

The Impact of Social Media Disclosure on Persons with Physical Disabilities

By

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**Abstract**

38.5 million people in the United States are identified as persons with physical disabilities. Persons with physical disabilities often face isolation from the general population in face-to-face settings resulting in limited opportunities to form relationships (Thoreau, 2006), due to an ongoing disability narrative that suggests this group has qualities that are not worthy of belonging among the non-disabled resulting in limited opportunities to form relationships (Thoreau, 2006). Social media has offered new opportunities for persons with disabilities to form relationships. Evidence of a safe user experience for persons with disabilities looking to disclose personal information about their disability on social media is difficult to find. This qualitative study establishes a theoretical framework to understand how, when, and why persons with physical disabilities choose to disclose his or her disability on social media platforms, and what rewards and challenges are encountered when sharing their disability disclosure on social media. Major findings from the study describe (1) three distinct approaches for disability disclosure, (2) the roles of age of discloser and age of the disability as key factors in approach selection, and (3) four incentives, which serve as driving factors for disability disclosure.

*Keywords:* social media, social isolation, disclosure, disability narrative, relationship-building, disability culture, disclosure approach, disclosure incentive, disclosure challenge

### The Impact of Social Media Disclosure on Persons with Disabilities

The Human Health and Services Office on Disability(2014) report that one out of five individuals in the United States (US) has some form of a disability. More specifically, This figure accounted for 56.5 million people, roughly 18.7% in 2010 (Brault, 2012), representing an increase of 2.2 million person increase since 2005 and demonstrating significant growth in the demographic. This increase is attributed to longer lifespans, returning veterans, and an aging baby boomer population moving into the category. Of this growing segment of our population, 38.3 million people are identified as having a disability that is physical in nature (Brault, 2012). The Human Health and Services Office on Disability (2014) classifies a physical disability is “*any type of physical condition that significantly impacts one or more major life activities*” (p.4). Unpacking of this definition indicates that identification as a person with a physical disability could include a physical condition potentially comprised of a loss of limb(s), or anatomical challenges, including neurological, cardiovascular, muscular, and skeletal issues. Each of these conditions could result from personal injury, illness, or a hereditary disorder that has drastically altered at least one main life function of the individual such as mobility, sight, and other sensory functions, or use of features of the human anatomy like arms, or hands. Some disabilities can be visually recognizable such as the inability to walk while other disabilities are not as immediately perceived such as the inability to hear (The Human Health and Services Office on Disability, 2014).

Persons with disabilities have often been stigmatized, isolated, and disregarded in society because of an ongoing stereotype that portrays this group as unable, resulting in limited opportunities to participate fully in society (Braithwaite, 1991). This suggests that persons with disabilities may have fewer opportunities to make friends, identify confidants, and pursue

relationships face-to-face that those without disabilities. As a result, many persons with disabilities have lived in isolation with few or no opportunities to cull the social skills necessary to create interpersonal bonds. This lack of the social skills such as understanding the right time to disclose private information elevates the probability of persons with disability sharing a personal narrative that could potentially lead to rejection on possible social networks (Goggin & Newell, 2002).

Coopman (2000) suggests that participation in social media for persons with disabilities allows this group new opportunities to emerge from social isolation. However, little research has been done in this area with persons with disabilities that are purely physical and visually noticeable in a face-to-face setting. Persons with physical disabilities are often faced with on-demand disability disclosure in face-to-face settings because of curiosity from the general public about the disability (Thoreau, 2006). Social media offers people with disabilities to make intentional decisions whether to publicly disclose information related to their disabilities.

While social media has given persons with disabilities a new vehicle for making friends, creating relationships, and disclosing personal information, very little evidence exists pointing to successful experiences. Research has yet to examine as to the ways that persons with disabilities have navigated disclosure about disabilities on social media, including how persons with physical disabilities manage privacy boundaries. Such research might investigate any number of timely questions. At what stage of Social Penetration theory might they disclose the information about disability, and how do they move through social penetration stages while managing privacy boundaries? How might social media practices change the connection between personal identity and the label of disability? With the ability to control the release of the personal information about the disability, when does an individual choose to disclose information about

his or her disability? What if any, are the rewards and costs of disclosing personal information about the disability on social media? Are there any successes in disclosing information about an individual's disability in terms of gaining acceptance from the other participants in social media? What successful models could potentially be duplicated by a person with a physical disability desiring to forge successful relationships on social media while still embracing the disability part of his or her identity and what approaches have produced undesirable results? By examining the decision-making process and experiences of persons with physical disabilities disclosing his or her disability online, a more accurate snapshot of the social media opportunities would be available. The following literature review seeks to investigate the variety of issue that intertwine in an understanding of the relationships between the disabled narrative, theories surrounding self-disclosure, and the role of social media in interpersonal connections.

### **Literature Review**

#### **Why Study Social Media Participation and Disclosure for Persons with Disabilities?**

**Disabled Narrative.** Within the paradigm of "being disabled" lie assumptions that persons with disabilities have no ability to lead an ordinary life or pursue goals considered typical in society. The disabled moniker means "not able," and this is the disabled narrative. This label is embedded within American culture through language surrounding disability. This disabled narrative is imposed upon persons with the disabilities by words attached to describe the kind of people they are "handicapped" (meaning cap in hand), "disabled" (meaning not able), and "crippled" (meaning damaged). This label or narrative is compounded for a person with a disability if he or she chooses to disclose the disability (Barnes, 1992). Schultz and Geremoth (1998) suggest that persons with disabilities are aware that they are often defined alongside their disabilities in the eyes of others: a situation that creates a fear of disclosure about the disability.

These perceived limitations are a major concern for persons with physical disabilities when disclosing information about their disabilities (Duggan, Bradshaw, and Altman, 2010). Schultz and Geremoth (1998) suggest that one of the first things that persons with disabilities find themselves having to do is transform their identities to pursue relationships and fit in with non-disabled people because of the stigma created by the disability narrative. In practice, this may be realized as a co-worker making sure she is seated before a meeting begins to hide the limp in her walk or a person with hearing limitations positioning himself close to the main speaker at an event. Medjesky (2008) suggests that an identity transformation, including an omission of the disability for persons with disabilities presents major problems from a self-esteem standpoint because disability is one important part of identity. Persons with disabilities ultimately desire acceptance of their disability as part of being a whole person so that they can join society.

Understanding the historical significance of social isolation experienced by persons with disabilities sheds light on why a new outlet to form relationships like social media presents a social opportunity for persons with disabilities. Ryan, Bajorek, Beaman, and Anas (2005) describe the concept of disability as one of the oppression through the language properties used to describe physical challenges. Ryan, Bajorek, Beaman, and Anas (2005, pg. 132) describe the often-used language of the disability narrative as a story of “*dependence and incompetence.*” This means they can’t do and don’t know how to do. According to Bajorek, Beaman, and Anas (2005) this misperception is enough for people to justify excluding persons with disabilities from society.

Because persons with disabilities have been stigmatized, isolated, and disregarded in society, they are disadvantaged in face-to-face social interactions, which limits opportunities to establish relationships (Braithwaite, 1999). The social discrimination this population faces

frequently includes a confusing combination of being expected to disclose information about the disability on demand by many members of the non-disabled population as an explanation of why they are not like everyone else and do not belong. This disclosure is repeatedly followed up by the rejection of the disability as a quality that a whole person can possess. This refusal to accept the disability as part of a whole person promotes isolation of this group from social belonging in a face-to-face setting (Thoreau, 2006). Goggin and Newell (2002) propose that this seclusion has often left persons with disabilities no outlet for creating friendships and relationships face-to-face. Chatterjee (2010) suggests that when persons with disabilities are not granted access to basic levels of belonging to society, they miss out on essential lessons for building social skills. Included in these missed lessons are key communication skills crucial to building a healthy self-esteem. A strong self-esteem is an important quality needed for persons with disabilities who grapple with the mental and physical challenges presented by the disability (Goggin & Newell, 2002).

**Merits of Disclosure for Persons with Disabilities.** Goddard and Torres (2006) suggest that many persons with disabilities struggle to communicate face-to-face without disclosing their disabilities. This is often because the disability is intertwined with identity as a part of the person's personal story. Thompson (1982) highlights vast benefits that are attained from disclosing personal information about an individual's disability, including the creation of more intimate and well-developed friendships, supportive allies, and acceptance from the non-disabled community.

Medjesky (2008) suggests that persons with disabilities should adopt their disabilities as only one part of their identities, but urges that a true struggle exists to include the disability without facing being stereotyped. If this is true, how can individuals with disabilities represent

this one aspect of their identities in a way that gains acceptance on social media? Braithwaite (1991) suggests that the disability narrative is shifting to a narrative that empowers persons with disabilities as having unique lenses in life with rich experiences to share. This is a shift away from the narrative of being “unable” that gives persons with disabilities the opportunity to be understood in a way that this population has not previously found possible. However, she shows concern about the implications of disclosing a disability, because the shift is far from being a change, and the stigma of being a “disabled person” that is unable to normally participate in society still exists.

Vidalli (2009) describes a similar example of the double-edged sword of disclosure for persons with disabilities. Her study of college recommendation letters written by persons with disabilities revealed a bias that does not always favor the disclosure. An example of this bias is the possibility of reviewers who question the capabilities of a person with disabilities being able to handle the demands and challenges of college life. She stresses that the disclosure of the disability actually enriches these letters in a way that is hard to accomplish without the shared information due to the unique experiential life lens of persons with disabilities. The struggle described in these letters reveals a wisdom well beyond the potential student’s age.

Obviously, complete transparency about disability is not suitable for every communication, but not having the ability to share a major aspect of self is problematic from an identity standpoint. The real issue lies with understanding how to weave the disclosure of the disability into a moment of conversation where it fits (Thompson, 1982). Persons with disability have less experience with disclosing personal information in the relationship-building process that the non-disabled population has due to ongoing issue with face-to-face social isolation. Also, this population has a fifty percent likelihood of not having the educational acumen to



communicate the disability in a positive light, making it difficult to pull off the experienced communication strategy of fitting the disability disclosure into casual conversation suggested for best results (Thoreau, 2006).

### **Rewards and Risks of Social Media Participation and Disclosure**

**Persons with Disabilities and Online Communication.** Persons with disabilities have been offered new opportunities to cultivate friendships and relationships on social media (Kaye, 2000). Coopman (2000) also describes the Internet as a vast opportunity that offers persons with disabilities a vehicle for connecting and conversing with diverse members of society. However, Coopman, like many other scholars, focuses the benefits on the accessibility of information for persons with disabilities rather than the acquisition of potential social networks (Coopman, 2000; Kaye, 2000; Chatterjee, 2010; Sourbati, 2011).

Walther (1996) highlights how computer-mediated communication has indeed bridged communication across a variety of populations and suggests that computer-mediated communication gives persons with disabilities a vehicle to escape social isolation that was simply not possible before. Social media also offers new opportunities for individuals to reinvent themselves and revise their personal images to attract potential relationships of all types (Turkle, 2011). Waters and Ackerman (2011) build on that by proposing that social media sites give persons with disabilities a multitude of ways to virtually meet a variety of individuals and pursue relationships and friendships without immediate judgment. However, Dobransky (2006) questions, whether the new access to online communication and societal connections through social media offerings has presented a more equal space for persons with disabilities to the non-disabled. He suggests that these new opportunities are actually creating a larger divide. The divide he describes is an entry into social interaction with little or no experience for persons with

disabilities due to previous exclusion and isolation, while many members of the non-disabled community have had extensive experience making friends and creating relationships face-to-face. This lack of experience makes the navigation of communication on social media an unequal experience. This presents a natural challenge for persons with disabilities, because they may not understand some of the social cues usually learned in face-to-face social communication.

Additionally, persons with disabilities have a lower probability of access to social media due to more socio-economic challenges (Dobransky, 2006). The economic challenges are real and significant. 53.1% of persons with disabilities lives below the poverty lines with 59% needing government assistance (Brault, 2012).

Very little data is present to clarify how persons with disabilities are actually using social tools on the Internet (Dobransky, 2006). Shpigelman & Gill (2014) expands on that idea by expressing concern over the lack of research available measuring the use of social media for persons with disabilities. While some data was presented suggesting persons with disabilities are connecting to a diverse population on social media, very little confirmation exists that would prove participation has made life better for persons with disabilities.

**Online Privacy.** Facebook is the most popular of all social media networking sites boasting a membership of over 100 million in North America alone (Elden, 2010). This social media site is an outlet to create and maintain social connections virtually with a very diverse group of members that has been a large contributing factor to changing the face of disclosing personal information from intimate and private settings to open and public settings. Despite record numbers of participants on Facebook, many concerns are highlighted by users. Some of the examples of privacy problems include access from employers, or unwanted voyeurs (Waters & Ackerman, 2011). Jones & Soltran (2005) suggest that even though privacy settings are

offered by Facebook, poor privacy control continues to be a problem. The reasons for this range from lack of understanding about consequences to what Jones & Archer (1976) described as blurred boundaries between how private and public is judged. Debatin, Lovejoy, Horn, and Hughes (2009) builds on those concerns describing Facebook as a hotbed of gossip where the disclosure of participants often produces unintended consequences such as bullying, or an individual losing a job because of inappropriate posts. The researchers explain how the creation of gossip can be one of this social media outlet's central roles. Gossip on this social media site often circulates around intentional and unintentional disclosures of personal information. Reasons for this could include that Facebook is a deeply intrusive social media platform dependent on relationships made from group members who form weak connections that lack an investment in a deeper relationship (Debatin, Lovejoy, Horn, and Hughes, 2009). Putnam (2000) describes these weak connections as "weak ties," which might provide useful information, but does not necessarily include adequate emotional support. Steinfield, Ellison, and Lampe (2008) state that social media sites like Facebook offer a multitude of opportunities to make these shallow connections, with fewer prospects of building deeper friendships. These weak connections could be problematic because a person with a disability could be frequently choosing to disclose information to an audience that may not be invested enough in the relationship to take a look beyond the surface of the disclosed disability. This could potentially open the person with disability up to negative consequences like ridicule or bullying instead of the desired emotional support (Shpigelman & Gill, 2014).

While multiple opportunities to present new, different, or nuanced identities exist for persons with disabilities on social media, this does not automatically provide a safe space for persons with disabilities to share details about their struggles with disabilities. Annabel, Goggin,

and Stienstra (2007) question, whether the stigma associated with the disability stereotype hinders the capability of persons with disabilities to gain a fair and equal experience to form meaningful, supportive relationships online. Shpigelman & Gill (2014) conducted research with surveys given to 52 respondents. Results of these surveys showed that persons with a variety of disability types can find relief from isolation and loneliness, but they do fear disclosing the disability on a social media account attached to their name because of the loose connections to social media friends. Putnam (2000) describes these loose connections as “weak ties” that are more of a group affiliation. A group affiliation does not always offer or guarantee the trust needed for disclosure of personal information (Granovetter, 1982).

While participation on the Internet does have the ability to help persons with disabilities develop deep friendships and meaningful social connections, the stigma associated with having a disability for persons with disabilities still exists online. Medjesky (2008) suggests that persons with disabilities might not experience a desired freedom from the disability. He stated that often persons with disabilities hide behind an identity that omits the disability on social media due to fear of a negative stereotype. He expresses concern that many non-disabled social media participants with negative biases about disabilities hide behind anonymity of his or her true identity to openly discriminate against and bully persons with disabilities.

While very little research on disability disclosure for persons with disabilities on social media exists, there is substantial research on the participation of the general public on social media. Petronio (2002) explains that understanding the differences of how disclosure of personal information is sent and received can provide best practices on how to share personal information. Tong, van der Heide, D’Angelo, & Schumacker (2012) describe an intricate evaluation process of social media participants that is placed on both textual and visual posts on Facebook. Both

these visual and textual posts are considered self-disclosures, which are often judged by social media friends equally, and together. Tong, van der Heide, Langwell, & Walther (2008) highlight concerns of affiliation signals, which are potential unintended social media disclosures. These signals can indicate a sense of popularity, non-popularity or desperation, and are derived from more than just textual messages. For example, images of an individual who never show the person with friends could be disclosing a lack of friends without words. This can be problematic if the discloser does not understand how these artifacts are potentially being judged by the receivers of these unintended messages.

### **Understanding how and when Personal Information is disclosed on Social Media**

**Communication Privacy Management Theory.** The balancing act of disclosure and privacy on social media has been frequently researched through the lens of communication privacy management theory (CPM) (Tyma, 2008; Child, Pearson & Petronio, 2008). Petronio's (2002) CPM theory proposes the need for boundary coordination by weighing the impact of co-owned information through boundary permeability, boundary linkage, and boundary ownership. Boundary permeability describes how the barriers keep the information private or leak the information. Boundary linkage describes how private information can be not only shared, but also intertwined in some way. Boundary ownership describes how co-owners of private information share in the responsibility of keeping the information private. When these elements of boundary coordination are not mutually understood by both the person disclosing and the individual being disclosed to, boundary turbulence is experienced.

Braithwaite (1991) suggests that communication privacy management opportunities for disclosure of disabled and non-disabled people are not created equally on social media. She suggests there is a lack of research that examines the impact (both positive and negative) on

persons with disabilities who publicly disclose their disabilities. The concern is that the privacy of persons with disabilities potentially needs tighter control and thicker boundaries due to the depth of disclosure necessary to articulate the disability, and cultural implications of the disabled narrative. Goldstein and Reinicker (1974) suggest that persons with disabilities are often caught in a situation where personal privacy boundaries are crossed because they are placed in a position when disclosing the disability encroaches on typically private themes around his or her well-being and body. Child, Pearson, and Petronio (2009) suggest that this kind of personal choice to disclose when faced with the judgments of an outside influence can be problematic. This provides an example of turbulence where information that is classically private becomes reluctantly co-shared.

CPM theorizes five privacy rule characteristics that individuals may use to develop regulations to govern privacy through social collaboration: Gender privacy, Contextual privacy, Cultural privacy, Motivational privacy, and Risk-Benefit. The gender privacy rule characteristic explains that privacy management rules established for male and female boundaries are often different. Contextual privacy rule characteristics are rules created around the sharing of information with the consideration of issues in the individual's social and physical environment. Cultural privacy rule characteristics are utilized where a discloser has formed an atmosphere to understand what elements of a disclosure can be shared within the culture. Motivational privacy rule characteristics describe criteria for an individual than is seeking to use the disclosure to create potential bonds. Risk-benefit criterion occurs when an individual considers the risks of disclosing information against the potential benefits of disclosure (Petronio, 2002).

Waters and Ackerman's (2011) research measures potential risks and benefits of disclosing on social media sites through the lens of Communication privacy management theory.

This study exhibits how all five characteristics of privacy rule criteria were found in disclosures on Facebook. This research reveals that a social media site possesses its own culture where many individuals have developed privacy rules and understand the difference between appropriate and inappropriate disclosures. Gender criteria come into play as men and women disclose on Facebook differently revealing dissimilar approaches to rule-making criteria that align with gender norms. Diverse motivations tend to shape and change the intensity of disclosure. The context of sharing information on Facebook changes the way information is shared on the site such as posts and likes. The risk-benefit criteria of the study reveal how more Facebook users tend to focus on the social benefits of social media sites rather than the risks from potential privacy issues they might incur.

**Social Penetration Theory.** Social Penetration theory provides a framework to understand how individuals use evolving layers of self-disclosure to develop closeness in relationships. Altman and Taylor (1973) describe these stages of revealing an individual personality during the relationship-development stage like peeling away layers of an onion. Each of these layers of self-disclosure are revealed as friendships become deeper. The layers are stages, including an orientation stage, exploratory affective stage, affective stage, stable stage, and depenetration stage. It is suggested that people always weigh the rewards and costs to produce the most desirable outcomes for disclosure while moving through these stages of uncovering their personalities.

The orientation stage of Altman and Taylor's (1973) onion reveals the getting-to-know-you basics like name, age, and birthplace. The exploratory affective stage dives into introductory topics that reveal guarded and carefully vetted opinions. The affective stage moves beyond the surface, taking an individual through a journey of a person's beliefs and biases to deeply private

information that strikes at the core of an individual's identity. This navigation to the identity core is monitored by an ongoing analysis of the risks and costs of doing so. The stable stage highlights shared beliefs and potential compromises. The depenetration stage is the time where a relationship begins to experience a failure, signaling an end to the disclosure process (Altman & Taylor, 1973).

Pennington (2008) offers an excellent example of how social penetration theory has been used to analyze the process of making friends on social media for the general population. The study includes a qualitative approach with both in-depth interviews and a focus group to evaluate how students move through personality stages on social media. In this study, he describes a change in what is considered personal information that is taking place as a result of participation on social media sites like Facebook. This change is disrupting how the layers of personality in social penetration theory are revealed. For example, the basic information can be accessed on the profile page without any communication at all in the getting-to-know-you phase. Ayers (1979) discusses how more questions are asked in the earlier stages, allowing individuals more prospects to develop friendships. These friendships produce more opportunities to communicate at a deeper level.

Participants in Pennington's (2008) study of relationship building on Facebook admit that if a Facebook profile shows anything that seems out of the ordinary, the potential for a relationship is altered. For persons with disabilities, the implications of this change are huge because the process of forming relationships could potentially be over before it ever begins if the disability is disclosed too early in the revealing process. While very little research exists to describe how persons with disabilities navigate the stages of social penetration theory on social



media, it would be beneficial to understand what stages persons with disabilities feel comfortable disclosing their disability in.

### **Gaps in the Literature**

Shpigelman & Gill (2014) propose that the research revealing how persons with disabilities use social media to disclose is vastly understudied. Annabel, Goggin, and Stienstra (2007) describe an important need to examine the different perspectives on how individuals have accessed and used online media to understand whether this vehicle is doing harm to persons with disabilities in the face of an ongoing “disabled” narrative that labels many as unable and thus not equal to the non-disabled population.

While some researchers have used communication privacy management theory to study disclosure on social media sites, and some researchers have studied social penetration theory to analyze social media participation of able-bodied participants, I found minimal research applying these theories to measure the risks and rewards of online disclosure for persons with physical disabilities. For example, what disclosure opportunities does social media present for persons with physical disabilities? How does one decide what information is safe to disclose, and who will be co-owners of that information? What does that process entail? Does it mirror social penetration theory? Or does it vary? If so, how? Why? What problems has the disclosure of personal information on social media sites presented for persons with physical disabilities? What are the risks? What, if any, are the perceived rewards? Closing the gap in research presents new opportunities for persons with physical disabilities to better understand the potential risks, rewards, and best practices in participation and disclosure of personal information on social media sites.

All of these ideas lead to the following research questions posed in this study:

RQ 1: Why, when and how do persons with physical disabilities disclose personal information about their physical disabilities on social media?

RQ 2: What are the perceived rewards and costs that persons with physical disabilities face when disclosing personal information about their physical disabilities on social media?

## **Methods**

### **Recruitment and Participants**

I interviewed 15 persons with physical disabilities for the study. The interviews ranged between 31-52 minutes and consisted of both a demographic form and a semi-structured interview script (see appendix). 11 females and 4 males participated in the study with pseudonyms provided to assure anonymity. All 15 study subjects were frequent participants on social media of at least 15 hours per week. The sample included research subjects with a variety of physical disabilities ranging from an assortment of different types of paralysis to missing limbs. Participants' ages ranged from 20 years old to 52 years old.

### **Data Collection**

The data was collected through 45 minute semi-structured interviews from an interview script previously approved by both the project advisor and Institutional Review Board (IRB). The script (see appendix D) includes 4 sections and 25 questions asking study participants about their experiences disclosing personal information about his or her disability. Informed consent is given by study participants when the Research Participant Informed Consent form (see appendix B) is signed. This details the scope and purpose of the study along with a demographics survey form (see appendix C) describing the details of each study subject's demographics information. Interviews with study participants were recorded in approved interview locations agreed upon by

interviewer, study subject, and advisor. Each recording accompanied by each set of research documents is safely stored in a secure file by the interviewer for a predetermined time under a pseudonym in accordance with IRB requirements.

### **Data Analysis**

The data from each one of the 15 recorded interviews conducted was transcribed with a pseudonym for each study subject to protect the identity of the individuals being studied in accordance with requirements from IRB.

Each transcript was analyzed and coded line by line in accordance with Strauss and Corbin's (1990) grounded theory framework. The analysis began with open coding to understand, label, categorize, and describe the narrative trends within the data. These narratives are key experiences from the study participants about experiences disclosing personal information about a disability when participating social media platforms. Each of these experiences was analyzed through the lens of social penetration theory to determine what stage(s) study subjects were potentially in when the disability was comfortably or uncomfortably disclosed. Communication privacy management theory provided a lens to evaluate how privacy rule characteristics guide the study participants in selecting an approach, and purpose for disability disclosure on social media. The qualitative data was also evaluated to understand why disclosures on social media might be withheld or altered based on negative experiences with privacy rule negotiations. This information is recounted completely from the point of view of the person(s) with a disability.

Using the axial coding procedure, the researcher grouped the open coding into categories. When identifying the categories, the researcher looked deeper in the open coding information on

how the subjects chose to participate on social media, when and how they disclosed personal information about their disability, how they contain that information, how they might describe a successful disclosure, and what they believe the key disclosures are that yielded negative results to determine the categories and sub-categories.

The categories and sub-categories of the axial coding process were captured under broader categories in the selective coding process to produce a theoretical framework on how, when and why persons with disabilities choose to disclose personal information about his or her disability on social media, and how that disclosure yielded positive or negative results (Strauss and Corbin, 1990).

## **Discussion**

Major findings from the study describe (1) three distinct approaches for disability disclosure, (2) the roles of age of discloser and age of the disability as key factors in approach selection, (3) four incentives, which serve as driving factors for disability disclosure, (4) the roles of age of discloser and age of disability as key factors in disclosure incentive, and (5) two responses to social media disclosure challenges.

### **Three Main Approaches to Social Media Disability Disclosure**

Every participant in the study expressed the importance of having an opportunity to share details of their personal experiences with their physical disabilities (disability disclosures) on a routine basis. Routine disclosures are described as at least once a month. The disability disclosure is a crucial part of their identities. However, the way the participants approach routine disability disclosures differs. Labels identified from the data reveal categories describing disability disclosure. The categories include coming out with the physical disability, sharing in a

safe place, and limiting the disclosure. These categories reveal three main approaches for disability disclosures. The *open comprehensive approach* includes routine full disability disclosure within an open social media audience mixed with both disabled and non-disabled populations. The *secure comprehensive approach* is a routine disability disclosure to a secure and private audience with carefully selected details of the disability disclosure to an audience of both disabled and non-disabled. The *limited disclosure approach* is a disability disclosure on social media with selected tidbits of the physical disability to safeguard identity.

**Open Comprehensive Disclosure Approach.** The act of “coming out” on social media and revealing personal details about a physical disability was practiced routinely by 5 of the 15 research participants. The *open comprehensive disclosure approach* is a proclamation of details of the physical disability on social media that often includes a visual and textual representation. This approach to disclosure involves blunt, uncensored, unapologetic, and upfront representations of the disability on an open social media platform. This *open comprehensive disclosure approach* often reveals complete details about the nature of the physical disability and is sometimes accompanied by humor or proclamations of strength.

Shelia, a 52-year-old brain aneurism survivor was left with multiple physical challenges, including paralysis from the waist down. She chooses not to censor her story on social media. She described how she was tempted to hide her disability at first on Facebook but stopped herself. She said: “At first I wanted to be somebody else on Facebook. I wanted to hide my disability, but I realized if I expect people to accept me, I have to learn to accept myself.” She regularly posts pictures in her wheelchair and openly shares the story of her struggles. She said, “the more I share, the easier it gets.”

One of the most prolific narrative examples provided in my research was by Tiffany, a 41-year-old female who lost the majority of her arm in a car accident. Tiffany sustained her disability in 2012, making her disability age 3 years old. She described the first picture she posted on social media after losing her arm in a car accident as her moment of “coming out” with the disability. She used the *open comprehensive disclosure approach* to help her face the loss of her arm and as a “power grab” of her disabled narrative. She described her *open comprehensive disclosure* by saying the following:

I posted a picture of me bowling with my arm clearly missing and I put a funny caption that said “Have you seen a one armed girl bowl?” At the time I was coming to grips with what had happened myself and I just kind of put it out there. I came out with my disability. This helped me accept what I was going to have to face from my friends and family who couldn’t relate to me anymore with a disability. I was surprised that the response was caring, and gave me the courage to not hide my physical disability.

Since the very first open comprehensive disclosure, Tiffany has disclosed routinely without reservation. However, she has pruned her Facebook account by removing friends and utilizing privacy settings like the non-search feature on Facebook over time to include only those social media friends who are more receptive to her disclosures.

Tiffany’s disability disclosure approach blurs the lines of both Altman and Taylor’s (1973) social penetration theory and Petronio’s (2002) communication privacy management theory. She shared comprehensive details of her physical disability to her social media audience at the very beginning of her disability. The boundary permeability of her approach to disclosure from Petronio’s (2002) communication privacy management theory is so high that open access at

the orientation stage from Altman and Taylor's (1973) social penetration theory was granted to almost everyone. She established co-ownership of her physical disability narrative by sharing her disability disclosure before anyone could draw other conclusions. She described this experience of disclosing as a new feeling of personal empowerment. She is the staunch supporter of the disability disclosure of the research sample.

The participants who chose this disclosure approach used it as a tool for accepting the disability themselves, demanding respect for the hardship they are facing, and weeding out those who might not be on board with the person they have become. Another common thread across participants who chose the *open comprehensive disclosure approach* is that they used it as a way of taking control of their disabled narrative from a non-disabled population that they believe may never accept them.

**Secure Comprehensive Disclosure Approach.** The *secure comprehensive approach* is the most utilized approach. 8 people preferred to disclose their disability at a secure social media venue without non-disabled. Participants 35 or younger whom have been disabled for 7 years or more used the *secure comprehensive disclosure approach* more frequently than the participants over 35. This group described prior and ongoing experiences of extreme face-to-face rejection and as a result approached social media involvement with caution. They participate on social media in a very guarded manner. The participants who used the *secure comprehensive approach* disclosed details about their physical disability in a controlled and gradual manner among non-disabled persons. However, they routinely disclose more comprehensive information among a secure population of persons with similar disabilities. They tend to describe their disclosure approach as safe, secure, or strategic. In the *secure comprehensive disclosure approach* privacy settings are often used to control the visibility of the posts with more comprehensive disability

disclosures from being displayed in the live feeds. The *secure comprehensive disclosure approach* often consists of an optimized environment. In these environments, persons with physical disabilities carefully manage their social media profile image portrayed to non-disabled friends by withholding defining details of their disabilities. They have outlets described as safe or secure on social media to share much more comprehensive information about their disability with disabled peers. One example of a *secure comprehensive disclosure approach* is the Facebook group, *Young Stroke Survivors*. In this social media group, the participants can disclose the physical disability in a closed, secure, and supportive social media environment that carefully monitors the activity of the users and eliminates abusers.

The *secure comprehensive disability approach* aligns with Petronio's (2002) cultural privacy criteria where the individual is inclined to either identify a secure space for open sharing. They often prune their existing social media space by eliminating non-supportive friends to create a culture for safe physical disability disclosure. The individuals make definite rules in either space, including the elimination of non-supporters through the defriending or blocking of social media friends who threaten the safety of the forum culture. Michelle and Eileen, provide excellent examples of how they use the *secure comprehensive disability approach*.

Michelle revealed that she would make intentionally vague posts on her Facebook page with a mixed audience of disabled and non-disabled, sharing few details about her life, and then would answer questions about those details through social media chat. She said; "*I never answer direct questions about my disability as comments on my profile. I have never felt comfortable disclosing many details of my physical disability with people who aren't like me.*" After years of carefully managing the information about her disability, she was able to identify peers she could



safely disclose to. She described this experience of carefully guarding her information and finding an audience that she could share her disability disclosures to with this statement:

I was very cynical and guarded for a long time on social media because my experiences with people who are not like me had been so hurtful. It seemed that even on Facebook people with no disabilities were always the ones who wanted more information. Usually they were looking for ways to make fun of me....you just don't understand how scared I was to lose the only friends I have ever been able to make. It took me years to completely be who I really am on social media because I had to learn who was trustworthy.

Michelle described a gradual process where she left intentional clues to her disability to audience mixed with disabled and non-disabled over a period of years. She did fully disclose her on social media until she eliminated most of the non-disabled population and all the non-supportive friends from her Facebook profile. Michelle exemplified Petronio's (2002) culture privacy criteria by only disclosing details of her disability more frequently once she had created a more secure social media culture. She described her experience as *"more useful and enjoyable"* among supportive peers within that culture.

Eileen is a 49-year-old female with a physical disability that limits movement in half of her body for the last seven years. She is an example of an individual who embraces full disclosure of her disability on social media once she feels secure among a group of her disabled peers. She found herself ready to establish control over the disability narrative on social media seven years after sustaining the disability, but still lacked the trust necessary within the non-disabled social media public. After a substantial search through social media for peers, she found a social media group on Facebook that promoted support for individuals who had sustained

disabilities with paralysis. She stated that once she found a peer group, she felt safe to talk about her experience. As an example of this, she recalled an incident in which she discussed her pride of how far she had come in accepting her disability and overcoming adversity in a Facebook group post. In her *secure comprehensive disclosure approach*, she stated that she posted the following:

Today is the seventh-year anniversary of my accident and in June I turn 29. In that accident I sustained a brain injury leaving me unable to speak clearly or use the left side of my body. While I still have severe paralysis of the left side and some issues with speaking, I am otherwise luckily healthy.

Eileen shared that the above post received 13 comments, and 56 likes. She explained how she has 58 Facebook friends and no supportive face-to-face friend. Just the thought of having 58 people willing to be her friend gave her courage she didn't know she possessed. However, to have 56 of them show some sort of support by responding in her new secure environment with a "like" or a comment empowered her to stop hiding or making excuses or apologies for who she really is.

She admitted that finding support on social media is not a perfect process. Sometimes people can be both intentionally and unintentionally insensitive and cruel. Nevertheless, Eileen insists that social media has provided the first tangible emotional support for her disability-related issues and has given her the courage to seek support through disclosure.

**Limited Disclosure Approach.** The *limited disclosure approach* was practiced by three of the research participants. This group self-identified as "shy," "reserved," and "introverted." The *limited disclosure approach* consists of only releasing information about the disability

through secretive channels such as private chat. Sometimes they disclosed through a strategic photo revealing partial details of the disability without explanatory text. All three individuals described their disclosure as limited, select, or partial. They choose a *limited disclosure approach* for fear of bullying, rejection, or lack of personal safety. All three are in the youngest age bracket of the research sample, ranging from 25 to 33 years old with long-term disabilities sustained at a young age.

Matt, a 27-year-old individual with a physical disability, outlined a 20-year history of face-to-face rejection and ridicule. He described social media as a second chance to distance himself from the social rejection that he had faced in the past. Because of this intense desire to avoid rejection, he has used disclosure in a more limited and strategic way, choosing to only disclose details on chat once a relationship has reached an advanced stage. This approach is similar to Altman and Taylor's (1973) stable stage where individuals have established shared interests and biases. He believed this rule tends to provide a safer environment for him that includes less rejection. Within the confines of the *limited disclosure approach*, individuals were constantly looking forward to minimizing potential risk and rejection, which is in line with Petronio's (2002) risk-benefit privacy criteria.

John, age 25 was born with Muscular Dystrophy and is permanently wheel-chair bound. John estimates that he has had to disclose intimate details of his physical disability with over 90% of the people he has met in the past 25 years in face-to-face settings. Not only has he found this practice exhausting and discouraging, but it also regularly has placed him at a disadvantage when making friends. John described how he never gets an opportunity to establish common ground in a potential relationship: "I am forced to share too much too soon." Petronio's (2002) concept of boundary turbulence explains how individuals experience negative effects from

disclosure when the boundary permeability is too high. In John's case, intimate details of his physical disability have often been disclosed upon meeting people face-to-face, creating an awkward tension between John and the other person because co-ownership occurs before a relationship is even formed. This early co-ownership usually positions John and potential friends at the end of a relationship in the de-penetration stage of Altman and Taylor's (1973) relationship development instead of the beginning, which does not result in friendship.

His narrative was full of rejection and isolation until he described his recent journey on social media. Because John has been skeptical about sharing too soon, he has chosen to disclose limited information about his physical disability to a select audience. He has used the narrative of his disability to deepen relationships in lieu of making a statement or proclamation, and this has helped him to establish a group of friends for the first time.

### **Disability Disclosure Approach Patterns of Age and Physical Disability Age on Social Media**

The age of the individual, and the age of the physical disability (physical disability age) emerged as factors in the disability disclosure approach. *Table 1* exhibits that individuals are more likely to choose an *open comprehensive disclosure approach* with a physical disability age of 1-to-5 years. The narratives suggest that these individuals have the least experience with face-to-face rejection because the physical disability is recent; therefore. Thus, they have the least fear of rejection on social media. Most of the study subjects that chose a *secure comprehensive disclosure* approach had a disability age of the 5-to-10-years. This data accompanied by narrative examples suggests that persons with disabilities ranging from 5-to-10 years chose the *secure comprehensive disclosure* approach because of skepticism based upon prior experiences over the

life of the physical disability with face-to-face rejection. All three limited disclosures came from individuals with long-term disabilities in the 10-to-20 year range. This data suggests a potentially a rejection point of no return beyond the 10 year disability age. Individuals who take a *limited disclosure approach* have a diminished trust in how their disabilities will be received and supported on social media. In most cases, they lack the confidence to face potential rejection.

Research participants from 19-35 years of age exclusively chose the *secure comprehensive disclosure approach* and the limited disclosure approach. This suggests that younger individuals tend to trust social media less as a place to disclose their physical disability. Research participants from 35-49 years of age most frequently disclosed comprehensive details to an open audience of disabled and non-disabled people, exhibiting how maturity plays a significant part in the demand for acceptance for the disability. Research participants from 50-69 that same trend, further demonstrating the significance of maturity in how secure a person feels disclosing details of his or her physical disability among an open social media population.

The analysis of the disability age reveals that disclosure approaches on social media are selected based upon years of exposure to negative face-to-face experiences. The participants age analysis suggests that acceptance of a disability becomes easier with advanced age of the individual. *Table 1* exhibits that age played a significant role in both how and when persons with physical disabilities decided to approach disability disclosure on social media.

Table 1. Impact of Age and Disability Age on Disclosure Approach Selection

Age of disability	19–35 years old	35–49 years old	50–69 years old
1–5 years	secure comprehensive (20)	open comprehensive (41) open comprehensive (43) open comprehensive (45)	open comprehensive (52) open comprehensive (52)
5–10 years	secure comprehensive (21) secure comprehensive (27) secure comprehensive (30) secure comprehensive (31)	secure comprehensive (44)	secure comprehensive (50)
10–20 years	limited disclosure (27) limited disclosure (25) limited disclosure (33)	secure comprehensive (49)	

#### Four Incentives for Social Media Disability Disclosure

In Petronio's (2002) communication privacy management theory, individuals utilize one or more of five privacy rule characteristics to manage the privacy of disability disclosures. The narratives expressed how the management of privacy when sharing the disability is a guiding factor for how and when they disclose. The qualitative data reveals that disabilities are disclosed with an emphasis on benefits or incentives that might be gained from the disclosure. The privacy of the disability disclosure is carefully weighed and measured to potential reduce risk. The labels for why persons with disabilities choose to disclose a disability disclosure on social media include relationship-development, inclusion, and motivation, control disability story, life skills, survival, and information. Four main incentives capture the categories describing strategic disability disclosure on social media: *relationship-building incentive*, *narrative control incentive*, *optimistic outlook incentive*, and *life skills incentive*. These incentives are fundamentally about

the potential reward they hope to gain, and the rules that govern the information release. Social media is their medium of choice for disability disclosure because they can control the information.

**Relationship-Building Incentive.** Some individual's disclosure information on social media to enhance the relationship-building process. The motivational privacy rule criteria of Petronio's (2002) communication privacy management theory suggest that individuals believe that privacy risks might be justified if the disclosure might create personal bonds with other people. This could explain why persons with physical disabilities disclose their disabilities might choose to disclose on social media. Every research participant in the study described social media as a much better alternative for relationship development for persons with disabilities to face-to-face social interaction. They each described extreme isolation and rejection from the non-disabled in face-to-face interaction, and an escape from that isolation on social media.

Tom, is a 50-year-old person with a physical disability explained that a social media platform such as Facebook provides an optimized environment for controlling and using disability disclosure to establish and deepen relationships. Tom's face-to-face opportunities to make friends were limited. His obvious right-side paralysis creates a premature disclosure. He described how his physical disability in face-to-face settings had traditionally blocked the practice of forming relationships because he was often forced to disclose deep personal details about his evident paralysis too soon in a relationship and often made the other person uncomfortable which prevented a potential friendship. He described how social media allowed him to pace the disclosure and use the information as a way to confide in a friend when ready.

Miriam, a 31-year-old woman with extreme scoliosis, described a “brand new world as I entered the Facebook group for stroke victims for the first time six years ago.” Within days of entering social media, she had met and interacted with dozens of new friends after 11 years of face-to-face rejection from the non-disabled population. She described her disability as being “no big deal” on the social media group for the disabled and gushed about how “she felt like part of a new culture,” while her disability in face-to-face social interaction was the only part of her that was noticed, or focused on. She had never had an opportunity to use disclosure to nuance and deepen relationships. She spoke about how disclosing her physical disability on social media platforms like the disability group on Facebook included her as a part of the group culture. This was new because the disclosures actually created new friends. For the first time ever, the disclosure was empowering and endearing to her new social media disability peers instead of revolting and disgusting to her non-disabled peers. Miriam said, “It is like, for the first time in my life, I was able to use the information about my disability to get closer to a friend instead of scare them off.”

Matt, a 27-year-old individual with paralysis, described how social media helped him use disclosure to develop relationships at a more advantageous pace. He stated:

On Facebook, I felt like I have legs that work, and for the first time in my life, I can get past my disability being the first thing I have to discuss with everybody I meet. People who are not disabled don't understand how lucky they are, because they do not have to tell everybody everything about their shortcomings in the first fifteen minutes after meeting them. I get to use those little details to enhance friendship. On Facebook I get to wait to talk about my disability to become closer to friends instead of scaring people away.



**Narrative Control Incentive.** The *narrative control incentive* is an extension of the *relationship-building incentive*. Seven of the research participants described the desire to control information around their disability, which extends beyond the release of the information to deepen relationships. In the *narrative control incentive*, individuals often use Petronio's (2002) risk-benefit privacy rule characteristic to weigh potential risks as they carefully crafted and controlled their own disability narrative.

Arya is a 21-year-old who has had a physical paralysis called dystonia and spasticity for the last six years. Dystonia and spasticity are very visible physical disabilities, which consist of paralysis that includes overreactions of muscles, and spatial relations issues. She described how many facts around her disability are embarrassing to her and sometimes leaves her feeling powerless. Arya explained how she had always longed for a relationship with people, and a self-identity that does not involve detailed descriptions of her daily needs. Arya also described her constant negative issues with self-esteem. She described how social media allow her to share the information she chooses and completely leave out the embarrassing details, such as the fact that she has to wear Depends undergarments. She also mentioned how leaving out those details gives her a break from the self-loathing she often faces because of her inability to escape her situation in face-to-face settings. This differs from the *relationship-building incentive* because Arya uses the privacy settings of withholding information about her disability to enhance relationship-building skills, but she is actually extending the purpose to control her narrative to enhance her personal identity. She explained that her Facebook profile does not automatically share details she finds embarrassing like lack of bladder control, or that she often loses muscle control. She sums this idea up by saying; "My disability is hard to escape sometimes. When I look at my Facebook page, I am free from the person I have to be every day."

Danielle, a 52-year-old teacher with limited motor function in her legs, described an excruciatingly painful experience of social isolation experienced face-to-face. She speculated that the narrative of her disabilities is so well known at her workplace. The majority of her peers at her work avoid her daily. She described feelings of anguish because she has no control over her identity. She mentioned that she had always been such a positive person before the accident two years ago: she described herself as an open book with a positive outlook. When attending a support group, she told her story of isolation and negativity as well as her deep desire to take control of her story to convey her true personality. The support group facilitator suggested that she try to connect with other people with similar disabilities on social media. Danielle said:

It was a godsend that...you know...that changed my life. I was finally able to make friends with a group of people that understood what I was going through and what I was facing. You see the hardest part of being disabled is that everyone assumes that you are a miserable person. I am not miserable. It is such an out-of-control feeling when someone else gets to decide how I feel. Finding this group of people that are completely comfortable talking about the challenges of a disability while still being happy to be alive taught me how to control my own disabled story better.

In the *narrative control incentive*, the research participants extend the concept of managing privacy to eliminate risks in building relationships. They are also managing risks associated with how they self-identify. They are potentially crafting their narratives and disclosing to not only build relationships with others, but redefining how they see themselves.

**Optimistic Outlook Incentive.** 14 of the 15 participants described an eventual migration to disabled culture hidden in social media groups for persons with disabilities on Facebook.

There are hundreds of these groups that serve multiple purposes. A vast majority of these groups are focused on optimism for persons with physical disabilities under some of the most challenging circumstances. Data from the interviews suggested that once the majority of persons with disabilities assimilate in these private and hidden groups on social media, they establish strong channels of support that include resources, and other daily rituals of encouragement. The optimistic outlook incentive suggests that individuals utilize the contextual, cultural, and motivational rule characteristics of Petronio's (2002) communication privacy management theory: they have set rules that place them in an environment with a disability culture disclosing information related to a particular context to empower and encourage those with disabilities.

Lexa, a 45-year-old amputee, explained how she uses social media participation to stay optimistic and communicate in a positive way about the quality of life ahead of her. She described how the inspirational stories of her peers within the Facebook disability group empowered her to believe that life is not over. She stated:

The group reminds me that I am not alone; that many people are going through the same struggles. Sometimes the testimonials give me the courage to get out of my bed, put my legs on, and try to participate in life again. I have learned that it helps to talk about my good days and my bad days in a positive and healthy way.

Annie, a 44-year-old female with a disability from a back injury which has left her with limited mobility described how her disability led her to feel like life was over. Since the accident 8 years ago, her friends deserted her, she lost her job, and she felt like she had very little to hope for the future. The discovery of a safe disability friends group on Facebook has changed her outlook. She said; "I needed a place to feel normal. My disability is minor compared to most

people, and it puts things in perspective.” She described how she wakes up each morning with a new sense of excitement as she reads positive stories of how others are overcoming their challenges. This inspires her to overcome challenges and share the results.

A common trend between each study participant is a fierce desire to either be or become positive and optimistic about his or her future with a physical disability. They understand the importance of sharing the physical disability in a safe environment to gain a positive outlook. This *optimistic outlook incentive* has a strong foundation in the contextual privacy rule characteristic of communication privacy management theory, because these individuals choose disclosure based on an environment that considers the issues in an individual’s social and physical setting (Petronio, 2002).

**Life Skills Incentive.** Hundreds of private groups on social media exist for intentional disability culture uses, but the most prevalent are like a swap meet for advice and practical disability strategies. With the *life skills incentive*, individuals practice all five of Petronio’s (2002) privacy rule characteristics. These social media groups provide access to information on how acquire life skills for living in the world with a physical disability. This life skills type of information is at the heart of disability culture on social media. The context of such groups is innately crafted for the physically disabled and is informational in nature. Users frequently warn potential trouble-makers to keep the risk at bay, and groups are available to accommodate gender-related issues like the erectile dysfunction that Jason described. Examples of the life skills content include new surgery procedures available for the disabled, how to ace a job interview with a disability, the best place to get leg braces, therapists to avoid, and many other issues that might be applicable to disability culture. These groups often available in Facebook encourage individuals to post the challenges they are facing so the group can help work out a

solution. The rules around the disclosure tend to be most frequently governed according to gender, culture, and context.

Annie is a 44-year-old female with a 7 year physical disability. A stroke has left Annie with limited function in her hands. She explained how she uses social media to gain a first-hand account of new medical procedures for her condition. She uses the disclosure of her disability difficulties to identify others who might have a similar disability. She explained to me how recently she found information on a robot hand that exercises fingers and helps restore hand function. She said that her Facebook disability group is “a way to get opinions from people who are actually going through the same thing I am going through.”

Michelle, a 30-year-old female with a 20-year-old disability, explained how incredibly useful social media has been and described how her intentional uses of social media have shifted from the quest for relationships to the quest for information by using the Facebook physical disability groups to gain life skills.. She explained how living with only one functional arm and no one to talk to about how to work around it has been the largest problem she has faced. It had taken some time to trust that the group was there to help, but she has learned that being honest about daily struggles has unearthed solutions, such as how to put toothpaste on a toothbrush, how to style her hair, and how to cook with one arm. She said:

Since the accident, all I ever wanted was a group of friends that I could trust to understand when I am having problems...someone to care enough to help me find an easier way to live. There is nothing more lonely than feeling like you are the only one with this disability in the world. Finding this group that I could trust enough with my

roughest days, and have them care enough to help me has made my life happier. My new friends have taught skills to handle problems my disability has created.

Jason, a 43-year-old and four-year-victim of traumatic brain injury with multiple paralysis issues, described a situation in which his face-to-face friends tended to be involved in his daily care, such as taking him to the doctor or helping him care for himself. In many ways, he has been reluctantly dependent on them. He suggested that the depth of information he has given them about the circumstances of his disability for this voluntary care has made it impossible for those relationships to ever feel dynamic or empowered for him. The lack of privacy has left him feeling powerless, helpless, and weak. He described the worst part as being unable to relate his problems to his friends without disabilities or gain support for the issues that he is facing. An example he provided was when his best friend took him to the doctor, and he brought up issues he was having with erectile dysfunction. He explained how his friend could not understand why he even cared since he had so many issues with paralysis. Jason described how a group for persons who suffered a traumatic brain injury on Facebook changed everything for him. He was able to connect with individuals who were also facing embarrassing problems such as erectile dysfunction and who had friends who could not understand why they cared. These connections led to support, advice, and recommendations. He stated:

This is exactly what I needed and what my friends with no disabilities could not give me. I needed someone to talk to, that could understand my problem and suggest help from their own experience. I also wanted to feel some level of being normal to someone. I wanted to feel human again.

It is important to note that persons with physical disabilities may choose one or more of these incentives. The data suggest that they often enter social media and disclose their disabilities based on one incentive and expand the use over time.

### **Disclosure Incentives According to Age and Physical Disability Age on Social Media**

Every participant used at least two of the four main incentives for social media disability disclosure. Evaluating these disclosure incentives by age of individual and disability age sheds light on how these factors influence the incentive choice. The most utilized incentive is the *optimistic outlook incentive*, and the least used is the *narrative control incentive*.

The 19-35 age group most frequently chooses the *optimistic outlook incentive* capturing 50% of the group utilizing this incentive. The 35-49 group most frequently chose the *relationship-building incentive*, and the 50-69 group was the lowest user of the *narrative control incentive*.

The 1-5 year age of disability group exhibits a domination of the optimistic outlook and relationship-building incentive, with only one participant choosing the Life Skills Incentive. The 5-10 year age of disability demographic was the most balanced group choosing *optimistic outlook incentive*, *relationship-building incentive*, and *life skills incentive* equally. The 10-20 year age of disability group represented 5 of 7 individuals who described the *narrative control incentive* as a reason for social media disability disclosure.

The utilization of the optimistic outlook incentive on social media reveals the willingness of persons with disabilities to trade disclosure for hope within every age of individual, and age of disability category. The *narrative control incentive* data points to two trends: one that suggests that individuals with longer disability ages who choose a *limited disclosure approach* tend to use

narrative control to guard private information more closely, and the other trend aligns with individuals who choose the open *comprehensive disclosure approach* to assure narrative accuracy by disclosing full details to a mixed social media audience. This is consistent with the identification of this group as individuals who chose the *limited disclosure approach* and could be a result of face-to-face rejections. Participants between the ages of 27 and 44 with a disability age of 5-10 years tend to more frequently use disability disclosure to gain more information that makes life with a disability easier.



Table 2: Impact of Age and Physical Disability Age on Social Media Disclosure Incentive Selection.

Age of disability	19-35 years old	35-49 years	50-69 years old
1-5 years	life skills incentive (20) optimistic outlook incentive(20) relationship-building incentive(20)	optimistic outlook incentive (41) relationship-building incentive(41) optimistic outlook incentive (43) Relationship-Building Incentive(43) narrative control incentive(43) optimistic outlook incentive(45) relationship-building incentive(45) narrative control incentive(45)	optimistic outlook incentive (52) relationship-building incentive(52) optimistic outlook incentive (52) narrative control incentive (52) relationship-building incentive(52)
5-10 years	optimistic outlook incentive (21) narrative control incentive (21) optimistic outlook incentive (27) life skills incentive (27) optimistic outlook incentive (30) life skills incentive (30) optimistic outlook incentive (31) relationship-building incentive (31)	optimistic outlook incentive (44) relationship-building incentive(44) life skills incentive (44)	optimistic outlook incentive (50) relationship-building incentive(50) life skills incentive (50)
10-20 years	life skills incentive (30) narrative control incentive (30) life skills incentive (27) narrative control incentive (27) optimistic outlook incentive(27) life skills incentive (25) optimistic outlook incentive(25) narrative control Incentive(25) life skills incentive (33) narrative control incentive (33)	optimistic outlook incentive (49) narrative Control incentive (49)	

## Two Responses to Social Media Physical Disability Disclosure Challenges

The reviewed literature suggests that one of the new opportunities for persons with disabilities on social media is the ability to form potential relationships with the non-disabled. All 15 research participants described an initial attempt to form relationships with the non-disabled but alluded to an eventual withdrawal from the non-disabled in different degrees. Two types of withdrawals were described with the least utilized action being a *complete withdrawal* and the most significant action being a *partial withdrawal*. When making these choices, persons with physical disabilities are using rules associated with Petronio's (2002) concepts of both the risk-benefit and cultural privacy rule characteristics: they are always measuring the risks and making adjustments to enhance a safer culture for disclosure.

**Complete Withdrawal.** The *complete withdrawal* is a total purge of the non-disabled from the social media profile, excluding family and church members in some cases. Three of the 15 study subjects cited irreconcilable differences with the non-disabled on social media. They described incidents of non-support, bullying, and intentional and unintentional exclusion.

Social media can be a sad reminder for persons with physical disabilities of the non-disabled world of which they are no longer a part. John, a 20-year-old stroke victim suffering from diminished motor skills for the last three years, stated:

You have no clue how left out you are until you get to see what everybody else has not invited you too. The constant pictures and party posts makes me sad because I used to be right in the thick of it, and now I am always left out. It is kind of like I died. I am only 20, and it was like I get to see how over my life is. It was easier for me to walk away and find

new friends like me. I did not want them to see how I was no longer like them so it was easier to cut them out of my life.

For John, his rule was to cut the non-disabled out of his life, so he could not unintentionally disclose how he was now different from his prior peers. In his mind, the risk of unintentionally disclosing on social media was far worse than any reward he might have gained from the association. His complete withdrawal was based on the potential risk, which falls under Petronio's (2002) concept of risk-benefit privacy characteristics: he clearly weighed potential risks and cultural privacy characteristics when disclosing because he prefers a safe environment with other disabled peers for intentional or unintentional disclosure.

Sarah, a 44-year-old female with multiple sclerosis, described severe cases of bullying from old friends and some family members that were on her Facebook page. She described how they used her Facebook posts to taunt her in face-to-face settings, and the encounters intensified her misery. Eventually, she purged her Facebook profile of all non-disabled persons and saved her social media participation for her new friends in the disabled groups. She described how this intense desire to belong to the non-disabled world was standing in the way of happiness in her new world. By eliminating the non-disabled from her profile, she utilized both a risk-benefit and culture privacy rule characteristic from Petronio's (2002) communication privacy management theory. In doing so, she was able to openly discuss her physical disability in a supportive culture with low risk.

**Partial Withdrawal.** *Partial withdrawal* was the most common action among research participants. 12 out of the 15 research subjects described an eventual partial withdrawal from social media participation with the non-disabled and an increased social media participation with

disabled peers. Of those 12, 10 participants established rules to govern who would be allowed to remain a Facebook friend, including the requirement of emotional support in the form of likes and comments on “bad day” posts. Any negative comments or sign of bullying resulted in a block for the profile unless the individual was truly apologetic. This was a clear example of the risk-benefit privacy rule characteristic because the partial withdrawals on social media were based upon potential risks.

### **Conclusion**

The literature reviewed from researchers such as Thoreau (2006) aligned seamlessly with my study: the narratives uncovered how persons with disabilities have indeed suffered greatly from both face-to-face rejection and isolation. Social media has offered different forms of relief from these challenges. As suggested by Medjesky (2008), my research substantiated that persons with physical disabilities have a strong desire and need to adopt and share their disability narrative as a part of their personality. One of the departures from possible opportunities discussed within the literature is the limited successful social connection with the non-disabled on social media. My research suggests that these opportunities are not as robust as some previous researchers like Coopman (2000) hoped. Annabel, Goggin, and Stienstra’s (2007) that people with physical disabilities might still face rejection from non-disabled the non-disabled online seems to be supported by my research.

Both Petronio’s (2002) communication privacy management theory and Altman and Taylor’s (1973) social penetration theory offered an excellent lens to understand how previous rejection and isolation often drive the decisions as to how, why, and when persons with physical

disabilities choose to disclose their disabilities on social media and how those disclosures have both rewarded and challenged this population.

One of the greatest revelations of the research was the discovery of how evolved social media disability culture has become and how seamlessly Petronio's (2002) concept of the culture privacy rule characteristic aligns with the choice to develop a culture that supports the disclosure activity. Hundreds of private groups for persons with a variety of physical disabilities on Facebook exist with thousands of very active participants socializing and sharing information about their physical disabilities. The Facebook groups uncovered during the study narratives have detailed how social media is a beacon of hope for many who lost faith in the possibilities of social activity.

The information pipeline to support this isolated population highlights one of the most organized activities on social media for persons with physical disabilities. They are aching for information ranging from how to get toothpaste on your toothbrush with no hands, to what might be happening when your left side goes completely numb, to how to get a job. Although other researchers (Chatterjee, 2010, Coopman, 2000; Kaye, 2000; Sourbati, 2011) lauded the most exciting new opportunities online as access to information, I did not expect that to be one of the most prolific opportunities detailed in the narratives of my research participants on social media. They want relationships, but they also want accurate information from others like them whom they trust. They are looking for ways to make life easier, improve their quality of life, and to be the best they are capable of being. Even when finding possible non-disabled relationships, they seek each other for information because they trust others in their culture to understand their perspective. In the search for information, thousands of physical disability disclosures are posted every week in these groups across different social media platforms. *Young Stroke Survivors*, and

*Disabled Friends for the Disabled* on Facebook, as well as *The Brain Injury Radio Network* on Blogtalkradio.com are just a few examples of the social media opportunities that exist for persons with physical disabilities. This suggests that they are not looking for an idealized version of themselves, but mostly are looking for acceptance and information from those who accept them. In my own experience participating on social media on my Facebook profile with both the non-disabled and persons with physical disabilities within these groups, I have seen much more disclosure within the culture on the disability Facebook groups than in interaction with the non-disabled population.

Lastly, very little research exists describing the experiences of persons with physical disabilities sharing their disability disclosure on social media, and the sample from this research is relatively small potentially limiting the result. A beneficial solution could be to extend this research to a larger group and capture any differences from a smaller sample to a larger research sample. An example of the limitations of the small sample can be found among the results from *Table One: Impact of Age and Disability Age on Disclosure Approach Selection*. This data presented a useful table to measure the impact that the age of persons with disability, and the age of the disability have on an individual's capability of feeling comfortable sharing disability disclosures on social media. However, one or fewer participants fit in 5 of the 9 categories in the table exhibiting a need for more research participants in a future study of a different design.

#### **Author Note**

While I do not have a conflict of interest in this study, the research was inspired by my 30-year-old daughter who has a physical disability sustained at age 6. Her disability will be 25 years old on October 1<sup>st</sup>, 2015. My daughter did not participate in the study, but I have observed her

experience similar experiences of isolation that participants described throughout this study, and I have also witnessed examples of her good and bad experiences on social media. I learned a great deal from the results about misconceptions I had including my assumptions that social media lacked a welcoming place for persons with physical disabilities. I had previously assumed there was no place for this population to safely disclose information about their disability on social media. An example would be that as a result of this study my daughter is now able to find social media friends and useful information on how to live in this world with a disability within the secret disability groups hidden just beneath the surface of Facebook.

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## Appendices

### Appendix A: IRB Approval



December 2, 2014

June Furr  
Knight School of Communication

#### **RESEARCH PROTOCOL APPROVAL, IRB FILE # 11-14-KSOC-0114**

The Institutional Review Board reviewed your research request:

*The impact of social media disclosure on persons with physical disabilities*

Your protocol (11-16-2014); Informed consent form, Focus group questions, Questionnaire; and Recruitment materials were approved for use within the facilities of Queens University of Charlotte. The Board determined your study poses minimal risk to subjects and meets the criteria for an exempt application. If you plan to use the protocol outside of Queens University of Charlotte, you may need to submit it to the IRB at that institution for approval.

**This approval expires one year minus one day from date above.** Before your study expires, you must submit a notice of completion or a request for extension. You are required to report any changes to the research study to the IRB for approval prior to implementation. This form can be found on the IRB site on MyQueens and should be sent to [irb@queens.edu](mailto:irb@queens.edu).

If we can be of further assistance, please do not hesitate to contact us. Please use the IRB file number when referencing your case.

Sincerely,

*Laree Schoolmeesters*

Laree Schoolmeesters, PhD, RN, CNL  
Chair, IRB

## Appendix B: Consent Form

### RESEARCH PARTICIPANT INFORMED CONSENT FORM

The Impact of Social Media Disclosure on Persons with Disabilities



June Furr, Graduate Student at the Knight School of Communication, Queens University of Charlotte

#### Purpose of Research

You have been asked to participate in a research study being conducted that has been reviewed by the Institutional Review Board (IRB) for Research with Human Subjects. Our goal is to learn more about disclosure opportunities and challenges on social media for persons with physical disabilities. Interviews are one of the best ways we have of learning if, when, and how you disclose your personal information to individuals or groups on computer-mediated forms of communication. Your participation in this interview is important and will contribute to a better understanding of the factors that determine advantages and disadvantages of using computer-mediated communication to disclose for persons with disabilities.

#### Investigators

This study is being conducted by June B. Furr from Queens University of Charlotte. I am a graduate student from the Knight School of Communication at Queens University of Charlotte. I will be responsible for conducting the interviews. I have been certified by the Collaborative Institutional Training Initiative (CITI).

#### Description of Participation

If you agree to participate in this research, we will ask you a variety of questions. The interview will be audio-taped for future data analysis.

Duration of Participation The interview session will take approximately 45 minutes.

Risks to the Individual The risks for participating in this study are no more than you would encounter in everyday life.

Anonymity and Confidentiality will be strictly maintained, and all data will be stored and reported anonymously. Your personal identity and any identifying workplace information will not be used or revealed in neither the analysis of

interview data nor the reporting of results. All personal information collected by the researchers will be kept confidential and not linked to your final data.

Voluntary Statement

Participation is voluntary and refusal to participate will involve no penalty or loss of benefits to which you, the subject, are otherwise entitled. You may discontinue participation **at any time** and elect to not answer any questions asked in the interview

Fair Treatment and Respect:

As a graduate student at Queens University of Charlotte, I want to make sure that you are treated in a fair and respectful manner. Contact the University's Institutional review Board at 704.688.2743 if you have any questions about how you have been treated as a study participant. If you have any questions about the project, please contact June Furr @ 704-807-8375 or june.furr@queens.edu

Participant Consent:

I have read the information in this consent form. I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction. I am at least 18 years of age, and I agree to participate in this research project. I understand that I am entitled to receive a copy of this form after it has been signed by me and the researcher.

\_\_\_\_\_  
Participant Name  
DATE  
(PLEASE PRINT)

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Researcher Signature

\_\_\_\_\_  
DATE



## Appendix C: Demographic Questionnaire

### The Impact of Social Media Disclosure on Persons with Disabilities

#### Demographic Questionnaire

1. I identify my gender as \_\_\_\_\_

2. What is your age in years? \_\_\_\_\_

3. In the past 6 months, what type of social media have you used to disclose (*The act of revealing personal information*) on?

\_\_\_\_ Facebook

\_\_\_\_ Twitter

\_\_\_\_ Instagram

\_\_\_\_ Vine

\_\_\_\_ Snapchat

\_\_\_\_ Blogs

\_\_\_\_ Other (There are a large variety of social media sites such as Pinterest and Second Life)

4. Have you ever disclosed (shared) personal information about your disability through on social media?

\_\_\_\_ Yes

\_\_\_\_ No

If yes:

what exactly did you disclose?

Did you disclose any information about your disability?

How did this disclosure affect you?

6. How many hours per week do you spend using social media?

\_\_\_\_ 0-9 hours

\_\_\_\_ 10-30 hours

\_\_\_\_ 31-50 hours

8. What are you top uses for social media?

- To do homework, or work
- To pay bills
- To make friends
- To connect with peers
- For social support

9. What is your ethnicity? (Please select one of the following)

- African American / Black
- Asian
- Caucasian / White
- Hispanic or Latino
- Native American
- Other

10. What is your marital status? (Please check one of the following)

- Married
- Cohabiting/Living with a partner
- Divorced or Separated
- Single, Never Married
- Widowed

11. What is the highest level of education you have completed? (Please check one of the following)

- Less Than high School
- High School Degree
- Some College
- College Degree
- Beyond College Degree

12. Are you currently employed?

- Yes
- No

14. Which of the following best describes the industry you work in?

- Government
- Health Care
- Social Services
- Education
- Entrepreneurial
- Manufacturing
- Professional
- Clerical
- Sales
- Construction
- Transportation

15. Do you use social media for work?

Yes

No

16. What is your physical disability?

17. How long have you had this physical disability?

## **Appendix D: Interview Script**

### **Interview Guide**

#### **The Impact of Social Media Disclosure on Persons with Physical Disabilities**

June Furr, Graduate Student  
Knight School of Communication  
Queens University of Charlotte

**Introduction (Read Aloud): Social Media has presented persons with physical disabilities with many new opportunities to form social networks and fulfill social needs that have not always been possible. Read Aloud): You do not have to share any knowledge that you are not comfortable sharing. You can ask me to skip a question during the interview by saying ‘next question’”**

#### **Section 1**

1. Tell me about one recent experience you have had using social media?
2. What type of social media did you use? (FaceBook, Twitter, YouTube, email) Why?
3. How, did you decide on which platform to use?

**(Read Aloud) When responding to the following questions, please keep in mind one recently experience using social media.**

#### **Section 2**

4. Did you disclose any personal information about yourself? Why?
5. What Personal information did you disclose?
6. How did you make decisions about what to reveal and withhold from others about yourself? Why?
7. What kind of information was most difficult to disclose? Why?
8. What kind of information was easiest to disclose to others? Why?

#### **Section 3**

9. How do you make decisions about whom to disclose to regarding your physical disability on social media? Why?
10. Is there a particular point in the social media friendship or relationship that you feel comfortable disclosing information about your physical disability? Why?
11. How, if at all, do you change the content of your messages when disclosing to different people (e.g., superior, subordinate, peers) face-to-face? Social media? Why?

12. Please explain one specific example in which you disclosed to one person/group (e.g., superior, subordinate, peers) on social media and not to others face-to-face?
13. Please explain one specific example in which you disclosed to one person/group (e.g., superior, subordinate, peers) on social media and not to others face-to-face? Why?
14. Why, if at all, did you attempt to withhold details about your physical disability from persons you communicated with on social media?
15. What factors helped determine *when* you disclosed to others about your physical disability face-to-face? How does this change on social media?
16. What factors helped determine *how often* you disclose to others about your physical disability face-to-face? How does this change on social media?
17. Do you establish rules for the information you disclose about your disability? (rules would be who the information can be shared with other or not shared with other, or what parts of the information that could be shared) Why?
18. Please provide one example of information you shared about your disability accompanied with a rule.
19. Is there an example of a time when you established a rule that was broken for the information about your disability? How did that make you feel?

#### **Section 4**

20. What medium of communication do you prefer to disclose information about your physical disability (face-to face, phone, email, social network, blog)? Why?
21. Which medium (face-to face, phone, email, internal and/or external social network, blog) of communication did you find most effective when disclosing information about your physical disabilities? Why?
22. Which medium (face-to face, phone, email, internal and/or external social network, blog) of communication did you find least effective when disclosing information about your physical disabilities. Why?
23. How, if at all, did your use of a preferred medium of disclosure (face-to face, phone, email, internal and/or external social network, blog) change over the course of your physical disabilities? Why?
24. What, if at all are challenges you have experienced when disclosing personal information about your physical disability on social media?

25. What, if any, are the rewards you have experienced when disclosing personal information about your physical disability on social media?

**Appendix E: Recruitment Letter**

**June B. Furr**  
**444 Iverson Way**  
**Charlotte, NC 28203**  
**704-807-8375**  
[June.furr@queens.edu](mailto:June.furr@queens.edu)

Dear .....

I am a graduate student at Queens University of Charlotte in the Knight School of Communication. I am currently conducting an academic study exploring the disclosure opportunities and practices for persons with physical disabilities. This study is of significant importance to me personally because I have an adult daughter with a physical disability since age six. This issue is also important because social media has established new possibilities for interpersonal communication for persons with disabilities. However, the opportunities and challenges associated with disclosing personal information on social media about an individual's physical disability is largely unexplored for persons with physical disabilities.

I am currently seeking to interview persons with physical disabilities between the ages of 19 and 65. This demographic would include any individual who communicates online and has a physical condition but not decisionally impaired which includes loss of a limb or limbs, anatomical challenges including neurological, cardiovascular, muscular, and skeletal issues, which could have resulted from personal injury, illness, or hereditary factors that alter life various different kinds of life functions. This informal interview will last approximately 45 minutes and will be conducted by myself, and I am a graduate student in the Master of Arts program from the Knight School of Communication at Queens University of Charlotte. Interviews will be conducted at a mutually agreed upon public location or by phone, if necessary. The names of all participants, references to specific organizations and/or policies will be confidential in our report analysis.

Thank you for your consideration. If you are interested in participating or know someone who is interested and meets the criteria for participation listed above, please contact me at **704-807-8375** or **june.furr@pearson.com**

Thank you,

**June B. Furr**  
**Queens University of Charlotte**  
**Knight School of Communication**  
**Graduate Student**