Denied

Cornel West (1993), speaking of the experience of being black in America, describes the experience of total exclusion as a threat to existence. Sustaining an existence that is robbed of meaning, hope, and love becomes a threat to life itself. I cannot and will not attempt to speak for the man involved in the case, for I too would be committing a crime against his existence, instead, I would like to end with questions and questioning statements to further interrogate the labels and the assumptions that lurk behind them. Literature on women in prison is complicating discourse around sexuality, in such a way that acknowledges the risk of oppression and abuse while holding on to desire and agency (Smith, 2006). Simply, this scholarship is recognizing that when a person experiences the violence of institutionalization one's yearning for love is not extinguished. How can we hold these same tensions when considering individuals oppressed by the label of intellectual disability? How can we conceptualize desire and agency for those who are assumed to lack the traditional capacity for consent? This is not limited to people who are oppressed by the label of intellectual disability, but is increasingly a pressing concern that more have to confront (Belluck, 2015, April 13). Finally, it is worth considering if the very real acknowledgement of past abuses and tragedies (Sobsey & Doe, 1991) may have inspired protectionist discourses that presume to be pro-disability but deny agency. This denial of agency is a dangerous breath away from dehumanization.

At the formidable intersection of desire and disability, based on the social representation of the case described above, there is the very real threat of one more d: dehumanization.

## References

- ALCORN D. E. (1974). Parental views on sexual development and education of the trainable mentally retarded. *Journal of Special Education*, 8, 119-130.
- BELLUCK, P. (2015, April 13). Sex, Dementia and a Husband on Trial at Age 78. Retrieved April 15, 2015, from <http://www.nytimes.com/2015/04/14/health/sex-dementia-and-a-husband-henry-rayhons-on-trial-at-age-78.html?emc=eta1>
- BIKLEN, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review*, 60, 291-314.
- BIKLEN, D., & BURKE, J. (2006). Presuming competence. *Equity & Excellence in Education*, 39(2), 166-175.
- BIKLEN, D. E., & CARDINAL, D. N. (1997). Contested words, contested science: Unraveling the facilitated communication controversy. *Teachers College Press*.
- BLANCHARD, R., WATSON, M. S., CHOY, A., DICKEY, R., KLASSEN, P., KUBAN, M., & FERREN, D. J. (1999). Pedophiles: Mental retardation, maternal age, and sexual orientation. *Archives of Sexual Behavior*, 28(2), 111-127.
- BRANTLINGER, E. A. (1985). Mildly mentally retarded secondary students' information about sexual and attitudes toward sexuality and sexuality education. *Education and Training of the Mentally Retarded*, 20, 99-108.
- CAREY, A. C. (2009). *On the margins of citizenship: Intellectual disability and civil rights in twentieth-century America*. Philadelphia, PA: Temple University Press.
- DANZIGER, K. (1997). The historical formation of selves. *Self and identity: Fundamental issues*, 137-159.
- DAY, K. (1993). Crime and mental retardation: a review. In *Clinical Approaches to the Mentally Disordered Offender* (eds K. Howells & C. Hollin), pp. 111-43. John Wiley & Sons, Chichester.
- DOBBINS, J. F. (2007). Connections of Care: Relationships and Family Caregiver Narratives. In *The meaning of others: Narrative studies of relationships*. American Psychological Association.
- DYER, T. G. (1992). *Theodore Roosevelt and the idea of race*. LSU Press.
- FERGUSON, P. (2013). The Development of Systems of Supports: Intellectual Disability in Middle Modern Times (1800 CE to 1899 CE). In *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Brookes Publishing.
- FLAHERTY, C. (2014, April 23). *Question of consent*. Retrieved October 26, 2014.
- GADAMER, H. G. (2008). *Philosophical hermeneutics*. University of California Press.
- FRITSCH, K. (2009, January 1). Resisting easy answers: An interview with Eli Clare. Retrieved March 3, 2015.



- GIROUX, H. A. (1992). *Border crossings: Cultural workers and the politics of education*. Psychology Press.
- JOSSELYN, R. (2004). The hermeneutics of faith and the hermeneutics of suspicion. *Narrative inquiry*, 14(1), 1-28.
- JOVCHELOVITCH, S. (2007). *Knowledge in context: Representations, community and culture*. Hove, UK: Routledge.
- KULICK, D., & RYDSTRÖM, J. (2015). *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. Duke University Press.
- LINDSAY, W. R. (2002). Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 46(s1), 74-85.
- LUND J. (1990). Mentally retarded offenders in Denmark. *British Journal of Psychiatry*, 156, 726-731.
- MCCLELLAND, S. I., & FINE, M. (2008). Writing on cellophane: Studying teen women's sexual desires, inventing methodological release points. *The methodological dilemma: Creative, critical and collaborative approaches to qualitative research*, 232-260.
- MCRUER, R., & MOLLOW, A. (EDS.). (2012). *Sex and disability*. Duke University Press.
- MOSCOVICI, S. (1988). Notes towards a description of social representations. *European journal of social psychology*, 18(3), 211-250.
- MOSCOVICI, S., & MARKOVÁ, I. (1998). Presenting social representations: A conversation. *Culture & psychology*, 4(3), 371-410.
- MOSTERT, M. P. (2001). Facilitated communication since 1995: a review of published studies. *Journal of Autism and Developmental Disorders*, 31(3), 287-313.
- OPOTOW, S. (1990). Moral exclusion and injustice: An introduction. *Journal of social issues*, 46(1), 1-20.
- SMITH, B. V. (2006). Rethinking prison sex: Self-expression and safety. *Colum. J. Gender & L.*, 15, 185.
- SMITH, J. D. (2006). Speaking of Mild Mental Retardation: It's No Box of Chocolates, or Is It? *Exceptionality*, 14(4), 191-204.
- SMITH, J. D., & WEHMEYER, M. L. (2012). Who Was Deborah Kallikak? *Intellectual and developmental disabilities*, 50(2), 169-178.
- SMITH, J. D., WEHMEYER, M., & NOLL, S. (2013). In search of Science: Intellectual Disability in Late Modern Times (1900 CE to 1930 CE). In *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Brookes Publishing.
- SOBSEY, D., & DOE, T. (1991). Patterns of sexual abuse and assault. *Sexuality and Disability*, 9(3), 243-259.
- TEO, T. (2010). What is epistemological violence in the empirical social sciences? *Social and Personality Psychology Compass*, 4(5), 295-303.
- THOMAS, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, 86(3c), 1155-1156.
- TOOMEY, J. F. (1993). Final report of the Bawnmore Personal Development Programme: staff attitudes and sexuality programme development in an Irish service organisation for people with mental handicap. *Research in developmental disabilities*, 14(2), 129-144.
- TRUDEL, G., & DESJARDINS, G. (1992). Staff reactions toward the sexual behaviors of people living in institutional settings. *Sexuality and disability*, 10(3), 173-188.
- VIRGINIA GOVERNOR APOLOGIZES FOR EUGENICS LAW. (2002, May 2). Retrieved December 5, 2014, from [http://usa today30.usatoday.com/news/nation/2002/05/02/virginia-eugenics.htm](http://usa.today30.usatoday.com/news/nation/2002/05/02/virginia-eugenics.htm)
- WEHMEYER, M., NOLL, S., & SMITH, J. D. (2013). Isolation, Enlargement, and Economization: Intellectual disability in late modern times (1930 CE to 1950 CE). In *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Brookes Publishing.
- WEST, C. (1993). *Race matters*. Vintage.
- WINGES-YANEZ, N. (2014). Why All the Talk About Sex? An Autoethnography Identifying the Troubling Discourse of Sexuality and Intellectual Disability. *Sexuality and Disability*, 32(1), 107-116.
- WOLFE P. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability*, 15, 69-90.
- ZAMBITO, T. (2014, April 25). Judge questions consent defense in case of Rutgers-Newark professor accused of sex assault. NJ Advance Media. Retrieved October 26, 2014.