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Charles Gaucher, Ann M. Beaton et Jérémie B. Dupuis,
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Représentations sociales et handicap : regards croisés sur le sens commun du handicap

Social Representations and Disability: Perspectives on the Common Sense Notions of Disability

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Social Representations and Disability: Perspectives on the Common Sense Notions of Disability

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Éditorial

Depuis les années 1980, beaucoup d'encre a coulé concernant les façons de montrer, de dire et d'imaginer le handicap. Des écrits concernant l'évolution historique des représentations du handicap (Doriguzzi, 1994; Stiker, 1991) à celles portant sur sa mise en icône (Fougeyrollas & Saillant, 2007), de nombreuses réflexions ont été faites afin de décrypter ce qui est dit de la différence des personnes ayant des incapacités. D'ailleurs, c'est à travers un clivage entre les représentations du modèle social et du modèle médical du handicap que naîtront les *Disability Studies.* Ce champ d'études mettra en place une grille de lecture analytique des représentations du handicap très critique des perspectives centrées sur le manque ou le pathologique qui accompagne souvent le processus de stigmatisation des personnes ayant des incapacités.

Différents points d'entrée ont alimenté cette critique des représentations prises au sens de Jodelet, c'est-à-dire comme des « phénomènes cognitifs engageant l'appartenance sociale des individus par l'intériorisation de pratiques et d'expériences, de modèles de conduites et de pensée » et qui régissent « notre relation au monde et aux autres, orientent et organisent les conduites et les communications sociales » (1989, p. 36). Plusieurs auteurs ont ainsi tenté de démontrer comment tel type de différence, physique, psychique ou cognitive, était caractérisé socialement par des représentations particulières influant à la fois l'expérience subjective de certaines différences, tels que la surdité (Gaucher, 2010; Lane, 1984), ou encore les cadres globaux de traitement du handicap dans certains contextes sociaux ou culturels (Gardou, 2010; Ingstad & Whyte, 1995). D'autres se sont penchés sur la convergence de domaines du monde vécu avec le handicap – la sexualité, le sport et la religion en tentant, par exemple, de comprendre la relation entre employeurs ou futurs employeurs et personnes ayant des incapacités (Beaton, Kabano, & Léger, 2014; Beaton & Kabano, 2011). Ces points d'entrée empiriques ont aussi permis le développement de questionnements théoriques concernant les rapports sociaux qui s'expriment ou se taisent à travers les représentations sociales du handicap (Fougeyrollas, 2010; Murphy, 1987), mais aussi sur les origines sociopolitiques de ces représentations (Barnes, 2012). Enfin, on peut dire que le principal extrant de ces différentes interrogations est d'avoir donné lieu à de nombreux travaux sur la nécessité et la possibilité de transformer les représentations du handicap.

Le présent numéro, dédié à l'exploration des représentations sociales du handicap, a donc tenté de remettre au goût du jour ces différentes interrogations en sollicitant différentes contributions provenant d'études empiriques afin de voir comment l'environnement, pris au sens du Processus de production du handicap (PPH), constitue un lieu de productions d'images, de perceptions, de préjugés et de stéréotypes qui influent sur la participation sociale des personnes ayant des incapacités. Deux axes se dégagent des contributions recueillies : les représentations provenant du vécu des acteurs, concernés directement ou non par le handicap, et les représentations issues du monde des médias. Dans un rapport dialectique, ces deux grands types de représentations s'alimentent et se confondent quelquefois.

D'une part, les articles abordant le point de vue des acteurs sur le handicap, que ce soit à partir de la définition identitaire des personnes elles-mêmes concernées par la notion de handicap (Curtis et al.), des perceptions des personnes reliées de près ou de loin à celles-ci (Breau et al.; Hamm; Germundsson) ou de manière plus générale par des individus à qui on a demandé de nous livrer leurs façons de voir le handicap (Beaton et al.; Kahina et al.), soulignent bien la persistance de perceptions relativement négatives concernant les personnes ayant des incapacités; perception conduisant inéluctablement à une vision réductrice de leur différence, voire à des représentations pessimistes quant à leur potentiel de participation sociale, notamment concernant leur capacité à intégrer le marché du travail comme individu autonome. Milot et al. mettent en évidence le fait que cette difficulté pourrait être surmontée, surtout pour les domaines directement concernés par le handicap, par la mise à profit plus systématique de l’expérience des personnes ayant des incapacités dans les programmes de formations.

D’autre part, les articles reprenant l’image du handicap dans les médias soulignent que l’expérience des personnes ayant des incapacités est encore très faiblement représentée (Goethals) et que si, dans certains contextes on y prend en compte les interactions entre le milieu et la personne (McGrail), lorsque les personnes ayant des incapacités y apparaissent, elles sont montrées en modèles, sources d’inspiration extraordinaires (Joselin & Popescu) ou encore discutées comme des objets, produisant du même coup une image échappant aux individus qui sont directement dépeints par celle-ci (Ilyes). Dans tous les cas, l’image médiatique du handicap que présentent ces récentes études n’est pas sans soulever le problème de la réduction des corps et des esprits différents à des usages sociaux qui confine le handicap dans un carcan qui est encore loin d’être un vecteur de participation sociale.

Enfin, le numéro que nous vous proposons se veut plus qu’une simple image en négatif du handicap. Notre intention était de raviver les débats autour des perceptions et des représentations qui marquent la vie des personnes ayant des incapacités et, plus spécifiquement, celles qui ont une incidence directe sur leur participation sociale. Derrière la visée critique à partir de laquelle nous avons constitué ce numéro, se profile l’idée de soulever les obstacles systémiques générés par des matrices normatives encore fortement marquées par des images et des stéréotypes réducteurs du handicap, mais aussi le désir de mettre en évidence les conditions de possibilité que peuvent véhiculer les représentations du handicap dans l’élaboration d’une réelle participation sociale des personnes ayant des incapacités.

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Editorial

Much has been written since the 1980s on the portrayal, discussion, and conception of disability. In the considerable literature on the historical evolution of the representation of disability (Doriguzzi, 1994; Stiker, 1991) and its iconification (Fougeyrollas & Saillant, 2007), much reflection has been devoted to decrypting what is said about the differences of people with disabilities. Moreover, *Disability Studies* is emerging from a cleavage between the social and medical representations of disability. Disability Studies, is a field that will implement an analytical framework for disability representation and it will be highly critical of deficit-based or pathology-focused perspectives, which only further stigmatize people with disabilities.

According to Jodelet's description of disability representation as a "cognitive phenomena that engages the group membership of individuals through the internalization of practices, experiences, and models of conduct and thought" and that govern "our relationship to the world and to others, guide, and organize social behavior and communication" (1989: 36; translation), this critique draws on different approaches. Many authors have tried to demonstrate how any given type of physical, psychological, or cognitive difference is socially and culturally characterized by specific representations and, in turn, influences both subjective experiences, such as deafness (Gaucher, 2010; Lane, 1984) and global frameworks for disability treatment (Gardou, 2010, Ingstad & Whyte 1995). Other researchers have explored the convergence of disability with other areas of experience (e.g., sexuality, sports, or religion). For example, research has been conducted to understand the relationships between present or future employers and employees with disabilities (Beaton, Kabano, & Léger, 2014, Beaton & Kabano, 2011). These empirical approaches have also led to the development of theoretical questions on the overt or covert social relationships rooted in the social representations of disability (Fougeyrollas, 2010; Murphy, 1987). They have also led to questioning the socio-political origins of these representations (Barnes, 2012). Finally, it can be said that the key outcome of this work is the focus on a need and the possibility to transform representations of disability.

Dedicated to the exploration of the social representations of disability, this issue has attempted to update these questions by soliciting various empirical contributions. The studies in this issue shed light on how the environment—as the Disability Production Process so defines it—is a space for the production of images, perceptions, prejudice and stereotypes affecting the social participation of people with disabilities. Two themes emerge from the contributions gathered here: representations originating from the experience of actors, directly or indirectly affected by disability, and representations stemming from the media. In dialectical relationship, these two types of representations feed each other and sometimes overlap.

First, articles addressing how different actors understand disability, whether through the definition of identity by disabled people (Curtis et al.), by others directly or indirectly related to the disabled (Breau et al.; Hamm & Germundsson), or, more generally, by individuals who have been asked to share their views on disability (Beaton et al.; Kahina et al.), highlight the persistence of negative perceptions of the disabled. These are reductive views of difference. They include pessimistic representations of the potential of people with disabilities for social participation, especially their capacity to enter the labor market as autonomous individuals. Milot et al. highlight how this difficulty might be overcome (particularly in areas directly affected by disability) by building on the experiences of people with disabilities in training programs.

Second, articles on the image of disability in the media show just how the experience of disability is still very underrepresented (Goethals). Although the interactions between people and their environments are considered in certain contexts (McGrail), people with disabilities are used as models, sources of extraordinary inspiration (Joselin & Popes-cu) or even discussed as objects. As such, this produces an image that eludes the individuals being depicted (Ilyes). Ubiquitously, the mediatized image of disability (as addressed in these recent studies) raises the issue of the reduction of different bodies and minds to social uses, thus confining disability to a restrictive framework that is hardly a driver of social participation.

Finally, our issue strives to be more than a negative image of disability. Our intention is to rekindle debate on the perception and representation that color the lives of people with disabilities and, more specifically, that have a direct impact on the social participation of these citizens. Behind the critical perspective from which this issue was drawn up lies the idea of raising the systemic obstacles generated by normative templates still strongly marked by images and reductionist stereotypes of disability. This issue was also driven by the desire to highlight the conditions of possibility that representations of disability can convey in developing the real social participation of people with disabilities.

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Personal and Collective Disability Identity Development

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Abstract

The purpose of this paper is to explore how individuals with disabilities establish and maintain a social identity that incorporates meaning and context into a personal and collective perspective defined as disability identity. Beginning with a broad lens, the concepts of identity and social identity are explored. Theories and concepts that have shaped and refined the concept of social identity, specifically within a context of disability, are introduced. Disability Identity development is explored as to the key components and constructs that bring forth a comprehensive view of identity development for individuals with disabilities. Finally, these components are brought together within the context of Independent Living in order to show how this movement supports a positive, life-enhancing worldview of disability.

Keywords: disability, disability identity, collective identity, personal identity, independent living

Résumé

Le but de cet article est d’explorer comment les individus avec un handicap établissent et maintiennent une identité sociale qui incluent un sens et un contexte dans une perspective personnelle et collective définis comme une identité handicap. En commençant avec un sens plus large, les concepts d’identité et d’identité sociale sont explorés. Des théories et des concepts qui ont créé et précisé le concept de l’identité sociale dans un contexte de handicap sont présentés. Le développement de l’identité handicap est exploré par rapport aux construits et composantes clés qui amènent une perspective compréhensive du développement de l’identité pour les gens avec handicaps. Finalement, ces composantes sont mises ensemble dans un contexte de Vie Indépendante afin de voir comment ce mouvement promut une vision globale plus positive du handicap.

Mots-clés : handicap, identité handicap, identité collective, identité personnelle, vie indépendante

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In recent years, scholars working in an array of social science and humanities disciplines have taken an intense interest in questions concerning *identity*. Much research has been devoted to the *identity politics* of race, gender, and sexuality (Abes, Jones, & McEwen, 2007; Mpofu & Harley, 2006; Putnam, 2005). In social theory, questions of identity are included in numerous arguments on gender, sexuality, nationality, ethnicity, and culture (Kymlicka, 1995; Taylor, 1989; Young, 1990). For example, Hogg and Abrams (1990, p. 2): Identity is "people's concepts of who they are and how they relate to others"; Deng (1995, p. 1): "Identity is used… to describe the way individuals and groups define themselves and are defined by others on the basis of race, ethnicity, religion, language, and culture,"; Jenkins (2000, p. 4): Identity "refers to the ways in which individuals and collectivities are distinguished in their social relations with other individuals and collectivities,"; Katzenstein (1996, p. 59): "The term [identity] (by convention) references mutually constructed and evolving images of self and other"; and finally, Taylor (1989, p. 344): "My identity is defined by the commitments and identifications which provide the frame or horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose."

The purpose of this paper is to explore how individuals with disabilities establish and maintain a social identity that incorporates meaning and context into a personal and collective perspective defined as *disability identity*. As an individual with a disability, how does one define oneself, in what manner, in what terms, with what accompanying attitudes and expectations? As a collective group, how do individuals with disabilities want to be defined and named by others in society; what is normative and life-enhancing compared to what is derogatory and shaming? Individually and collectively, we are in a place in time and history to shape Disability Identity formation by movements composed of people with disabilities who have a vested interest in the disability rights movement seeking independent living rights and responsibilities. These efforts have the ability to establish Disability Identity as a normalized aspect of society by defining the lived experience of those with disabilities and by normalizing that lived experience.

Additionally, this paper serves as a call to activism. A basic component of Feminist Theory espouses – *the personal is the political* – and where better to examine this concept brought to life than in the disability rights movement? The four basic assumptions that form the philosophy of the independent living movement state that all life is of value; *anyone*, whatever their impairment, is capable of exerting choice; people who are disabled by society's reaction to physical, intellectual, or sensory impairment have the right to assert control over their lives; and disabled people have the right to fully participate in society (Morris, 1993a). We need an enhanced understanding of Disability Identity in order to bring these concepts into an everyday reality; one that occurs as an individually lived-experience and one that provides a meaningful context within society for *all* people.

Disability Identity Development

Models that help to undergird the concept of Disability Identity include those that are non-linear and view identity from multiple perspectives. Conceptually, this includes the integration of disability both physically and from a psychosocial perspective into an individual perspective in a positive, life-affirming, enhancing manner. If individuals with disabilities are regarded in a normalized and positive perspective on an individual basis then a collective societal perspective will follow. In this way discrimination and oppression can be named for what they are and directly addressed because individuals with disabilities realize they are not alone in their lived experiences that all too often hold discrimination and oppression. Additionally, the focus on disability would be perceived as one aspect of a person's life; not the wholly defining and labeling persona. Finally, by incorporating the uniquely *positive* aspects of being a person with a disability, individuals could experience life on their own terms. In this way insight and problem-solving which typically are associated with the disability experience are emphasized and named as positive attributes of such individuals and potentially viewed as positive character traits associated with people in our society.

Personal Identity Development

Initial ventures into understanding the development of personal identity were focused on the development of individuals singularly. Identity theory generally focused on role identities of the *individual* from a uniquely *internalized* perspective*. Identity* was conceptualized as internal, consisting of internalized meanings and expectations associated with an individual's role (Burke & Tully, 1977), and, *roles* were considered external and linked to social positions within the social structure. Each role or set of roles was embedded in one or more groups that provide context for meanings and expectations associated with the role. Stryker and Serpe (1982) give examples of groups that provide contextual meanings to roles such as networks, organizations, classes, unions, and other social units that have a set of established and accepted ideals and standards for group membership. Social Role Valorization (SRV) theory (Wolfensberger's, 1982) indicates that social roles dominate people's lives and that individuals perceive themselves and each other in terms of these respective roles. The value attributed to various social roles tends to instrumentally affect the behaviors directed toward individuals, depending upon the value or devalue of that particular role as it exists within the social hierarchy. Those individuals in valued roles tend to be treated well and those in devalued roles tend to be treated poorly (Wolfensberger, 2011).

Wolfensberger's (2011) discusses those roles that are stereotypically devalued in most Western societies and the possible results of this societal role devaluation. It is theorized that SRV can be utilized to "upgrade" some of the more devalued roles, thereby elevating the value of those individuals who typically occupy those roles. Not surprisingly, at the top of Wolfensberger's (2011) list of devalued roles are those individuals who are impaired in some way, including those with sensory impairments, physical, psychological and/or cognitive disabilities. The next most devalued individuals on his list are those whose behavior is considered socially deviant, including individuals who are excessively hyperactive, are unorthodox in their sexual orientation, and those who use alcohol and/or drugs. Next are those who possess extreme physical characteristics such as excessive tallness or shortness; individuals who rebel against the social order; the poor; the illiterate or those with seemingly nothing to contribute to the intellectual growth of society; and, finally; those individuals who are unassimilated into the culture such as religious minorities and racial and ethnic minorities (Wolfensberger, 2011).

Collective Identity Development

- *Moving from individual identity to social identity*

Tajfel (1982) first introduced the concept of social identity as an individual's knowledge that she belongs to certain social groups together with some emotional and value attachments that fit in with this group membership. Motivated by an underlying need for self-esteem, social identity rests on intergroup social comparisons that seek to confirm or establish ingroup membership and create distinctiveness between the ingroup and the outgroup (Turner, 1985).

To explain the nature of the relationships between groups including concepts such as status, stability, permeability, and legitimacy, and the way these concepts influence a positive social identity, Tajfel and Turner (1979) utilized the concept of social categories in describing one's social identity. For example, social categories are defined by implicit and/or explicit rules of membership. These membership rules are driven by the individuals who are assigned or not assigned to the category. Additionally, social categories are understood in terms of sets of characteristics. Beliefs, desires, moral commitments, or physical attributes thought typical of members of a category, or behaviors expected of said members in certain situations define the parameters of the group characteristics. This is true in the case of social roles such as mother, professor or student (Tajfel, 1982).

- *Social identity composed of multiple dimensions*

Multiple dimensions of identity offer a conceptual depiction of relationships that are socially constructed and recognize that each dimension cannot be fully understood in isolation. The model is based on the work of Reynolds and Pope (1991) and Deaux (1993) and also founded on the results of grounded theory research with women college students by Jones, et al. (1984).

The model of multiple dimensions of identity describes the dynamic construction of identity and the influence of changing contexts on multiple identity dimensions, such as race, sexual orientation, culture, and social class. The model portrays identity dimensions as intersecting rings around a core, signifying how no one dimension can be understood without considering its relationship to other dimensions (Jones, et al., 1984). At the center of the model is a core sense of self, comprising “valued personal attributes and characteristics” (Jones, et al., 1984, p. 383). Surrounding the core and identity dimensions is the context in which a person experiences life, i.e., family, socio-cultural conditions, and current experiences. The salience of each identity dimension to the core is fluid and depends on contextual influences. For example, both Feminist and Queer Theory help to illustrate and enhance this model.

- *Social identity and Feminist Theory*

A greater understanding of social identity is seen by the incorporation of constructivist thought and the idea that individuals possess multiple identities. Feminist literature introduced a framework of intersectionality that recognized how socially constructed identities are experienced simultaneously, not hierarchically (McCann & Kim, 2002). Much of the study on multiple identities in the literature grew out of Black feminist scholarship that challenged feminism’s Eurocentric assumptions (Hooks, 1984). Collins (1990) termed this framework a “matrix of domination” and explained that viewing relationships from an intersecting perspective expands the analysis from merely describing the similarities and differences to distinguishing these systems of oppression and how they interconnect (p. 222).

Autobiographical narratives from two feminist scholars, Lorde (1984) and Anzaldua (1987), illustrated a “new consciousness” (Anzaldua, pp. 101) associated with integrating multiple identity dimensions within a matrix of domination rather than a hierarchical structure. Lorde, an African American lesbian feminist socialist mother of two and a member of an interracial couple explained that her “fullest concentration of energy is available… only when I integrate all the parts of who I am… without the restrictions of externally imposed definition” (pp. 120-121). Anzaldua, a Mexican American lesbian and a mestiza discussed her ability to bring together multiple identities into a new, integrated identity where “the self has added a third element which is greater than the sum of its severed parts. That element is a new consciousness.” (pp. 101-102). To fully embrace individual experiences, it is necessary to explore differences within each aspect of identity as each is influenced by the simultaneous experience of the other dimensions (McCann & Kim, 2002).

- *Social identity and Queer Theory*

Relevant to the re-conceptualization of social identity as including multiple identities is the postmodern perspective of queer theory, which suspends the categories of lesbian, gay, bisexual, masculine, and feminine (Tierney & Dilley, 1998). Components of queer theory challenge traditional identity categories based on the assumption that identity is performed and therefore unstable (Butler, 1991) and comprised of fluid differences rather than a unified, singular identity (Fuss, 1989). Fuss suggests that the failure to study identity as difference implies a false unity that overlooks variations that exist within identity categories such as race and class (1989). She goes on to explain that categories are insufficient because differences within those categories cause them to have “multiple and contradictory meanings” (Fuss, 1989, p. 98).

- *“Meaning making” - Constructivist-developmental theories and social identity*

Constructivist-developmental theorists began to enhance the concept of identity as being composed of multiple dimensions by incorporating intrapersonal, cognitive, and interpersonal domains of development into a single unit and describing the interrelated development of each domain from simple to complex (Kegan, 1994). Kegan’s integrated theory consists of five orders of consciousness representing increasingly complex meaning-making structures. These meaning-making structures are sets of assumptions that determine how an individual perceives and organizes life experiences (1994). The intrapersonal dimension of such a framework presents a relationship between theorized orders of consciousness and theories of social identity development (Kegan, 1994).

Abes, Jones, and McEwen (2007) considered Kegan’s (1994) constructivist-developmental theory and the model of multiple dimensions of identity in a study exploring how lesbian college students perceived their sexual orientation identity and its interaction with other dimensions of identity, such as race, religion, social class, and gender. Results of Abes, Jones, and McEwen’s study suggested that meaning-making capacity served as a filter through which contextual factors are interpreted prior to influencing self-perceptions of sexual orientation identity and its relationship with other identity dimensions. How context influenced these perceptions depended on the complexity of the meaning-making filter. Participants with complex meaning-making capacity were able, more so than those without less developed capacity, to filter contextual influences, such as family background, peer culture, social norms, and stereotypes, and determine how context influenced their identity. Complex meaning-making also facilitated the ease with which sexual orientation was integrated or peacefully coexisted with other dimensions of identity (Abes, Jones, & McEwen, 2007).

The results of Abes, Jones, and McEwen’s (2007) study suggest that incorporating meaning-making capacity would more thoroughly depict the relationship between context and salience of identity dimensions, as well as the relationship between social identities and the core of identity. This re-conceptualized, the integrated model portrays the interactive nature of the relationships among components of the identity construction process: context, meaning-making, and identity perceptions. Meaning-making capacity is depicted as a filter in the model and how contextual influences move through this filter depends on the depth and permeability of the filter. The filter is in direct proportion to the person’s meaning-making capacity. Regardless of differences in meaning-making, context influences identity perceptions (Abes, Jones, & McEwen, 2007).

Incorporating meaning-making capacity into the concept of social identity within a context provides a richer portrayal of not only *what* relationships people perceive among their personal and social identities, but also *how* they come to perceive them as they do. By incorporating personal and multiple social identities, Abes, Jones and McEwen’s model provides a holistic representation of the intrapersonal domain; with the inclusion of meaning-making capacity, the re-conceptualized model provides a holistic representation of the integration of intrapersonal development with cognitive and interpersonal domains. It also provides a lens to understand more clearly how people view themselves and this knowledge allows professionals to more effectively engage in meaningful and individualized partnerships to help them develop a more complex understanding of their identity and the power associated with defining identity for themselves (Abes, Jones, & McEwen, 2007).

Definitions of Disability and their Impact on Identity Development

The definition of disability, much like the definition of ethnicity (Aspinall, 2001) and more recently, gender (Barr, Budge, & Adelson, 2016), may be defined several different ways, often with contradictory meanings. Three major themes of how disability is defined include a) functional limitations which stem from a medical understanding of disability, b) administrative definitions which determine an individuals' eligibility for benefits and services, and c) subjective definitions which include a person's identity and self-categorization as having a disability (Gronvik, 2009). There is a definite fragmentation of meaning between society's definition, which often views disability as distinct categories and academia, which attempts to operationally define disability into a single category that can be quantitatively studied (Altman, 2014). These conflicting and often confusing definitions of disability directly contribute to the complexity and diversity of disability identity formation.

Disability, Functional Limitations and the Medical Model

Typically, the majority of society views the definition of disability from a medical model perspective in that the disability resides within the body and is something to be cured (Smart, 2009). This perspective often leads to defining disability as distinct categories of impairment related to medical diagnoses as "deaf," "blind," or "diabetic" (Shakespeare, 2013). This viewpoint completely disregards environmental impact and individual response to disability and therefore offers only a linear, one-dimensional definition of a complex process. This perspective presents many complicated issues for the person with the disability, one of the most difficult being the potential negative impact this view has on disability identity development. Not only is there the possibility of internalization of these largely negative views by the person with the disability, there is also the creation of a power differential between the person with a disability and "normal" (or nondisabled) members of society.

Based on a medical model of disability, those with disabilities often feel the need and social pressure to seek a "cure" (Marks, 1999). Attitudinally, society typically reflects that physical and mental impairments are a general devaluation of the person (Wright, 1983). Disability is associated with a body that is weak, inadequate, or abnormal and these attributes are often generalized into dispositional character traits (Taub, Blinde, & Greer, 1999; Wolfensberger, 1982) and consensually held stereotypical assigned identities (Nario-Redmond, 2010). To protect the self from such negatively assigned identities, one may seek to increase the permeability of the boundary between "disabled" and "nondisabled" groups. In this way social pressures are created for people with disabilities to distance their identity of "self" from one of disability as a social category (Schur, 1998). If medical intervention can eliminate or hide impairments one can escape being identified as having a disability. For example, individuals may choose to have plastic surgery to alter characteristic facial features of children with Down syndrome in an effort to alleviate some of the stigma associated with this label. One may strive to overcome the disability and the adaptation of a disability identity by compensating or trying harder in the face of obstacles, rejecting accommodations and striving to meet normative standards of achievement (McVittie, Goodall, & McKinlay, 2008; Phillips, 1985). The emphasis across these strategies is disability identity suppression, grounded in the assumption that a person with a disability can improve self-esteem and increase feelings of acceptance by minimizing or suppressing their impairments and trying to appear as much like the norm as possible (Charmaz, 1995).

In response to this medical model mindset, Nagi (1965) introduced a definition of disability that included functional limitations that were related to the *impact* of limitations on activities of daily living (Hahn & Pool-Hegamin, 2001). Surveys and censuses world-wide conceptualize disability's functional limitations in so far as they impact activities of daily living (United Nations, 1996).

In order to fully understand how disability definitions impact identity formation, Altman (2014) defines disability emphasizing how it is necessary to be examined completely. For example, she explains that the process may begin with an accident, birth defect, or disease and includes both personal and environmental characteristics associated with each. Whatever physical or environmental functional limitation(s) that is produced becomes a characteristic of that person, one of many, that impacts individual and collective disability identity development (Altman, 2014). The impact of the specific functional limitation is then dependent on how receptive the environment is or is not to that limitation. This explanation of the disability process demonstrates that the disability resides both within the individual, as well as within specific societal environments. Therefore, environment may impact disability identity development in either a positive or negative way depending upon how it interacts with the individual's response to the functional limitation. To summarize, Altman presents disability identity development as a result of a combination of individual physical limitations as they relate to specific environments and in doing so, demonstrates the diverse and broad nature of the definition of disability (2014).

Administrative Definitions of Disability

Administrative definitions of disability provide benefits and services to those deemed eligible (Gronvik, 2009). Federal and state legislation are what dictate eligibility criteria in relation to specific benefits (Hedlund, 2004). Therefore, if a person is granted a benefit or service intended for people with disabilities, he or she is considered disabled [sic] (Barron, Michailakis, & Soder, 2000). The eligibility criteria are different for different benefits and services which results in a large variety of definitions of disability (Altman, 2014; Mashow & Reno, 2001). Again, these confounding qualifications for eligibility to receive various benefits and services also serve to confuse the disability identity development process.

Psychosocial Factors of Disability and Identity Development

Psychosocial factors associated with disability have the potential to add additional meaning-making to one's disability identity development. One such psychosocial factor is the meaning-making attached to disability based on the nature in which the disability occurs, i.e., a disability that is acquired in the course of one's life versus a disability that is congenital in nature. Theories of adaptation to disability abound, however, disability identity is not the same as acceptance of disability (Mpofu, 1999). Until recently, the stages' theories of adaptation to disability (STADs) proposed that there are predictable or "normal" stages of responding to a disability (Bishop, 2005; Chan, Cardosa, & Chronister, 2009; Linveh & Parker, 2005). Taken from the Stages of Loss theory (Kessler & Kubler-Ross, 2005), most existing STADs' models include six phases or stages that a person with a disability (PWD) is likely to experience; they are: shock, defensive retreat, depression or mourning, personal questioning, and finally, integration (Kessler & Kübler-Ross, 2005; Smart, 2009). Traditionally, STADs theories have been applied only to the individual who is experiencing the disability and ignores additional psychosocial factors (Linveh & Parker, 2005).

Although most PWDs have these same generalized experiences that are analogous to the phases of the grieving process *when dealing with an acquired disability,* there are other significant considerations that the STADs' models fail to address when the disability is congenital (Linveh & Wilson, 2003; Smart, 2009). Smart contends there is an important distinction concerning the individual responses to disability between those with acquired disabilities versus those with congenital disabilities. With congenital disabilities, the parents, siblings, and often grandparents, progress through these stages, not necessarily the PWD (Smart, 2009). The person with a congenital disability knows no other way of life other than the one her or she was born with (Smart, 2009). Therefore, it is a logical conclusion that the individual is more likely to progress through the "typical" stages of external environmental control development, very similar to a child born without a disability. It is also a logical conclusion to assert that a child born with a congenital disability does not adapt to his or her environment, rather he or she develops the coping mechanisms that most typically developing children possess in order to manage his or her environment (Chan, Cardosa, & Chronister, 2009).

A significant psychosocial factor that often is ignored, however, is that as an integral part of the PWDs immediate environment, the family and friends' dynamic affects the individual's positive or negative response to the disability. Smart makes the argument that in cases of congenital disabilities, it is often the mother who internalizes much of the guilt and pain associated with having given birth to an imperfect child. As a result of legitimate medical questions about the mother's health and/or decisions she may have made during the pregnancy, society passes judgment and the mother internalizes these judgments more than other family members because she is biologically responsible for the child's well-being during the pregnancy.

The STADS theories are more accurately applied when the disability is acquired. Nonetheless, the loss theory (which includes distinct and identifiable stages of grief) is missing two important components when addressing individual response to acquired disability: the impact of stigma and prejudice and the lack of mental preparatory time to prepare for the loss. There is usually a period of time to prepare emotionally and behaviorally for the loss associated with impending death, aging and chronic/terminal illness (Smart, 2009). Conversely, this is not the case with an acquired disability. It is often sudden and traumatic with little to no time to prepare psychologically for the death of the person before the disability. Essentially, the feelings of loss and grieving that stem from mourning the loss of the pre-disability identity. Additionally, factors like education level, economic security, family support, the availability of treatment and the stigma and prejudice that exist within the individual's community, all influence the disability experience (Bishop, 2005; Chan, Cardosa, & Chronister, 2009; Livneh & Antonak, 2005; Smart, 2009). Environmental factors to consider include the degree of prejudice within the individual's community; discrimination toward type and severity of disability; and whether the individual is also subject to prejudice and discrimination because of other perceived identities such as belonging to cultural/ethnic/racial minority groups.

Subjective Definitions of Disability

Subjective definitions of disability mean that a person defines him or herself as having a disability (Gronvik, 2009). This means that disability is incorporated into that person's sense of identity. Depending upon context and environment, it may be incorporated in positive ways at times and negative ways at others. However, the key to this definition of disability is one of subjectivity and voluntariness of self-labeling. In other words, conscious choice by the individual with the disability is at work. This can provide a source of individual and collective disability identity empowerment.

The Influence of Disadvantaged Identities

As stated by Calderon-Almendros and Ruiz-Roman, identity gives sense of meaning to individuals and collective groups and forms the way they see themselves and others (2016). However, these sources of meaning are being constructed from places of inequality (Calderon-Almendros & Ruiz-Roman, 2016). This puts some individuals and groups at a disadvantage. The terms "advantaged" and "disadvantaged" are used to refer to individuals belonging to groups with relative high or low status or power within a specific social context (Curtin, Kende, & Kende, 2016). Groups such as ethnic minorities, people with disabilities, LGBTQ persons, and individuals who belong to a lower socioeconomic group exhibit commonalities in identity formation. They begin with a disadvantage: discrimination and social inequality (Fraser-Burgess, 2012). This unequal starting point that marginalized groups derive meaning from negatively impacts identity formation and again, creates a power differential. Collective culture, through power and perceived control over reality, impose certain interpretations on others (Calderon-Almendros & Ruiz-Roman, 2016). In other words, they proclaim a collective identity that is perceived as legitimate and can be referred to as one's legitimating identity. These groups in positions of power produce meaning from seemingly legitimate sources and have no interest in legitimating the identities of those groups considered to be from devalued social statuses as in the case of people with disabilities. Also, the terms advantaged and disadvantaged identities tend to focus on singular aspects of identity, rather than intersections or multiple identities (Curtin, Kende, & Kende, 2016).

Another disadvantage that minority identities experience is a sense of belonging only within identity-specific communities as is the case with ethnic minorities and transgender individuals (Barr, Budge, & Adelson, 2016). Due to the ambiguity of the definition of disability, people with disabilities are perhaps at an even greater disadvantage for healthy collective identity development. In that the term disability is so indefinite and confounding, both among individuals with and without disabilities, group membership and a sense of belonging are challenging to establish. As Tajfel and Turner (1979) point out in their theory of social identity development, identity is formed through interactions with social groups. When one is continuously excluded from social groups, identity development is impeded and/or adversely affected.

Impacting Disability Identity: Independent Living

Macro issues that continue to exist for PWDs are numerous and include a lack of inclusion into mainstream society that is fueled by stigma, prejudice and discrimination; a lack of empowerment, including personal choice as a person living in a democracy; real work for real pay; and finally, the inability to create a successful and effective collaboration between people with and without disabilities to help reduce some of the stigma and prejudice between the two communities (Martin, 2001). While we applaud some of the efforts and progress made as a society in these areas, at times, however, only minimal consideration is given to the promotion of independent living for individuals with disabilities.

The concept of independent living is not a new one and, typically, we all desire to take control and responsibility of our own life. Unfortunately, for people with disabilities, particularly significant physical disabilities requiring assistance, many are excluded from this process. For many, the opportunity to be independent, self-determining, and exert choices may be rare. Due to a combination of social and economic factors, many people with disabilities are relegated to the margins of a society, provided only with obligatory consideration with regard to primary social issues. They are oftentimes hidden away in institutions, receive special education, participate in supported employment and provided with segregated housing. As a result of the numerous attitudinal, architectural, and institutional barriers, assisting people with a disability falls mainly on family members, local organizations and government agencies. The reality of many disabled people's lives is merely one of daily existence. It is a life of survival at minimal levels of subsistence and tolerance and thus contributes to the historically reinforced dependency status that many with disabilities hold (Faughnan, 1979).

No one can stop an idea whose time has come (Disabled People's International, 1991). Independent living is an idea whose time has come as all over the world people with disabilities are themselves acting as catalysts for change. The independent living movement has evolved from a social movement to a catalyst of change by redirecting the course of disability policy and practice. In this way, the felt presence and impact of the independent living movement will become a major factor shaping disability identity development within the larger culture. According to Turner (1969), "there is a revision in the manner in which a substantial group of people looking at some misfortune see it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society" (p. 321).

The independent living movement emerged in the United States in the 1970's and was inspired by strong and proactive leadership from individuals with disabilities. The first practical manifestation of the movement resulted in the establishment of a Center for Independent Living (CIL) at Berkeley University in California.

The CIL was incorporated as a self-help group in 1972 and managed by persons with disabilities (Dejong, 1979). Critical to its organization at that time was the university's masses of young people who, free from familial or economic responsibilities, were better able to organize around the issue of independent living. Since Berkeley, numerous CIL's have emerged in the United States and Europe offering a wide range of related services such as peer consultancy, advocacy services, training in independent living skills, and personal assistance services. Regardless of the type of services offered or role played, the CIL's have one thing in common; it is people with disabilities who are at the center.

The philosophy of the independent living movement is based on four assumptions; that all human life is of value; that anyone, whatever their impairment, is capable of exerting choices; that people who are disabled by society's reaction to physical, intellectual, or sensory impairment have the right to assert control over their lives and that disabled people have the right to fully participate in society (Morris, 1993a). Essentially, the independent living philosophy espouses living like everyone else. Some examples are being able to have control of one's own life, having opportunities to make decisions that affect one's life and being able to pursue activities of one's own choosing, regardless of disability. The philosophy is not designed to avoid the possibility of risk or potential failure. Dejong (1979) points out that it is the dignity associated with personal decision to take a risk that defines precisely what the independent living movement is all about. Without the possibility of failure an individual with a disability lacks true independence. Furthermore independent living must be distinguished from living independently. The latter implies that a person with a disability is trained by so called "experts" and "professional" to do everything for themselves and live without help, whereas the former is concerned about quality of life, with help. The person with a disability is not a patient in need of care, but is someone who requires assistance with certain activities, a process over which he or she must control and manage.

The independent living movement and its underlying philosophy give rise to many unique accounts of personal achievement. While some accounts may expose noteworthy triumphs resulting in widespread social change, others may be more subdued resulting in a positive change affecting only the life of a single individual. Regardless of the perceived magnitude, it is the change that is present in the day-to-day lives of individuals with disabilities that give life to the movement. Without the realization of these individual victories, the movement serves no real purpose. Individuals with disabilities need to share their unique perspective of what is wrong in society and how to make it right. All individuals committed to the movement need to be willing to get involved, speak out and take risks.

Implications for Disability Identity Development

Disability identity is characterized as a cultural-developmental phenomenon by which an individual with a disability incorporates the disability-related difference into his or her self-definition and regards that difference as a resource for participation in normative activities of his or her society (Barnartt, 1996; Grant, 1997; Hahn, 1997; Hahn & Belt, 2004; Mpofu, 1999). The term disability holds different meanings for different people and has historical, social, legal and philosophical influences on its interpretation (Gronvik, 2009). Therefore, disability identity development is complex and involves both individual and collective group processes.

Currently, there are those with disabilities who seek to find ways for the lived experience of disability to be a positive, life-enriching experience; a positive cultural heritage, or a centrally defining aspect of identity (Grandin, 1996; Olney & Brockelman, 2003). This approach is consistent with the independent living movement and the disability rights movement, which have challenged the strategies of curing the person, passing as if there is no disability, and the social disengagement of those with disabilities. Instead, these social justice movements *by* people with disabilities *for* people with disabilities encourages people, with both visible and less apparent conditions, to own the disability and with this ownership, the right to minority group membership in an effort to begin to positively identify with one another (Barnartt, Schriner, & Scotch, 2001). More specifically, group members may use the same social construction theories that have assigned them to the socially devalued categories of “less than” and “sick” to establish new standards or dimensions of social comparison, transform normative values, and bolster pride (Hinkle, Taylor, Fox-Cardamone, & Ely, 1998). For example, *ableism* is the automatic assumption by those without disabilities that those with disabilities cannot perform certain tasks because of their disability (or *type* of disability) (Mpofu & Harley, 2006). A healthy disability identity would be a protective factor for ableism (Mpofu & Harley, 2006).

A self-actualized and healthy identity for people with disabilities would contain relevant content and goals linked to disability. Therefore, disability identity is characterized as a source of difference and at the same time regarded as a resource for participation in the activities that people without disabilities participate in, in mainstream society. Additionally, there is at present no widely recognized theory on disability identity development. The lag in the development of theories of disability identity relative to identity development in other minority statuses parallels the historical delay by civic society in recognizing people with disabilities as a minority or culturally distinct group (Mpofu & Harley, 2006).

Constructs do exist that have the capability to be the foundation for a theory of disability identity development (Mpofu & Harley, 2006). Interactional models appear to be the most logical and practical models to explain the identity formation process of intersecting marginalized identities (Whitney, 2006). Interactional models are those which dynamically incorporate aspects of biology, cognition, and social and historical surroundings without using a fixed linear scale (Cramer & Gilson, 1999). Furthermore, interactional models posit identity as fluid and dynamic. These models share the following assumptions: a) defining one’s self within the salience of disability status; b) understanding and accepting the psychosocial ramifications of the disability as a component of self-actualization; c) creating a higher awareness of disability-related prejudice and discrimination by those without disabilities; and d) possessing a strong disability identity used to recognize and combat disability related stigma (Noonan et al., 2004).

Inspired by the civil rights struggle of other minority groups such as African Americans and women, people with disabilities have begun to define who they are and where their place is in society. Gill (1997) emphasizes the concept of integration and provides a foundation based on strength for a future model of disability identity development. Gill’s (1997) work focused on the importance of the integration of self in forming identity and presents a multi-stage, non-linear model for the identity formation of individuals with disabilities. Gill’s four aspects of disability identity formation explain the process of integrating the disability aspect, both physical and psychosocial, into the individual’s salience hierarchy in a positive way. *Coming to feel we belong* focuses on recognition of oppression; *Coming home* focuses on initial contact with others with disabilities thus the realization that one is not alone; *coming together*, defines the process of integrating one’s whole self and abandoning the references to certain body aspects or traits as “good” or “bad”; and finally *coming out* focuses on the external presentation of one’s self to the world, or in other words, taking pride in a disability identity. Therefore, separation-individuation is seen as a primary struggle for people with disabilities to improve their prospects of integration into a foundation for group identity development (Mahler, 1968) as well as individual growth and identity development.

Additionally, issues of social justice do relate to laws and legal protections that have been afforded to disadvantaged groups and serve to bolster identity for such groups. The Americans with Disabilities’ Act (ADA) (1990) is a prime example of how legislation and policy, although slow at times, can and does affect social change in the U.S. based on legal precedent. This anti-discriminatory legislation that protects those with disabilities from inequitable practices under the law has helped to give people with disabilities a sense of equal value and an expectation of societal acceptance and accommodations for their differentness. It also places the blame for "not fitting in" more on the creators of the restrictive environments, roles and occupations, and less on the individuals with disabilities themselves (McCann & Kim, 2002).

It is the intersection of disadvantaged and advantaged identities that better predict politicized identification and activist commitment toward promoting social change to overcome discrimination and social injustices (Case, Iuzzini, & Hopkins, 2012). Indeed, the process of identity politics is shaped by the multiplicity of available identities and their intersections, as well as experiences of marginalization and privilege connected to one's identities. Therefore, disability rights activism, with the inclusion of the philosophical foundation of the independent living movement has the potential to serve as a foundation for a comprehensive understanding of disability identity development. By utilizing the four assumptions of independent living, i.e.: that *all human life is of value*; that anyone, whatever their impairment, is *capable of exerting choices*; that people who are disabled by society's reaction to physical, intellectual, or sensory impairment have *the right to assert control over their lives*; and, that *disabled people have the right to fully participate in society* (Morris, 1993a), a definition of disability identity would include a sense of pride one has in assured self-acceptance regarding one's right to a normalized existence, fully participating in society based upon individual choice, *despite and at the same time because of one's disability*. Essentially, the independent living philosophy espouses living like everyone else. Such a foundation coupled with an enhanced understanding of identity development from both an individual and collective perspective would help to provide a rare but valued source of pride. The resulting theories regarding disability identity development would serve as a source of empowerment in the development of the aspect of identity that includes disability making the previously disadvantaged aspect of identity (disability) now an advantage.

References

ABES, E. S., JONES, S. R., & MCEWEN, M. K. (2007). Reconceptualizing the model of multiple dimensions of identity: The role of meaning-making capacity in the construction of multiple identities. *Journal of College Student Development, 48*(1), 1-22.

ALTMAN, B. M. (2014). Definitions, concepts, and measures of disability. *Annals of epidemiology*, *24*(1), 2-7.

AMERICANS WITH DISABILITIES ACT OF 1990, 42 U.S.C. Section 12101 *et seq.*

ANZALDÚA, G. (1987). *The New Mestiza.* Borderlands/La Frontera.

ASPINALL, P. J. (2001). Operationalizing the collection of ethnicity data in studies of the sociology of health and illness. *Sociology of health & illness*, *23*(6), 829-862.

BARNARTT, S. N. (1996). Disability culture or disability consciousness? *Journal of Disability Policy Studies*, *7*(2), 1-19.

BARNARTT, S., SCHRINER, K., & SCOTCH, R. (2001). Advocacy and political action. In G. L. Albrecht, K. D., Seelman, & M. Bury (Eds.), *Handbook of disability studies.* Thousand Oaks, CA: Sage.

BARR, S. M., BUDGE, S. L., & ADELSON, J. L. (2016). Transgender community belongingness as a mediator between strength of transgender identity and well-being. *Journal of counseling psychology*, *63*(1), 87.

BARRON, K., MICHAILAKIS, D., & SÖDER, M. (2000). People with disabilities and the public support system. In M. Szebehely (Ed.) *Welfare, nursing and care*. (pp. 137-170). Stockholm: Fritzes.

BISHOP, M. (2005). Quality of life and psychosocial adaptation to chronic illness and acquired disability: A conceptual and theoretical synthesis. *Journal of Rehabilitation*, *71*(2).

BURKE, P. J., & TULLY, J. C. (1977). The measurement of role identity. *Social Forces, 55*(4), 881-897.

BUTLER, J. (1991). Imitation and gender subordination. In D. Fuss (Ed.), *Inside/out: Lesbian theories, gay theories* (pp. 13-31). New York: Routledge.

CALDERÓN-ALMENDROS, I., & RUIZ-ROMÁN, C. (2016). Disadvantaged Identities: Conflict and Education from Disability, Culture and Social Class. *Educational Philosophy and Theory*, *48*(9), 946-958.

CASE, K. A., IUZZINI, J., & HOPKINS, M. (2012). Systems of privilege: Intersections, awareness, and applications. *Journal of Social Issues*, *68*(1), 1-10.

CHAN, F. E., DA SILVA CARDOSO, E. E., & CHRONISTER, J. A. (2009). *Understanding psychosocial adjustment to chronic illness and disability: A handbook for evidence-based practitioners in rehabilitation.* USA: Springer Publishing Co.

CHARMAZ, K. (1995). The body, identity, and self: Adapting to impairment. *The Sociological Quarterly, 36,* 657-680.

COLLINS, P.H. (1990). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment.* New York: Routledge.

CRAMER, E. P., & GILSON, S. F. (1999). Queers and crips: Parallel identity development processes for persons with nonvisible disabilities and lesbian, gay, and bisexual persons. *International Journal of Sexuality and Gender Studies, 4*(1), 23-37.

CURTIN, N., KENDE, A., & KENDE, J. (2016). Navigating multiple identities: The simultaneous influence of advantaged and disadvantaged identities on politicization and activism. *Journal of Social Issues*, *72*(2), 264-285.

DEAUX, K. (1993). Reconstructing social identity. *Personality and Social Psychology Bulletin, 19*, 4-12.

DEJONG, G. (1979). Independent Living: From Social Movement to Analytical Paradigm. *Archives of Physical Medicine and Rehabilitation, 60*(3), 436-446.

DENG, F. M. (1995). Frontiers of Sovereignty: A Framework of protection, assistance, and development for the internally displaced. *Leiden Journal of International Law, 8*(02), 249-286.

DISABLED PEOPLE'S INTERNATIONAL. (1991). *Vax Nostro By Laws.* Retrieved from http://www.dpi.org/ByLaws

FAUGHNAN, P. (1979). *The Dimensions of Need: A Study of the Members of the Irish Wheelchair Association.* Clontarf, Dublin: International Wheelchair Association.

FRASER, BURGESS, S. (2012). Group identity, deliberative democracy and diversity in Education. *Educational Philosophy and Theory*, *44*(5), 480-499.

FUSS, D. (1989). *Essentially speaking: Feminism, nature, and difference.* New York: Routledge.

GILL, C. J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation, 9*(1), 39-46.

GRANDIN, T. (1996). *Thinking in pictures and other reports from my life with autism.* New York, NY: Vintage Books.

GRANT, S. K. (1997). Disability identity development: An exploratory investigation*. Dissertation Abstracts International: Section B: The Sciences and Engineering*, 57 (09), 5918.

GRÖNVIK, L. (2009). Defining disability: effects of disability concepts on research outcomes. *International Journal of Social Research Methodology*, *12*(1), 1-18.

HAHN, H. (1997). An agenda for citizens with disabilities: Pursuing identity and empowerment. *Journal of Vocational Rehabilitation*, *9*(1), 31-37.

HAHN, H. D., & BELT, T. L. (2004). Disability Identity and Attitudes Toward Cure in a Sample of Disabled Activists*. *Journal of Health and Social Behavior*, *45*(4), 453-464.

HAHN, H., & HEGAMIN, A. P. (2001). Assessing scientific measures of disability. *Journal of Disability Policy Studies*, *12*(2), 114-121.

HEDLUND, M. (2004). *Shaping Justice: Defining the disability benefit category in Swedish social policy* (Vol. 58). Department of Sociology, Lund University.

HINKLE, S., TAYLOR, L. A., FOX-CARDAMONE, L., & ELY, P. G. (1998). Social identity and aspects of social creativity: Shifting to new dimension of intergroup comparison. In S. Worchel & J.F. Morales (Eds.), *Social identity: International perspectives* (pp. 166-179). London, UK: Sage.

HOGG, M. A., & ABRAMS, D. (1990). Social motivation, self-esteem and social identity. *Social Identity Theory: Constructive and Critical Advances,* 28(47), 317-334.

HOOKS, B. (1984). *Feminist theory from margin to center.* Boston, South End.

JENKINS, R. (2000). Categorization: Identity, social process and epistemology. *Current Sociology, 48*(3), 7-25.

JONES, E. E., FARINA, A., HASTORG, A. H., MARKUS, H., MILLER, D. T., & SCOTT, R. A. (1984). *Social stigma: The psychology of marked relationships.* New York: Freeman.

KATZENSTEIN, P. J. (ED.). (1996). *The culture of national security: Norms and identity in world politics.* Columbia University Press.

KEGAN, R. (1994). *In over our heads: The mental demands of modern life.* Cambridge, MA: Harvard University Press.

KESSLER, D., & KÜBLER-ROSS, E. (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss.* Scribner, NY, 17-20.

KYMLICKA, W. (1995). *Multicultural citizenship: A liberal theory of minority rights* (p. 174). Oxford: Clarendon Press.

LIVNEH, H., & PARKER, R. M. (2005). Psychological adaptation to disability perspectives from chaos and complexity theory. *Rehabilitation Counseling Bulletin, 49*(1), 17-28.

LORDE, A. (1984). *Sister outsider: Essays and speeches by Audre Lorde.* Freedom, CA: Crossing.

MAHLER, M. S. (1968). *On Human Symbiosis and the Vicissitudes of Individuation. Infantile Psychosis,* Volume 1.

MARKS, D. (1999). *Disability: Controversial debates and psychosocial perspectives.* London, UK: Routledge.

MARTIN, E. D. (ED.). (2001). *Significant disability: Issues affecting people with significant disabilities from a historical, policy, leadership, and systems perspective.* Springfield, IL: Charles C. Thomas.

MASHAW, J. L., & RENO, V. P. (2001). *Balancing security and opportunity: The challenge 0f disability income policy.* Washington DC: National Academy of Social Insurance.

MCCANN, C. R., & KIM, S. (2002). *Feminist theory reader: Local and global perspectives.* New York: Routledge.

MCVITTIE, C., GOODALL, K. E., & MCKINLAY, A. (2008). Resisting having learning disabilities by managing relative abilities. *British Journal of Learning Disabilities, 36,* 256-262.

MORRIS, J. (1993a). *Community care or Independent Living?* New York: The Joseph Rowntree Foundation.

MPOFU, E. (1999). *Social acceptance of Zimbabwean early adolescents with physical disabilities.* Madison: University of Wisconsin.

MPOFU, E., & HARLEY, D. A. (2006). Racial and disability identity implications for the career counseling of African Americans with disabilities. *Rehabilitation Counseling Bulletin*, *50*(1), 14-23.

NAGI, S. (1965). Some conceptual issues in disability and rehabilitation. *Sociology and rehabilitation*. (pp. 100-113). Washington DC: American Sociological Association.

NARIO-REDMOND, M. R. (2010). Cultural stereotypes of disabled and non-disabled men and women: Consensus for global category representations and diagnostic domains. *British Journal of Social Psychology, 49,* 471-488.

NOONAN, B. M., GALLOR, S. M., HENSLER-MCGINNIS, N. F., FASSINGER, R. E., WANG, S., & GOODMAN, J. (2004). Challenge and success: A qualitative study of the career development of Highly achieving women with physical and sensory disabilities. *Journal of Counseling Psychology, 51*(1), 68.

OLNEY, M. F., & BROCKELMAN, K. F. (2003). Out of the disability closet: Strategic use of perception management by select university students with disabilities. *Disability and Society, 18,* 35-50.

PHILLIPS, M.J . (1985). “Try harder”: The experience of disability and the dilemma of normalization. *Social Science Journal, 22,* 45-57.

PUTNAM, M. (2005). Conceptualizing disability developing a framework for political disability identity. *Journal of Disability Policy Studies*, *16*(3), 188-198.

REYNOLDS, A. L., & POPE, R. L. (1991). The complexities of diversity: Exploring multiple oppressions. *Journal of Counseling and Development, 70,* 174-180.

SCHUR, L. (1998). Disability and the psychology of political participation. *Journal of Disability Policy Studies, 9,* 3-31.

SHAKESPEARE, T. (2013). *Disability rights and wrongs revisited*. Routledge.

SMART, J. F. (2009). The power of models of disability. *Journal of Rehabilitation, 75*(2), 3.

STRYKER, S., & SERPE, R. T. (1982). *Personality, roles, and social behavior: Commitment, identity salience, and role behavior* (pp. 199-218). New York: Springer.

TAUB, D., BLINDE, E., & GREER, K. (1999). Stigma management through participation in sport and physical activity: Experiences of male college students with physical disabilities. *Human Relations, 52,* 1469-1483.

TAJFEL, H. (1982). Social psychology of intergroup relations. *Annual Review of Psychology, 33*(1), 1-39.

TAJFEL, H., & TURNER, J. C. (1979). An integrative theory of intergroup conflict. *The social psychology of intergroup relations*, *33*(47), 74.

TAYLOR, C. (1989). *Sources of the self: The making of the modern identity.* Harvard University Press.

TIERNEY, W. G., & DILLEY, P. (1998). Constructing knowledge: Educational research and gay and lesbian studies. In W.F. Pinar (Ed.), *Queer theory in education* (pp. 49-71). Mahwah, NJ: Lawrence Erlbaum.

TURNER, J. C. (1985). Social categorization and the self-concept: A social cognitive theory of group behavior. *Advances in Group Processes, 2,* 77-122.

TURNER, R. (1969). The Theme of Contemporary Social Movements, *British Journal of Sociology, 20(*5), 320-331.

UNITED NATIONS. (1996). *Manual for development of statistical information for disability programs and policies.* New York: United Nations.

WHITNEY, CHELSEA (2006). Intersections in identity – Identity development among Queer women with disabilities. *Sexuality and Disability, 24(1),* 39-52.

WOLFENSBERGER, W. (1982). A brief overview of social role valorization. *Mental Retardation, 38*(2), 105-123.

WOLFENSBERGER, W. (2011) Social role valorization and, or versus, “empowerment”. *Intellectual and Developmental Disabilities, 46(*6), 469-476.

WRIGHT, B. (1983). *Physical disability: A psychosocial approach (2nd Ed.).* New York: Harper & Row.

YOUNG, I. M. (1990). *Throwing like a girl and other essays in feminist philosophy and social theory* (p. 13). Bloomington: Indiana University Press.

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Le rôle des représentations sociales (surdité, parentalité, services professionnels) dans l'engagement des parents auprès de leurs enfants vivant avec une surdité au Québec

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Résumé

Les parents entendants d'un enfant vivant avec une surdité (PEES) sont aux prises, dès le début, avec une réalité peu familière qui occupe rapidement une place considérable dans leur vie. Cela est dû, entre autres, à l'arrivée quasi immédiate d'une gamme de services professionnels, ce qui sollicite un engagement de la part des PEES. Dans cet article, nous analysons l'engagement des PEES à partir de la théorie des représentations sociales. Vingt-neuf parents entendants ayant un enfant vivant avec une surdité dans la province de Québec (Canada) ont participé à notre enquête mixte combinant la technique d'évocation et des entrevues semi-dirigées. Nos résultats ont permis de montrer comment les représentations sociales de la surdité, de la parentalité et des services professionnels façonnent l'intensité et l'orientation du processus d'engagement des PEES auprès de leur enfant.

Mots-clés : surdité, parentalité, services professionnels, représentations sociales, engagement

Abstract

Parents of deaf children are immediately confronted with an unfamiliar reality that quickly occupies a significant part in their lives. This is due, amongst other things, to the almost immediate arrival of a range of professional services, which calls for the parent's engagement. In this article, we analyze the engagement of hearing parents of deaf children from the theory of social representations. Twenty-nine hearing parents with deaf children from the province of Quebec (Canada) participated in our research combining the evocation technique and semi-structured interviews. Our results have shown how social representations of deafness, parenthood and professional services shape the intensity and direction of the parent's engagement process with their child.

Keywords: deafness, parenthood, professional services, social representations, commitment

Les parents entendants d'un enfant vivant avec une surdité (PEES), avant de recevoir le diagnostic concernant leur enfant, ont habituellement très peu de contacts avec le monde de la surdité. De cette manière, ils se retrouvent soudainement dans la situation où ils doivent confronter leurs représentations concernant cette nouvelle réalité qui leur est totalement étrangère avec celles que véhiculent les professionnels. Dès les premiers soupçons d'une surdité chez leur enfant, les parents sont donc très rapidement plongés dans le « monde de la surdité ». La surdité, qui devient un objet central dans la vie familiale impliquant une panoplie de changements, sollicite un engagement important de la part des parents. Cet engagement, qui mobilise inévitablement d'une manière inégalée le temps des parents et leur énergie, est sollicité aussi en rapport avec les services professionnels entourant la surdité de leur enfant (Breau, 2016). Cela étant dit, l'engagement parental est à la fois volontaire et exigé (Breau & Gaucher, en rédaction). D'une part, les parents vont eux-mêmes, de manière volontaire, chercher à s'engager au maximum dans l'éducation de leur enfant. D'autre part, les professionnels de la surdité, qui constituent l'équipe d'encadrement de leur enfant, vont solliciter l'engagement des parents pendant certaines de leurs interventions. Nous partons de la prémisse que l'intensité et l'orientation de cet engagement sont façonnées par les représentations sociales des parents de la surdité, de la parentalité et des services professionnels.

Problématique

Les PEES vont chercher à s'intégrer dans le monde de la surdité en recueillant le plus d'informations possible concernant cette nouvelle vie qui les attend. Les PEES vont s'engager volontairement dans cette démarche en allant poser des questions aux professionnels de la surdité, participer à des activités organisées par des associations qui œuvrent dans le domaine, faire des recherches sur Internet, etc. (Breau, 2016). Les PEES seront aussi sollicités par les professionnels de la surdité qui cherchent à les engager dans les interventions. Les parents sont donc « bombardés » de nouvelles informations, de rendez-vous avec des professionnels, de décisions à prendre, et ces parents doivent faire le tri entre tous ces éléments tout en composant avec une gamme d'émotions particulièrement difficiles.

Dans l'histoire du traitement des personnes vivant avec une surdité, surtout sur le plan de la scolarisation des enfants, il y a depuis des siècles une lutte entre deux courants de pensée, soit le courant oraliste et le courant gestuel (Encrevé, 2008; Gaucher, 2009). Les tenants du courant oraliste vont militer pour que la surdité soit considérée comme une déficience ou un handicap que l'on peut réadapter à l'aide de prothèses auditives et de méthodes d'articulation dans le but de donner aux enfants sourds l'accès à la parole (Gaucher, 2009). Les tenants du courant gestuel, quant à eux, vont considérer la surdité comme la caractéristique distinctive d'une minorité linguistique qui permet aux personnes vivant avec une surdité de s'organiser autour d'une culture commune qui valorise leur langue signée (Gaucher, 2009). Ces deux discours dominent le monde de la surdité tout en se confrontant et les parents doivent se positionner du mieux qu'ils le peuvent dans ces débats dont les tenants et les aboutissants leur échappent souvent.

Étant donné que 90 % des enfants vivant avec une surdité sont nés de parents entendants[1] (Clerebaut, 2005), la majorité des PEES n'ont jamais côtoyé de près des personnes vivant avec une surdité. Cela dit, les parents partagent souvent les représentations sociales de la surdité des personnes entendantes (Dagron, 2006). En étant de plus en plus baignés dans cette nouvelle réalité qu'est le monde de la surdité, les parents sont maintenant à l'affût des multiples discours qui circulent, ce qui contribue à la diversité des prises de position concernant les représentations sociales des parents (Clémence, Doise, & Lorenzi-Cioldi, 1994). Les réponses qu'ils vont aller chercher, les histoires et les anecdotes qu'ils vont entendre, ainsi que les émotions qu'ils vont vivre,

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[1] Selon la nomenclature de la communauté sourde, les parents entendants ne vivent pas avec des incapacités auditives et ne font pas partie du monde identitaire sourd (Gaucher, 2008).

vont façonner leur représentation de la surdité à la suite du diagnostic. L'intensité de leur engagement envers leur enfant sourd transformera leurs représentations sociales de la surdité (Tafani, 2001).

Afin de mieux comprendre l'engagement parental qui est l'objet de la recherche, nous avons choisi de l'observer à travers la théorie des représentations sociales. Plus précisément, nous nous proposons d'étudier le contenu et l'organisation de trois représentations sociales des PEES au Québec, soit la représentation sociale de la surdité, la représentation sociale de la parentalité et la représentation sociale des services professionnels. Nous supposons que l'engagement des parents se manifeste au sein de ces trois représentations sociales, lesquelles viennent à leur tour façonner cet engagement.

La théorie des représentations sociales

Selon Moscovici (2013), les personnes appartenant au même groupe social vont se former des représentations sociales relatives à des objets de leur environnement afin de rendre familier ce qui leur est « étrange, troublant, mystérieux » (p. 39). Et, c'est à partir de ces représentations sociales que l'on peut avoir accès à la signification accordée par les gens à différentes réalités de leur vie quotidienne. Les représentations sociales peuvent être définies ainsi comme des systèmes d'éléments cognitifs constitués d'opinions, de connaissances et de croyances propres à un groupe social et « relatives à des objets de l'environnement social » (Rateau & Lo Monaco, 2013, p. 3).

Abric (2001) propose une approche structurale de la théorie des représentations sociales. Selon cet auteur (2001), une représentation sociale « constitue un système sociocognitif particulier composé de deux sous-systèmes en interaction : un système central (ou noyau central) et un système périphérique » (p. 82). Selon Abric (2001), le noyau central de la représentation sociale, lequel est résistant au changement, détermine « la signification de la représentation (fonction génératrice), son organisation interne (fonction organisatrice) et sa stabilité (fonction stabilisatrice) » (p. 82). Les éléments du noyau central organisent la représentation sociale et génèrent sa signification. Ils sont acceptés par la majorité des membres du groupe et considérés comme essentiels pour définir le caractère unique de l'objet de représentation.

Les éléments périphériques vont à leur tour assurer trois fonctions, selon Flament (1995). Premièrement, ils influencent les comportements et les prises de position des individus puisqu'ils régissent ce qui est normal ou ce qui ne l'est pas dans chaque situation présentée. Deuxièmement, le système d'éléments périphériques s'adapte au contexte dans lequel il se trouve pour permettre une « personnalisation de la représentation et des conduites qui lui sont attachées » (Rateau & Lo Monaco, 2013, p. 11). Troisièmement, le système périphérique protège le système central de la représentation sociale en étant plus souple et plus malléable que le système central.

Les éléments périphériques ont un rôle considérable à jouer dans la dynamique représentationnelle, car, même s'ils sont moins répandus et non essentiels dans la définition de l'objet de représentation, ils permettent aux membres du groupe de s'adapter aux différents contextes sociaux qui concernent cet objet. La structure de la représentation sociale est importante, car, bien que deux représentations sociales puissent contenir les mêmes éléments, si leur structure est différente, cela aboutit à deux représentations sociales complètement distinctes.

Les représentations sociales et leurs fonctions dans l'engagement des PEES

Les représentations sociales peuvent remplir au moins quatre grandes fonctions en lien avec l'engagement des PEES : une fonction de connaissance, une fonction identitaire, une fonction de guide pour le comportement et une fonction motivationnelle.

Les représentations sociales remplissent une fonction de connaissance de la surdité à travers un processus de précodage et une intégration de l'information dans un cadre de référence commun et en cohérence avec les valeurs, les normes et les pratiques des parents (Abric, 1994). En côtoyant de plus en plus de PEES, d'enfants sourds et de professionnels de la surdité, les parents ont accès à une panoplie de nouvelles informations. Ils intègrent ces représentations qui reflètent leur vécu lié à la situation dans laquelle eux et leur enfant se retrouvent (Jodelet, 2006). Ainsi, armés de ces connaissances, les parents sont en meilleure position pour s'engager activement dans les services professionnels de manière efficace. Sans ces représentations, les parents restent perdus face à toutes les tâches qui leur sont demandées de réaliser et aux adaptations qu'ils doivent apporter à leur fonctionnement quotidien (Tafani, 2001).

Les représentations sociales assument un autre rôle fondamental dans la vie des parents entendants qui ont appris la surdité de leur enfant. Ces représentations assument une fonction identitaire (Abric, 1994) qui permet à ces parents d'exprimer leur appartenance au monde de la surdité. Comme les parents sont maintenant amenés à s'intégrer dans le monde de la surdité, lequel inclut tous les services professionnels, les associations de personnes sourdes, les forums de discussion, les échanges entre parents, etc., les représentations sociales qui y circulent permettent aux parents entendants ayant un enfant vivant avec une surdité de définir et d'affirmer leur appartenance et leur position par rapport à cette nouvelle réalité (Deschamps & Moliner, 2012). Ces parents doivent apprendre comment faire partie de ce groupe et cet apprentissage se fait tout au long de leur appropriation des représentations sociales qui circulent par l'intermédiaire des différents acteurs du groupe.

Les représentations sociales ont aussi une fonction de guide du comportement et des pratiques (Abric, 1994; Moscovici, 1961); elles permettent de définir la finalité de la situation, de produire des anticipations et des attentes, et de définir ce qui est une conduite normative ou une conduite non normative. En tant que lignes directrices, les représentations sociales permettent de mieux comprendre certains comportements démontrés par les parents ainsi que les réactions que ceux-ci ont face à des situations dans lesquelles ils se retrouvent (de Sà, 1994). L'engagement se crée dans l'action (Thévenot, 2000; Valence & Rousiau, 2014); ainsi, en tant que guides pour l'action, les représentations sociales jouent un rôle fondamental dans son orientation.

Les représentations sociales ne sont pas composées uniquement de cognitions, elles ont également une composante affective qui, selon certains auteurs (De Rosa, 1993; Delouvée, 2006; Jodelet, 1989), est même essentielle. Ce qui suggère une dernière fonction des représentations sociales en lien avec l'engagement des PEES, celle de la motivation. Le caractère « sensible » de certains objets sociaux, comme la parentalité par exemple, est en mesure de susciter certaines émotions chez les PEES. Ces émotions, en plus de contribuer à une organisation spécifique de la représentation (Campos & Rouquette, 2000; Deschamps & Guimelli, 2002; Lheureux & Guimelli, 2009), peuvent mobiliser une action par l'intensité que ces émotions génèrent en raison de certaines perceptions partagées (Rimé, 2005) par les parents. Les pratiques « seraient ainsi mises en œuvre sous l'impulsion motivationnelle des émotions constitutives de la composante émotionnelle » (Lheureux & Guimelli, 2009) des représentations sociales.

Si, par leurs fonctions de connaissance, identitaire et de guide pour le comportement, les représentations sociales peuvent nous informer sur l'orientation que l'engagement des PEES peut prendre. Elles peuvent également, par leur fonction motivationnelle, nous permettre d'observer l'intensité de cet engagement.

Méthodologie de recherche

Les données présentées dans cet article émergent d'une recherche plus large, qui a porté sur l'expérience d'engagement de parents entendants francophones ayant un enfant vivant avec une surdité, dans quatre pays francophones : le Canada, la France, la Suisse et la Belgique. Dans cet article, nous allons présenter seulement les données obtenues au

Québec, un sous échantillon des participants canadiens.

Les témoignages de quatorze mères et de quinze pères, soit au total 29 PEES provenant du Québec (Canada), ont constitué le matériel analysé dans le cadre de cet article. Les participants ont été recrutés sur une base volontaire. Le recrutement a été effectué par l'intermédiaire de l'Association du Québec pour enfants avec problèmes auditifs (AQEPA), qui a fait circuler un appel dans ses réseaux invitant les parents intéressés par notre recherche à communiquer avec nous. Nous avons ensuite proposé à ces parents d'organiser une rencontre afin de discuter de leur expérience en tant que PEES. L'échantillon obtenu a permis d'interroger des parents vivant dans différentes régions du Québec, utilisant différents types de services et ayant des enfants d'âges différents ayant des niveaux variés de surdité.

Nous avons utilisé une méthode de collecte de données mixte en combinant la technique d'évocation de Verges (2002) et des entrevues semi-dirigées. Nous avons commencé par la technique d'évocation. Les parents étaient invités à nous donner trois à cinq mots qui leur venaient à l'esprit lorsqu'ils entendaient les mots stimulus : « sourd », « parent » et « professionnel de la surdité ». Ensuite, les parents étaient invités à mettre les mots ainsi fournis en ordre d'importance, 1 étant le plus important et 5 étant le moins important. L'entrevue se poursuivait avec des questions regroupées en six grands thèmes, soit le contexte familial, l'annonce de la surdité, la communication, l'accompagnement, le contact avec la communauté sourde et le contact avec l'AQEPA. À l'intérieur de ces grands thèmes, nous avions prévu une série de questions qui nous a permis d'interroger les parents pour mieux comprendre ce que signifie pour eux être le parent entendant d'un enfant vivant avec une surdité et les défis qu'une telle situation implique.

Nous avons effectué l'analyse de ces données en deux temps. Tout d'abord, nous avons effectué un travail de catégorisation qui nous a permis de regrouper les mots qui avaient un sens proche dans une catégorie thématique[2]. Par exemple, si les parents ont évoqué les mots amour, aimer et aimant, nous avons regroupé ces mots dans une catégorie que nous avons appelée « amour ». Le discours des PEES lors des entrevues semi-dirigées nous a permis de préciser au besoin les significations accordées aux évocations par les participants. Ensuite, nous avons calculé la fréquence des mots et la moyenne des rangs d'importance attribués aux mots qui composent chaque catégorie. Il convient de noter que nous avons exclu de l'analyse les mots exprimés une seule fois, les mots qui ne se retrouvaient dans aucune des catégories et les mots qui étaient jugés comme peu importants par les PEES pour définir les objets des représentations étudiées.

Cette analyse nous a permis de produire un tableau à quatre cadrans pour illustrer la structure de chaque représentation sociale (surdité, parentalité et services professionnels). Afin de classer les éléments représentationnels, nous nous sommes référés aux calculs de la moyenne d'importance et de la fréquence. Dans les tableaux, chaque élément est suivi de deux chiffres. Le premier chiffre entre les parenthèses indique la moyenne d'importance alors que le deuxième la fréquence moyenne des mots composant la catégorie qui constitue l'élément. Le premier cadran comprend les éléments qui sont ressortis comme à la fois importants et fréquents. Ce sont les catégories thématiques qui peuvent constituer les éléments centraux de la représentation sociale étudiée. Les autres cadrans contiennent les éléments périphériques. Le deuxième cadran représente les éléments qui sont ressortis comme très importants, mais qui étaient peu fréquents. Ces éléments sont partagés par une minorité, mais considérés en même temps par elle comme

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[2] Nous utilisons le concept « catégorie » ou « catégories thématiques » lorsque nous faisons référence au résultat du travail de catégorisation thématique comme composante de l'analyse de contenu. Nous utilisons le concept « élément » ou « élément central » ou encore « élément périphérique » lorsque nous analysons le contenu de la représentation sociale en question. Finalement, nous utilisons le concept « évocation » ou simplement « mot » ou encore « expression » pour rendre compte des associations que les répondants ont produites dans le cadre de la méthode d'évocation.

ayant un degré d'importance élevé. Le troisième cadran représente les éléments qui sont moins importants, mais fréquents. Les mots de ces catégories thématiques ont été mentionnés par beaucoup de parents, mais ceux-ci n'y ont pas attribué une très grande importance pour définir l'objet de représentation. Le quatrième cadran comprend les catégories thématiques constituées des évocations qui sont moins importantes et moins fréquentes. Ces éléments représentationnels sont sans doute périphériques, leur rôle étant d'assurer l'adaptation du discours aux modulations du contexte.

Les limites de l'étude

La technique d'évocation a l'avantage de nous donner un accès à des associations spontanées faites par des parents en lien avec les objets de représentation, ce qui nous permet de saisir toute la richesse du contenu représentationnel. Cependant, les significations générales des mots ou des expressions produits ne permettent pas toujours de bien saisir le sens subjectif qui leur est attribué par les répondants. Pour dépasser cette limite, nous avons pu corroborer les significations des évocations, surtout lorsqu'elles étaient ambiguës ou polysémiques, avec le discours des répondants lors des entrevues. Ce travail d'analyse fera l'objet d'une autre publication.

L'analyse de la fréquence et du rang d'importance des évocations nous a permis de bien saisir la structure des représentations sociales des PEES, sans pour autant nous permettre de recenser avec précision les éléments qui font partie du noyau central ou du système périphérique. D'autres techniques, comme l'induction par scénario ambigu (ISA) ou la méthode de mise en cause (MEC), sont nécessaires pour confirmer l'appartenance des éléments au noyau central de la représentation (Abric, 2003). D'autres recherches sont nécessaires pour valider nos hypothèses de centralité des éléments représentationnels étudiés. Notre objectif était cependant de comprendre le rôle des représentations sociales étudiées dans l'engagement des parents et, dans une moindre mesure, de constater l'appartenance des éléments représentationnels au noyau central.

Les représentations sociales des parents ayant des enfants vivant avec une surdité

- Représentation sociale de la surdité

La représentation sociale de la surdité est au centre de notre analyse. Nous supposons que l'engagement des parents dans les services professionnels de la surdité de leur enfant est fortement influencé par la manière dont ces parents se représentent la surdité. Les parents ont produit un total de 117 évocations en association avec le mot inducteur « sourd ». À partir de ces évocations, nous avons formé quatorze catégories thématiques qui ont regroupé 103 de ces mots. N'ayant été mentionnées qu'une seule fois, les quatorze évocations restantes ont été mises de côté.

Dans le premier cadran, nous retrouvons les éléments représentationnels importants et fréquents de la représentation sociale de la surdité pouvant prétendre à un statut central dans l'organisation représentationnelle. Nous retrouvons dans ce cadran des évocations qui témoignent des « difficultés » (2,5[3]; 18[4]) que les parents associent à la surdité. Par difficultés, les PEES mentionnent entre autres des défis associés à l'intégration, à l'épanouissement, à la socialisation et à l'apprentissage de leur enfant. La variété des mots évoqués dans cette catégorie par les PEES atteste de la multitude et de la complexité de difficultés que ces parents attribuent à la surdité.

Dans les éléments représentationnels moins fréquents, mais ayant une grande importance, plusieurs cas de figure ressortis se retrouvent dans le deuxième cadran du tableau 1. Les catégories « enfant » (1; 3) et « isolement » (1; 2) contiennent toutes les deux des évocations qui ont été évaluées par les répondants comme étant en moyenne plus importantes que tous les autres éléments représentationnels. Les parents qui ont mentionné ces deux éléments étaient tous d'accord pour leur attribuer

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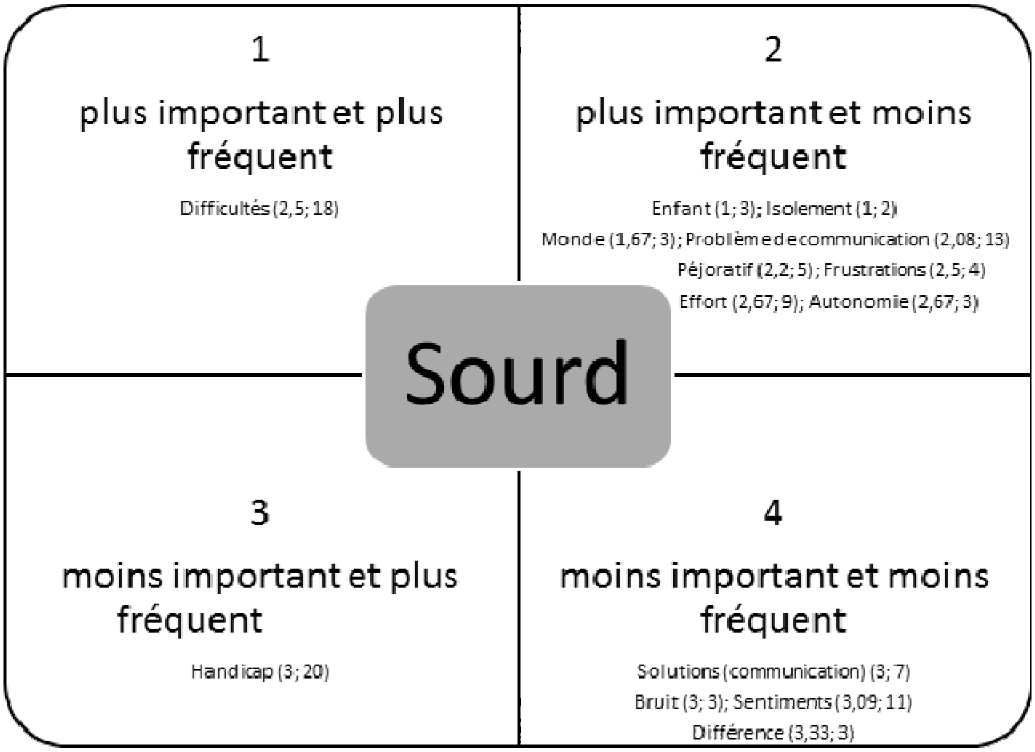
[3] Numéro d'importance attribué en moyenne aux évocations de cette catégorie.

[4] Fréquence des évocations appartenant à cette catégorie.

TABLEAU 1 : LES ÉLÉMENTS REPRÉSENTATIONNELS DE LA REPRÉSENTATION SOCIALE DE LA SURDITÉ ET LEUR ORGANISATION SELON LEUR IMPORTANCE ET LEUR FRÉQUENCE



l'importance la plus élevée (1). Donc, malgré le fait qu'ils ne sont pas très fréquents, ces éléments représentationnels sont considérés comme les plus importants pour ces PEES. Ces deux éléments représentationnels sont suivis, en ordre d'importance moyenne, par « monde » (1,67; 3), « problèmes de communication » (2,08; 13), « péjoratif[5]» (2,2; 5), « frustrations » (2,5; 4), « effort » (2,67; 9) et « autonomie » (2,67; 3).

Dans le troisième cadran, nous retrouvons l'élément représentationnel « handicap » (3; 20) dans lequel nous avons regroupé toutes les évocations qui font référence au manque de capacité auditive. Ces termes sont souvent utilisés pour décrire la situation de leur enfant, telle que : « handicapé », « malentendant », « muet », « qui n'entend pas ». Cet élément représentationnel est ressorti comme le plus fréquent, soit à 20 reprises. Toutefois, son importance moyenne est de trois, ce qui est un peu plus bas que l'importance moyenne des évocations qui composent l'élément représentationnel déjà mentionné des « difficultés ».

Dans le quatrième cadran, la catégorie « solutions à la communication » (3; 7) contient des évocations qui s'associent à chacun des deux courants dominants dans le monde de la surdité, soit le courant oraliste et le courant gestuel. Les appareils (courant oraliste) ont été nommés par quatre parents et la notion de langue des signes (courant gestuel) par trois parents. Bien que l'élément langue des signes soit mentionnée par moins de parents, son importance est plus élevée. Cela met en relief, à notre avis, le clivage entre les deux options. D'autres éléments représentationnels : « bruit » (3; 3), « sentiments » (3,09; 11) et « différence » (3,33; 3) se retrouvent aussi à la périphérie de cette représentation sociale.

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[5] Il faut noter que l'association du mot « péjoratif » s'explique par l'utilisation du mot à connotation péjorative « sourd » comme mot-stimulus. Nous avons dû changer de mot dans d'autres sites (voir notre note 3).

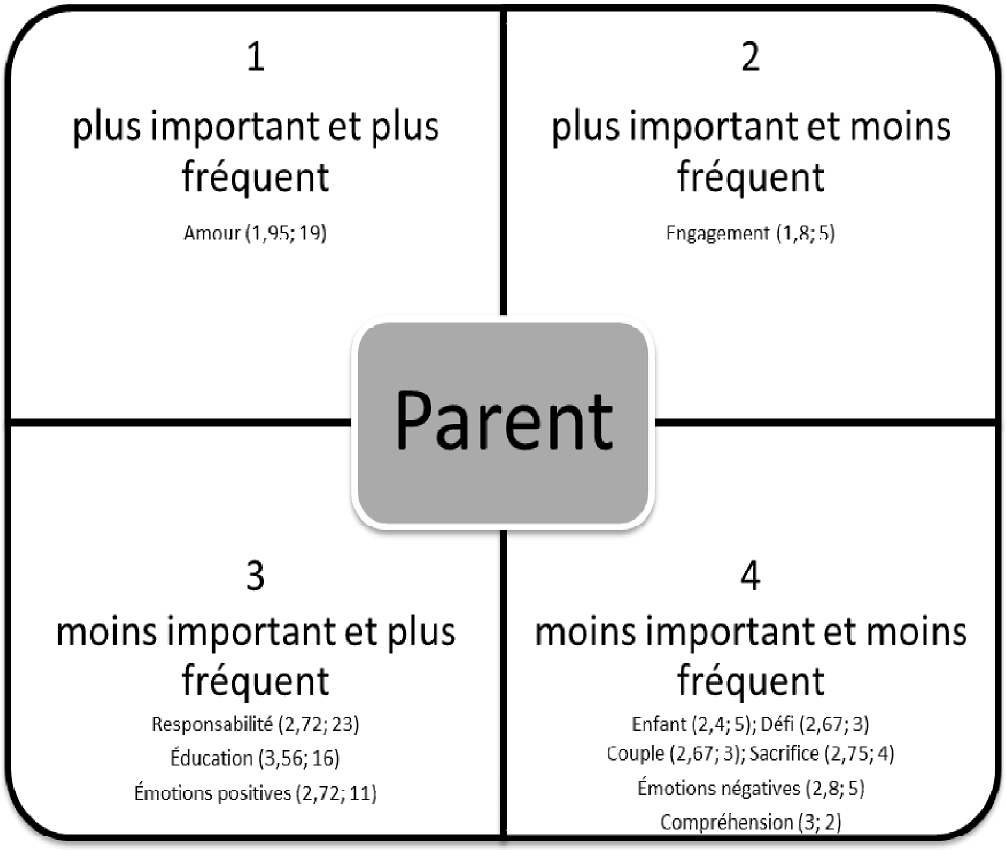
Représentation sociale de la parentalité

Les parents sont des acteurs importants dans tout ce qui entoure la vie de leur enfant et en ce qui a trait à sa surdité. Ainsi, en plus de la représentation sociale de la surdité, nous nous sommes intéressés à la représentation sociale que les PEES ont de la parentalité. La représentation sociale de la parentalité est formée de douze éléments qui comprennent 110 des 124 évocations mentionnées par les PEES que nous avons rencontrés.

L'« amour » (1,95; 19), qui se situe dans le premier cadran du tableau 2, constitue l'élément à la fois fréquent et important de cette représentation sociale. Les parents vont évoquer des mots comme amour, aimant, aimer, famille et valeur pour parler de leur amour en tant que parents. Cet élément central témoigne de la force, de l'énergie énorme que les parents sont prêts à investir pour agir et trouver des solutions aux difficultés de leur enfant.

L'élément représentationnel considéré comme le plus important par les parents, même s'il est moins fréquent, est cependant « l'engagement » (1,8; 5), qui se situe dans le deuxième cadran. L'élément représentationnel des évocations les plus fréquentes, dans le troisième cadran, renvoie à la « responsabilité » parentale (2,72; 23). Dans cet élément représentationnel, nous avons inclus tous les mots qui font référence à la responsabilité des parents, soit leurs obligations, leur présence, la protection et le soutien qu'ils assurent à leur enfant. Ce fait révèle l'idée que même si la responsabilité est considérée par un plus grand nombre comme une caractéristique de la parentalité des PEES, l'engagement est considéré comme un élément plus important pour définir cette parentalité. Il y a aussi le terme « éducation »

TABLEAU 2 : LES ÉLÉMENTS REPRÉSENTATIONNELS DE LA REPRÉSENTATION SOCIALE DE LA PARENTALITÉ ET LEUR ORGANISATION SELON LEUR IMPORTANCE ET LEUR FRÉQUENCE



(3,56; 16**)**, un élément représentationnel dans lequel nous avons mis les évocations qui sont en lien avec l'éducation scolaire formelle et les évocations que les parents vont associer au fait qu'ils sont des exemples pour leur enfant et qu'ils participent à leur développement en tant qu'éducateurs. Ainsi, les parents vont avoir le rôle d'encadrer et de stimuler leur enfant.

Les parents ont aussi mentionné des « émotions positives » (2,72; 11), telles que plaisir, fierté, joie, bonheur et aventure, et des émotions négatives » (2,8; 5) tels que défi, sacrifice et couple brisé, qu'ils associent avec le fait d'être parent. Nous voyons que les PEES ont mentionné deux fois plus d'émotions positives que d'émotions négatives. Être parent est donc une expérience plus positive que négative pour les PEES que nous avons rencontrés.

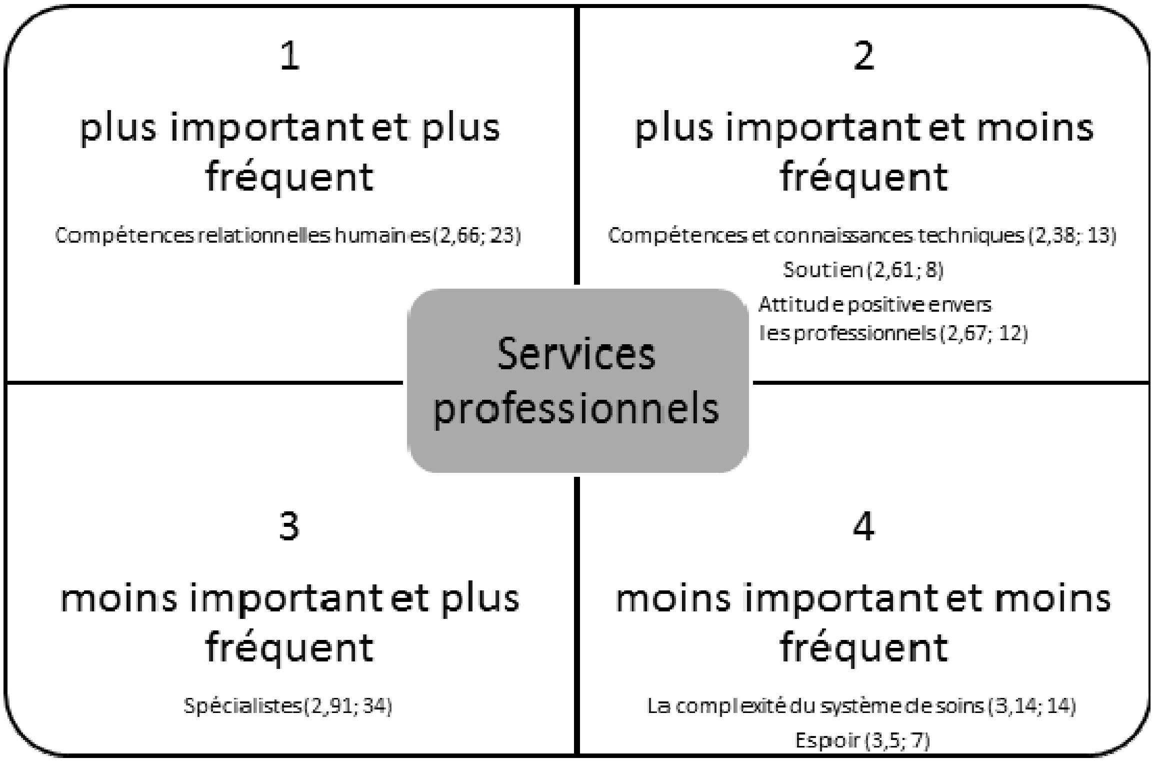
En plus des « émotions négatives » (2,8; 5) dans le quatrième cadran, des éléments comme « enfant » (2,4; 5), « défi » (2,67; 3), « couple » (2,67; 3), « sacrifice » (2,75; 4) et « compréhension » (3; 2) complètent cette représentation de la parentalité dans sa périphérie.

Représentation sociale des services professionnels

Finalement, nous nous sommes intéressés à la représentation sociale des services professionnels. Étant donné que les professionnels de la surdité sont des acteurs importants dans le suivi de l'enfant vivant avec une surdité, nous supposons que la représentation sociale que les parents ont d'eux aura une influence sur leur engagement dans les services qu'ils offrent. La représentation sociale des services professionnels est formée de sept éléments représentationnels. Ces catégories thématiques comprennent 116 des 121 évocations mentionnées par les PEES que nous avons rencontrés.

Les données que nous avons recueillies sur le terrain nous portent à penser que les parents organisent leur représentation sociale des services professionnels autour des « compétences relationnelles et humaines des professionnels » (2,66; 23); ce sont les données situées dans le premier cadran du tableau 3. Cet élément représentationnel comprend les évocations qui reflètent les compétences que les

TABLEAU 3 : LES ÉLÉMENTS REPRÉSENTATIONNELS DE LA REPRÉSENTATION SOCIALE DES SERVICES PROFESSIONNELS ET LEUR ORGANISATION SELON LEUR IMPORTANCE ET LEUR FRÉQUENCE



1 plus important et plus fréquent Compétences relationnelles humaines (2,66; 23)	2 plus important et moins fréquent Compétences et connaissances techniques (2,38; 13) Soutien (2,61; 8) Attitude positive envers les professionnels (2,67; 12)
3 moins important et plus fréquent Spécialistes (2,91; 34)	4 moins important et moins fréquent La complexité du système de soins (3,14; 14) Espoir (3,5; 7)

Services professionnels

parents s'attendent à voir chez les professionnels. La majorité des PEES ont évoqué l'importance de compétences comme la compréhension, l'empathie, la collaboration, etc. lorsque des professionnels travaillent auprès de leur enfant. Même les trois parents qui ont mentionné que les professionnels de la surdité n'étaient pas compréhensifs ont fait cette affirmation pour montrer l'importance qu'ils accordent à ce type de compétence chez les professionnels qui font les interventions auprès de leur enfant.

Cela dit, les « compétences et connaissances techniques » (2,38; 13), l'élément le plus important dans le deuxième cadran, sont des qualités passablement moins importantes pour définir le bon travail des professionnels; elles sont également partagées par beaucoup moins de parents que « les compétences relationnelles humaines » (2,66; 23). Les PEES associent à cet élément des connaissances spécialisées, des compétences professionnelles, des expériences thérapeutiques, des habiletés techniques, etc. Encore une fois, un mot à connotation négative, « incompétence », mentionné (1/13) par un des parents rencontrés, souligne l'importance qu'ils accordent à cet élément. Le « soutien » (2,61; 8) que les parents reçoivent des professionnels est aussi ressorti comme important pour définir les services professionnels, malgré sa faible fréquence. Les « attitudes positives » (2,67; 12) envers les professionnels se situent aussi parmi ces éléments représentationnels.

La représentation sociale des services professionnels semble confirmer le rôle important que jouent les professionnels de la santé dans l'orientation de l'engagement des parents. L'élément le plus fréquent de la représentation sociale des services professionnels est celui qui renvoie aux différents « spécialistes » (2,91; 34) de la surdité. Il convient de noter que dans les 34 mots évoqués qui constituent cet élément, « interprète » est ressorti à deux reprises seulement. Les 32 autres évocations sont toutes associées à des professionnels de la santé qui se sont spécialisés dans un domaine médical lié à la surdité : audiologistes, orthophonistes, audioprothésistes, oto-rhino-laryngologiste (ORL), médecins, etc. Finalement, « la complexité du système de soins » (3,14; 14), élément situé dans le quatrième cadran, qui contient les éléments les moins fréquents et les moins importants de la représentation, renvoie à la difficulté des parents à se retrouver dans le système de soins, tout en ayant l'« espoir » (3,5; 7) que ce dernier apporte la solution aux difficultés de leurs enfants.

Discussion

Selon nos résultats, les représentations sociales des parents entendants ayant un enfant vivant avec une surdité façonnent aussi bien l'orientation que l'intensité de l'engagement des parents dans tout ce qui entoure la surdité de leur enfant. Au cours de nos entrevues, nous avons discuté avec des parents qui vivent dans des régions différentes et qui ont accès à différents services, qui ont des enfants d'âges variés et qui ont des enfants ayant divers niveaux de surdité. Bref, le parcours diffère pour tous les parents. Bien que cette diversité de parcours explique les multiples prises de position minoritaires ou même individuelles (Vergès, 1995), nous avons également recensé des éléments communs autour desquels les parents construisent leurs représentations de la surdité, de la parentalité et des services professionnels. Cette dernière constatation témoigne non seulement des préoccupations et expériences communes des parents, mais aussi de leur sentiment d'appartenance au même monde, celui de la surdité (Cohen-Scali & Moliner, 2008; Fraysse, 2000). L'irréversibilité perçue du changement survenu dans leur vie contribue d'une manière fondamentale à l'adoption de cette nouvelle identité (Tafani, Mugny, & Bellon, 1999).

La représentation sociale de la surdité des PEES est organisée autour de l'élément « difficultés », lequel renvoie à une réalité complexe (Zaidman-Zait et coll., 2016) qui leur pose beaucoup de défis et de contraintes (Friedman Narr & Kemmery, 2014). Pour eux, la surdité constitue en quelque sorte un problème qu'ils doivent résoudre. Ce problème de la surdité est, selon cette représentation des parents, largement lié à la communication. Cette association de la surdité au problème de communication résonne, dans un contexte de représentation médicale de la surdité, comme un handicap, association qui se fait de manière « implicite parmi la population entendante » (Dagron, 2006, p. 242). Ainsi, le fait que les parents ciblent directement le problème de la communication vient en quelque sorte préciser le chemin qui doit être emprunté pour y apporter des solutions. Malgré le peu d'études menées sur l'engagement des PEES (Sugden et coll., 2016), il est connu que c'est surtout ce désir de chercher des solutions aux « difficultés » de communication de leur enfant qui amène les parents à s'engager dans les services professionnels.

Contrairement aux résultats d'une étude effectuée en France (Dagron, 2006), la représentation sociale de la surdité de nos répondants ne se limite pas exclusivement à une réponse médicale aux « difficultés » de communication de l'enfant sourd. Notre étude dévoile, en effet, parmi les éléments périphériques, deux types de solutions représentées par les parents québécois participants. D'un côté, les parents voient effectivement comme solution les « appareils » ou les solutions techniques ou médicales. De l'autre, la solution qui se présente est liée aux « langues des signes ». Il est tout de même intéressant de voir que le dernier élément, « langue des signes », a un rang d'importance plus élevé que l'élément « appareils » qui, lui, est plus fréquent. Autrement dit, ceux qui se représentent des solutions médicales pour le « problème » de la surdité de leur enfant sont plus nombreux, même si une minorité de parents trouvent que l'intégration de leur enfant dans la communauté sourde est une meilleure solution. Dans ces conditions, il est légitime de se demander s'il s'agit, dans le cas de l'élément « langue des signes », simplement d'une représentation minoritaire ou plutôt d'un possible indice de l'émergence (Negura, 2006) d'une nouvelle représentation des parents.

Compte tenu, encore une fois, que les parents voient la surdité comme un problème auquel ils cherchent à remédier, ils sont très réceptifs à la solution qui leur est présentée par les professionnels de la santé à la suite du diagnostic officiel (Allen, Crawford, & Mulla, 2016; Dal Forno et coll., 2015). Ce n'est pas par hasard que la quasi-totalité des praticiens mentionnés par les parents dans leurs évocations œuvraient dans le domaine de la santé et non dans la communauté sourde. De plus, les parents ont évoqué et complimenté plusieurs compétences et connaissances propres aux professionnels de la santé et des services que ces derniers offrent, ce qui pourrait témoigner de l'autorité que ces spécialistes ont auprès des parents. Dans les moments les plus difficiles, les médecins et les autres membres de l'équipe médicale auxquels les parents font confiance leur présentent des « solutions » (Dagron, 2006) qui vont prétendument venir remédier à la situation qui leur cause tant d'angoisses : leur enfant n'entend pas et conséquemment ne peut pas communiquer avec eux.

La représentation sociale de la parentalité vient appuyer cette volonté des parents de régler les « difficultés » de communication de leur enfant, de l'« aider », de s' « occuper » de lui et d' « être présent » auprès de leur enfant (Erbasi et coll., 2016; Suden et coll., 2016; Zaidman-Zait et coll., 2017). C'est en ayant beaucoup d' « amour » que les parents réussissent en « défonçant les portes » et en étant « débrouillards » à devenir des agents de changement dans la vie de leur enfant. La représentation sociale de la parentalité vient donc témoigner de l'immense amour des parents pour leur enfant, amour qui soutient leur sentiment d'être responsables de régler les difficultés de communication de leur enfant. C'est en s'engageant, autrement dit en s'occupant de lui et en étant investis dans la vie de leur enfant, que les parents sentent qu'ils prennent leurs responsabilités en tant que parents (Moeller et coll., 2013). L'« amour », qui semble ressortir comme élément central de cette représentation, témoigne de la force, de l'énergie que les parents sont prêts à investir pour agir et trouver des solutions aux difficultés de leur enfant (Steinberg et coll., 1997; Szarkowski & Brice, 2016). Malgré les défis et les sacrifices que cela comporte, le fait d'être parent d'un enfant sourd suscite des émotions positives et quelques fois aussi des émotions négatives. L'intensité de l'engagement des PEES est donc façonnée par cette représentation sociale. La motivation pour l'engagement est très élevée chez les PEES; ceux-ci sont prêts à s'impliquer à un très haut niveau pour améliorer le sort de leur enfant.

La représentation sociale à l'égard des services professionnels semble confirmer le rôle important que jouent les professionnels de la santé dans l'orientation de l'engagement des parents. L'élément le plus fréquent de la représentation sociale des services professionnels est celui qui renvoie aux différents spécialistes de la surdité. Le discours des parents est donc fortement influencé par ces professionnels qui les encadrent dans leur parcours de recherche de solutions pour leur enfant (Allen, Crawford, & Mulla, 2016; Zaidman-Zait et coll., 2014). Cela dit, le discours de la communauté sourde, qui s'oppose sur plusieurs points au discours médical, est noyé par ce dernier du fait qu'il est sous-représenté, en plus d'être peu connu dans la population entendante (Dagron, 2006). L'engagement des parents vient avec le sentiment d'espoir qui lui est rattaché (Alias, Dahlan, & Azizan, 2017). Lorsque les professionnels de la santé peuvent donner cet espoir aux parents cherchant à avoir une bonne communication avec leur enfant, ils ne vont pas nécessairement ressentir le besoin d'aller chercher du soutien ailleurs. Malgré cela, la représentation sociale des services professionnels témoigne du fait que les parents ne s'appuient pas seulement sur les compétences techniques des professionnels. Ils vont accorder une grande importance aux compétences relationnelles des intervenants qu'ils rencontrent. La surdité représente donc pour eux plus qu'une « déficience auditive ».

Selon nos données, la communauté sourde n'est pas très bien connue des PEES. Bien que certains parents aient évoqué des mots qui font référence à la culture sourde ou à la communauté sourde, il n'est pas encore clair si cela représente une minorité isolée de participants ou il s'agit de l'émergence d'une nouvelle représentation de la surdité alimentée par le discours provenant de la communauté sourde. Il est clair, cependant, que l'image positive du Sourd, avec un grand S, et de la richesse de sa culture qui domine le discours des militants du courant gestuel ne semble pas encore faire partie des représentations sociales des PEES. Les PEES vont plutôt associer la surdité à une gamme de difficultés et de responsabilités parentales qu'ils réussissent à surmonter avec l'aide des professionnels de la surdité.

Conclusion

La surdité représente un événement nouveau pour les parents entendants ayant un enfant vivant avec une surdité. Les PEES sont plongés très rapidement dans le monde de la surdité, sans trop savoir comment y naviguer. Ils vont donc être engagés dans différents services professionnels ainsi que dans leur propre quête de solutions pour la situation de leur enfant. Nos résultats mettent en relief le rôle des représentations sociales de la surdité, de la parentalité et des services professionnels dans l'intensité et l'orientation de l'engagement des PEES auprès de leur enfant. L'intensité de l'engagement des parents est assurée, selon nos résultats, par une représentation de la parentalité dynamisée par l'amour. L'orientation de l'engagement des parents vers des services professionnels de santé est dictée, cependant, par une représentation de la surdité en tant que difficulté, handicap et problème de communication; cette représentation est façonnée par les connaissances diffusées par les professionnels de la santé et par une identité déchirée entre deux mondes : le milieu médical et la communauté sourde.

Ainsi, l'amour alimente la représentation sociale de la parentalité des PEES malgré les difficultés, les problèmes de communication, le handicap, etc. qui parsèment plus particulièrement la représentation sociale de la surdité. En ayant une représentation beaucoup plus chaleureuse de leur parentalité, les parents sont en mesure de trouver la force de relever les défis qu'ils associent à la surdité de leur enfant, ou même de les contrer, en s'engageant fortement auprès de leur enfant ou dans les interventions des professionnels de la surdité.

Références

ABRIC, J. C. (1994). Les représentations sociales : aspects théoriques. In Abric (Éd.) *Pratiques sociales et représentations* (pp. 11-35). Paris : PUF.

ABRIC, J. C. (2001). L'approche structurale des représentations sociales : développements récents. *Psychologie et société*, *4*(2), 81-104.

ABRIC, J. C. (2003). *Méthodes d'étude des représentations sociales*. Paris : Erès.

ALIAS, N. A., DAHLAN, A., & AZIZAN, A. (2017). "I have faith…": An exploration of hopefulness in providing care for children with Spesific Learning Difficulties (SpLD). *Environment-Behaviour Proceedings Journal*, *2*(6), 3-9.

ALLEN, S., CRAWFORD, P., & MULLA, I. (2016). Exploring the acceptability of innovative technology: A pilot study using LENA with parents of young deaf children in the UK. *Child Language Teaching and Therapy*.

BREAU, J. (2016). *L'engagement des parents entendants ayant un enfant vivant avec une surdité – le recours aux stratégies d'adaptations dans la recherche du bien-être familial.* Mémoire de maitrise, Université de Moncton.

BREAU, J., & GAUCHER, C. (en rédaction). *L'engagement des parents entendants ayant un enfant vivant avec une surdité – le recours aux stratégies d'adaptation*.

CAMPOS, H. F., & ROUQUETTE, M.-L. (2000). La dimension affective des représentations sociales : deux recherches exploratoires. *Bulletin de Psychologie, 53*(4), 448, 435-441.

CLEMENCE, A., DOISE, W., & LORENZI-CIOLDI, F. (1994). Prises de position et principes organisateurs des représentations sociales. *Structures et transformations des représentations sociales*, 119-152.

CLEREBAUT, N. (2005). Enfants entendants et parents sourds : aspects émotionnels et relationnels*. Connaissances et surdité, 13,* 14-20.

COHEN-SCALI, V., & MOLINER, P. (2008). Représentations sociales et identité: des relations complexes et multiples. *L'orientation scolaire et professionnelle, 37*(4), 465-482.

DAGRON, J. (2006). 12. Représentations sociales de la surdité. In *Psychologie de la surdité* (Vol. 3, pp. 239-252). De Boeck Supérieur.

DAL FORNO, I., PIEROPAN, S., FACCI, M., DOSSO, G., RAVAGNANI, V., CARAMASCHI, P.,... & ADAMI, S. (2015). AB0982 Juvenile Idiopathic Arthritis: Parental Stress Reaction After Diagnosis of a Chronic Desease of their Sons. *Annals of the Rheumatic Diseases, 74,* 1227.

DE ROSA, A. M. (1993). Social representations and attitudes: problems of coherence between the theoretical definition and procedure of research. *Papers on Social Representations, 2*(3), 1-15.

DE SA, C. P. (1994). Sur les relations entre représentations sociales, pratiques socio-culturelles et comportement. *Textes sur les représentations sociales*, *3*(1), 40-48.

DELOUVEE, S. (2006). Haine populaire, monnaie satirique et oubli : Le nexus « Sedan » d'hier à aujourd'hui. *Bulletin de Psychologie*, *59*(4), 484, 407-420.

DESCHAMPS, J. C., & MOLINER, P. (2012). *L'identité en psychologie sociale: des processus identitaires aux représentations sociales*. Armand Colin.

DESCHAMPS, J.-C., & GUIMELLI, C. (2002). La composante émotionnelle des représentations sociales : émotions rapportées et tendances à l'action dans une étude comparative des représentations sociales de l'insécurité en France et en Suisse. *Nouvelle Revue de Psychologie Sociale*, *1*(1), 78-84.

ENCREVE, F. (2008). *Sourds et société française au XIX^{e} siècle : 1830-1905* (Doctoral dissertation, Paris 8).

ERBASI, E., SCARINCI, N., HICKSON, L., & CHING, T. Y. (2016). Parental involvement in the care and intervention of children with hearing loss. *International journal of audiology*, 1-12.

FLAMENT, C. (1995). Approche expérimentale de type psychophysique dans l'étude d'une représentation. *Cahiers internationaux de Psychologie sociale*, *28*, 67-76.

FRAYSSE, B. (2000). La saisie des représentations pour comprendre la construction des identités. *Revue des sciences de l'éducation*, *26*(3), 651-676.

FRIEDMAN NARR, R., & KEMMERY, M. (2014). The nature of parent support provided by parent mentors for families with deaf/hard-of-hearing children: voices from the start. *Journal of deaf studies and deaf education*, *20*(1), 67-74.

GAUCHER, C. (2008). Comment dire et faire avec les Sourds? La mise en dialogue de la différence comme enjeu de la reconnaissance. *Service social*, *54*(1), 55-66.

GAUCHER, C. (2009). *Ma culture, c'est les mains. La quête identitaire des Sourds du Québec.* Québec : Les presses de l'Université Laval, 183 pages.

JODELET, D. (1989). *Folies et représentations sociales.* Paris : Presses universitaires de France.

JODELET, D. (2006). Place de l'expérience vécue dans le processus de formation des représentations sociales. Dans Valérie Hass, *Les savoirs du quotidien. Transmissions, Appropriations, Représentations,* 235-255. Rennes : Les Presses universitaires de Rennes, 274 pages.

LHEUREUX, F., & GUIMELLI, C. (2009). Organisation interne et affectivité des représentations sociales : une étude exploratoire. *Anuario de psicología/The UB Journal of psychology*, *40*(3), 357-376.

MOELLER, M. P., CARR, G., SEAVER, L., STREDLER-BROWN, A., & HOLZINGER, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *The Journal of Deaf Studies and Deaf Education*, *18*(4), 429-445.

MOSCOVICI, S. (1961). *La psychanalyse, son image et son public : étude sur la représentation sociale de la psychanalyse.* Presses universitaires de France.

MOSCOVICI, S. (2013). *Le scandale de la pensée sociale : Textes inédits sur les représentations sociales réunis et préfacés par Nikos Kalampalikis* (Vol. 28). Éditions de l'École des hautes études en sciences sociales.

NEGURA, L. (2006). L'analyse de contenu dans l'étude des représentations sociales. *SociologieS, 57*(3), 1-16.

RATEAU, P., & MONACO, G. L. (2013). La théorie des représentations sociales : orientations conceptuelles, champs d'applications et méthodes. *CES Psicología*, *6*(1), 1-21.

RIME, B. (2005). *Le partage social des émotions.* Paris : Presses universitaires de France.

STEINBERG, A. G., DAVILA, J. R., COLLAZO SR, J., LOEW, R. C., & FISCHGRUND, J. E. (1997). "A little sign and a lot of love...": Attitudes, perceptions, and beliefs of Hispanic families with deaf children. *Qualitative Health Research*, *7*(2), 202-222.

SUGDEN, E., BAKER, E., MUNRO, N., & WILLIAMS, A. L. (2016). Involvement of parents in intervention for childhood speech sound disorders: a review of the evidence. *International Journal of Language & Communication Disorders*, *51*(6), 597-625.

SZARKOWSKI, A., & BRICE, P. J. (2016). Hearing parents' appraisals of parenting a deaf or hard-of-hearing child: Application of a positive psychology framework. *Journal of deaf studies and deaf education*, *21*(3), 249-258.

TAFANI, E. (2001). Attitudes, engagement et dynamique des représentations sociales : études expérimentales. *Revue internationale de psychologie sociale*, *14*(1), 7-30.

TAFANI, E., MUGNY, G., & BELLON, S. (1999). Irréversibilité du changement et enjeux identitaires dans l'influence sociale sur une représentation sociale. *Psychologie et société*, *1*(2), 73-104.

THEVENOT, L. (2000). « IX - *L'action comme engagement* », dans *L'Analyse de la singularité de l'action.* Paris : Presses universitaires de France, « Éducation et formation / Formation permanente – Éducation des adultes », p. 213-238.

VALENCE, A., & ROUSSIAU, N. (2014). Le rôle de l'implication et des systèmes de croyances au sein des représentations sociales. *Psychologie française*, *59*(4), 301-315.

VERGES, P. (2002). *Ensemble de programmes permettant l'analyse des évocations : EVOC 2000.* Aix-en-Provence.

VERGES, P. (1995). Représentations sociales partagées, périphériques, indifférentes, d'une minorité : méthodes d'approche. *Les Cahiers internationaux de psychologie sociale*, *28*, 77-95.

ZAIDMAN-ZAIT, A., & CURLE, D. (2016). Complexity: An interpretative phenomenological analysis of the experiences of mothers of deaf children with cochlear implants and autism. *Journal of health psychology*, 135910531664 6171.

ZAIDMAN-ZAIT, A., CURLE, D., JAMIESON, J. R., CHIA, R., & KOZAK, F. K. (2014). Cochlear implantation among deaf children with additional disabilities: Parental perceptions of benefits, challenges, and service provision. *Journal of deaf studies and deaf education*, *20*(1), 41-50.

ZAIDMAN-ZAIT, A, MOST, T., TARRASCH, R., & HADDAD, E. (2017). Mothers' and fathers' involvement in intervention programs for deaf and hard or hearing children. *Disability and Rehabilitation, 1-9.*

Revue Développement humain, handicap et changement social, 2018, **(24)**, 1, p. 35-52.
Journal of Human Development, Disability, and Social Change

Qu’entend-on par sourd?
La perception sociale à l’égard des personnes sourdes

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Résumé

L’objectif de cette recherche est l’étude des réactions affectives et du jugement social à l’égard des personnes sourdes selon la familiarité des participants avec elles. Soixante-dix-sept personnes ont été enquêtées à partir d’échelles de mesure conçues par Louvet et Rohmer (2000, 2004, 2006). Les personnes sans contact avec la population sourde ont les réactions émotionnelles les plus négatives vis-à-vis des sourds. Toutefois, le jugement social des personnes familiarisées avec la surdité est assez négatif par rapport aux autres participants. Cette familiarité paraît reposer sur la connaissance de la surdité comme une déficience difficile à surmonter. Enfin, les individus ayant des contacts épisodiques avec les sourds ont les réactions affectives et le jugement évaluatif les plus positifs : ils semblent avoir une représentation de la surdité qui dépasse et pallie les problèmes qui y sont liés.

Mots-clés : jugement social, réaction affective, familiarité, sourd, langue des signes

Abstract

This research aims at studying people’s emotional reactions and their social attitude towards deaf persons, relative to familiarity their with deafness. 77 subjects were interviewed based on measurement scales devised by Louvet and Rohmer (2000, 2004, 2006). The subjects with the least contact with deaf persons had the most negative emotional reactions. But, the social judgment of persons familiar with deafness is rather negative when compared to other participants. People most familiar with deafness seemed to think the handicap as a deficiency difficult to overcome. Finally, the group with occasional contacts had the most positive evaluative reactions. Those subjects seemed to consider deafness as a problem to be mitigated and overcome.

Keywords: social judgment, emotional reactions, familiarity, deaf, sign language

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La représentation sociale est une forme de connaissance socialement élaborée et partagée, ayant une visée pratique et concourant à la construction d'une réalité commune à un ensemble social ou culturel (Jodelet, 2003). C'est une sorte de « savoir commun » orientant certains comportements. Comment se représente-t-on celui qui n'entend pas? Déficient auditif, handicapé de l'ouïe, malade de l'oreille, infirme auditif, malentendant, deaf and dumb (sourd et idiot, en anglais), Gehörlos (sans audition, en allemand), Schwerhörig (qui a des difficultés à entendre, en allemand), sourd et muet, sourd et sans voix, sourd non parlant, sourd comme un pot, sourdingue[2]… Autant de termes qui qualifient et souvent personnalisent la représentation sociale et culturelle du sourd?

Nous nous intéresserons, ici, au jugement évaluatif porté sur les personnes sourdes et aux réactions affectives qu'elles suscitent chez ceux qui les côtoient et chez ceux qui ne les côtoient pas. À partir de ces deux dimensions, nous mènerons une enquête expérimentale auprès de trois groupes de participants : les familles et les professionnels qui ont des contacts réguliers avec la population sourde, les personnes ayant des contacts épisodiques et celles qui sont sans contact avec le milieu sourd. L'objectif de notre recherche est de déterminer s'il y a une corrélation entre le degré de familiarité et la nature du jugement social, d'une part, et des réactions affectives, d'autre part.

Aujourd'hui, on observe des avancées dans la recherche, dans les réflexions et les dispositions législatives et dans la prise de parole des personnes sourdes (voir la section « considérations sur les résultats de l'enquête »). Mais comment le « sourd et muet » est-il perçu par notre société? Nous rappellerons les différents travaux menés sur la représentation sociale et le handicap, et montrerons le cas particulier de la surdité. Puis, nous présenterons la méthode et les analyses de notre enquête. Et nous terminerons par des considérations sur les résultats de l'enquête du groupe des « contacts réguliers », des « contacts épisodiques » et des « sans contact » avec la population sourde.

Représentation sociale et handicap

Selon Fiske et Neuberg (1990, 2008), les impressions d'autrui se construisent à partir d'une catégorisation primaire qui repose sur des éléments saillants du sujet. La plupart des handicaps sont marquants d'un point de vue perceptif, ce qui n'est pas – ou presque pas – le cas de la surdité. Toutefois, certaines surdités présentent des signes cliniques et des symptômes particuliers. C'est le cas notamment du syndrome de Waardenburg, cause la plus fréquente de surdité syndromique à transmission dominante. Le sujet atteint de ce syndrome peut avoir une pigmentation de la peau, des cheveux ou de l'iris assez singulière. Mais les surdités syndromiques ne représentent que 30 % des surdités d'origine génétique; les autres sont non syndromiques[3]. Les aides auditives sont certes des indices susceptibles de rendre visible la surdité. Cependant, elles génèrent des confusions pouvant laisser croire que des appareils auditifs corrigent une surdité comme une paire de lunettes rectifie une myopie (Delaporte, 2002, p. 181). Si la surdité, elle-même, ne se voit pas, elle se révèle lorsque deux sourds communiquent entre eux dans une langue signée ou dès que le rapport entre un entendant et un sourd est engagé : difficulté, voire impossibilité de se faire comprendre de l'autre, et ceci quelle que soit la configura-

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[2] On peut relever d'autres termes associés ou désignant le sourd : handicapé de la communication, professeur Tournesol, deaf as a doornail (sourd comme un clou, en anglais), deaf as a stone, as a post, as a beetle (sourd comme une pierre, un poteau, un scarabée, en anglais), stochtaub (sourd comme un bâton, en allemand), Sordo como una tapia (sourd comme un mur, en espagnol), sord com una tapia (sourd comme un mur, en catalan), Ser surdo como uma porta (sourd comme une porte, en portugais), Być głuchym jak pień (sourd comme un tronc, en polonais), Döv som en stock (sourd comme une souche, en suédois), sourd comme un toupin (à Marseille), dur d'oreille, faire la sourde oreille, sourd comme un sonneur de cloches, Quasimodo le boiteux, le borgne, le bossu, le dur d'oreille (le sonneur de Notre-Dame de Paris de Victor Hugo), etc.

[3] Voir l'article de Manrique et Huarte (2007) et celui sur les surdités syndromiques à https://fr.wikipedia.org/wiki/Surdit%C3%A9_d%27origine_g%C3%A9n%C3%A9tique (consulté en juillet 2015).

tion de ce rapport (Poizat, 1996, p. 27). Cette expérience peut entraîner des représentations et des réactions émotionnelles qui restent à être étudiées.

La perception sociale dépend du jugement social vis-à-vis des informations disponibles concernant la cible, mais aussi des réactions affectives du percevant (Monahan, Murphy, & Zajonc, 2000; Zajonc, 1994). Toutefois, le jugement social et les réactions affectives évoluent en fonction de la familiarité entre le percevant et la cible du jugement. L'hypothèse du contact (Corneille, 1994; Kassin, Brehm, & Fein, 2005) suggère que le fait de mieux connaître des personnes et d'interagir avec elles permet une perception plus hétérogène, plus individualisée et donc moins catégorielle et moins stéréotypée. Mais ce n'est pas tant le contact en soi que la nature de la relation qui influence la perception vis-à-vis des personnes ayant des incapacités. Cette nature de la relation dépend des facteurs environnementaux décrits par le modèle du Processus de production du handicap (1998). D'autres modalités interviennent. Pour des raisons essentiellement familiales ou professionnelles, il y a ceux qui côtoient le milieu sourd tous les jours ou de façon plus sporadique, et ceux qui, dans la majorité des cas, n'ont jamais rencontré une personne sourde. Quelle est leur perception vis-à-vis des sourds? Dépend-elle de la familiarité des « percevants » avec la surdité? Influence-t-elle certains comportements?

Représentation sociale de la surdité, aujourd'hui

On distingue habituellement quatre types de surdités : légère (à partir d'une perte de 20 à 40 dB), moyenne (entre 40 et 70 dB), sévère (entre 70 et 90 dB) et profonde (à partir d'une perte de plus de 90 dB). La surdité est définie comme un « affaiblissement ou abolition complète du sens de l'ouïe », selon le dictionnaire Le Petit Robert (Rey et al., 2001). Cette définition peut sembler bien sommaire[4]. En effet, la surdité varie selon de nombreux critères, dont l'exploitation possible ou non des restes auditifs, la période à laquelle elle est survenue et l'environnement socioculturel dans lequel baigne celui qui n'entend pas ou mal. On peut, en outre, distinguer les sourds en fonction de leur perte auditive (définition médicale) ou en fonction de la langue qu'ils pratiquent prioritairement (définition linguistique). On rencontre des sourds profonds parvenant presque parfaitement à comprendre les paroles d'autrui et des malentendants ayant de grandes difficultés d'élocution. De plus en plus de sourds sont porteurs d'un ou de deux implants cochléaires. L'implant cochléaire est un appareil électromagnétique qui, après une importante intervention chirurgicale, stimule directement les terminaisons nerveuses de l'audition situées dans la cochlée[5]. La France est le premier pays à avoir posé un implant cochléaire (en 1957; voir notamment Cajal, 2013, p. 16). Après une période d'expérimentations auprès de devenus sourds (et volontaires), l'application de cette technologie aux enfants sourds a commencé au début des années 1990. Certains affirment qu'il s'agit d'« une innovation de rupture à l'instar du pacemaker »[6]. Toutefois, les controverses à ce sujet sont nombreuses et houleuses.

Qui sont les sourds? Tous ne sont pas sourds profonds, pratiquants de la langue des signes ou du code de la Langue française parlée complétée (LPC)[7], et tous ne sont pas issus d'une école spécialisée. Ce n'est que de-

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[4] … surtout pour les sourds eux-mêmes! Voir, par exemple, l'émission « On n'est pas que des sourds » d'I. Voizeux et de L. Valo (2009) ou « Sourds et fiers de l'être » de J. Kaempfer Louis et S. Brasey (2011).

[5] Description de l'implant cochléaire : http://www.canal-u.tv/video/universite_bordeaux_segalen_dcam/implant_cochleaire_binaural.7141 (consulté en juin 2014)

[6] Entretien avec Bruno Frachet, médecin, chirurgien ORL et universitaire de l'Hôpital Rotschild de Paris sur http://www.futuremag.fr/interview/limplant-cochleaire-est-une-innovation-de-rupture-a-linstar-du (consulté en mars 2014).

[7] **LPC** : Langage Parlé Complété ou code Langue française Parlée Complétée. Le code LPC est un codage manuel des sons de la langue parlée. Mis au point par Orin Cornett (1913-2002) en 1967, le Cued Speech (le CS, nom anglais du code LPC) comporte une série de configurations manuelles (les « clés » ou « cues ») qui, combinées aux mouvements des lèvres, permettent l'identification des phonèmes.

puis la loi du 11 février 2005[8] de l'égalité des droits et des chances que la langue des signes est reconnue comme une langue à part entière. Cette dernière loi a pour intention de réaffirmer le droit des parents à choisir une éducation bilingue (voir une recension des travaux à ce sujet de H. Lane, 1991 et Minguy, 2009). Depuis, la langue des signes a progressivement « retrouvé droit de cité » (Renard, 2008, p. 273). Elle est désormais étudiée et enseignée à l'université. À partir de 2008, elle est admise comme langue vivante au baccalauréat et commence à être enseignée au lycée. Ces changements en faveur de la langue des signes ont sans doute suscité un nouveau regard envers ceux qui la pratiquent, tant au niveau des diverses institutions qu'au niveau du grand public. Aujourd'hui, la langue des signes est très médiatisée. Mais combien d'entre nous l'ont apprise? Et quelle est la réalité des relations entre les sourds et les entendants?

Méthode

- La population

Entre 2001 et 2003, une première enquête est menée auprès de 77 personnes, n'ayant aucun problème auditif, 25 hommes et 52 femmes (moyenne d'âge : 41,36 ans). Les participants sont interrogés chez eux, sur leur lieu de travail, dans les institutions spécialisées, à des réunions d'enseignants et de parents d'élèves, à des conseils de classe, dans les associations des sourds et durant une journée d'étude « Vivre avec une surdité », organisée par l'Université de Strasbourg. Une variété de vécus est ainsi rencontrée : parents d'enfant sourd, enseignants, médecins, ingénieurs, libraires, travailleurs sociaux, interprètes en langue des signes, etc. Certains sujets pratiquent la langue des signes, d'autres le code LPC. Pour des raisons de contrôle des variables culturelles, nous nous sommes limités à une région française, l'Alsace, qui comprend un grand nombre d'écoles pour sourds (Delaporte, 2015, p. 24).

- La démarche

Certains interrogés ont été rencontrés à partir de notre propre réseau de connaissances, lors de réunions associatives ou de journées consacrées à la surdité. Notre population s'est également constituée à partir d'un nombre restreint de personnes auxquelles d'autres sujets se sont adjoints avec lesquels les premières se déclaraient en relation, et ainsi de suite. Cette forme de sondage en « boule de neige » est relativement « économique », mais risque d'introduire quelques biais (Javeau, 1992, p. 61). Pour parer à certains de ces biais, comme celui de l'influence des avis et réponses les uns sur les autres, nous demandions à chaque participant d'éviter de parler du contenu du questionnaire à ses connaissances tant que ces dernières n'avaient pu, à leur tour, remplir le formulaire.

- Le matériel

Nous sollicitions quelques minutes et adressions à chaque participant un questionnaire composé de deux parties. La première partie contient cette consigne : « quand vous pensez aux personnes sourdes, que ressentez-vous? », suivie de huit échelles bipolaires, dont les dimensions affectives sont : l'angoisse, la compassion, la gêne, le dégoût, la révolte, l'inquiétude, la pitié et la déprime (voir ci-dessous la section « les limites de l'étude »). La deuxième partie du questionnaire se réfère au jugement social. Elle est composée de la consigne suivante : « comment vous représentez-vous les personnes sourdes? » et de quatorze échelles bipolaires qui portent sur des traits de personnalité : être intelligent, être ouvert, être attentif, être chaleureux, avoir de l'humour, être consciencieux, être serein, être autonome, être sûr de soi, être prudent, être volontaire, être entreprenant, être créatif, être optimiste. Ces échelles de mesure ont été conçues par Louvet et Rohmer (2000, 2004, 2006), à partir d'études préliminaires qui s'appuient notamment sur le test de personnalité de Cattell (Cattell, 1974). La fiabilité des échelles mesurant les réactions affectives et le jugement social a été vérifiée statistiquement (alpha de Cronbach = 0,77 pour les affects et 0,91 pour le juge-

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[8] Loi n°2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées : https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000809647

ment[9]). À la fin du questionnaire, les participants ont été invités à s'exprimer librement. De nombreux échanges épistolaires avec plusieurs de nos interrogés ont continué après notre enquête. Ces données ont été saisies dans des tableaux qui rassemblent les principaux propos des sujets. Nous nous sommes donc retrouvés avec une grande quantité d'informations discursives, outre les données venant du questionnaire lui-même. Notre travail est une recherche quantitative menée à partir d'échelles bipolaires ayant pour objet de vérifier la corrélation entre les représentations sociales et le degré de familiarité avec les sourds. Cette recherche s'est, en outre, complétée d'entretiens semi-dirigés avec support écrit, donnant lieu à une analyse du discours, non présenté ici.

- *Les critères de sélection et les caractéristiques des groupes de participants*

Une série de questions nous ont permis de nous assurer que les participants n'ont pas eux-mêmes de problèmes auditifs et de vérifier le type de lien avec les sourds, la nature du handicap (surdité profonde ou légère) de ceux-ci et la fréquence des contacts avec le monde des sourds. Trois groupes sont constitués en fonction de la familiarité des sujets avec la surdité (voir tableau 1).

▪ Le premier groupe comporte 26 personnes n'ayant aucun contact avec les sourds.

▪ Le deuxième comprend 25 personnes ayant des contacts réguliers avec les sourds, soit :
  - les familles;
  - les amis proches;
  - les médecins oto-rhino-laryngologistes (ORL);
  - les interprètes en langue de signes;
  - les enseignants;
  - les éducateurs des institutions spécialisées.

▪ Le dernier groupe contient 26 personnes ayant des contacts épisodiques. Pour ces dernières, il s'agit de sujets « sensibilisés », ayant soit :
  - un proche sourd (un cousin, un neveu ou un petit-fils) sans contacts réguliers avec lui;
  - des amis dont les enfants sont sourds;
  - un ou des voisins sourds dans le même immeuble d'habitation;
  - un (ou des) collègue(s) de travail sourd(s) sans contacts réguliers avec lui (ou eux);
  - quelques patients sourds (pour les médecins généralistes);
  - un (ou plusieurs) élève(s) sourd(s) parmi un ensemble d'élèves entendants (pour les enseignants des écoles ordinaires);
  - effectué un stage de quelques mois parmi des personnes sourdes (pour les travailleurs sociaux et les professions paramédicales);
  - eu des contacts épisodiques avec le milieu sourd depuis moins de deux ans (interprète en langue des signes débutant, par exemple, fréquentant une association de sourds à raison de deux heures par semaine);
  - suivi un cycle de cours de langue des signes avec un ou deux professeurs sourds.

TABLEAU 1. LA POPULATION DIVISÉE EN TROIS GROUPES

	Nombre de sujets
Sans contact avec des personnes sourdes :	26
Ayant des contacts réguliers avec des personnes sourdes :	25
Ayant des contacts épisodiques avec des personnes sourdes :	26
Total :	**77**

- Le traitement des données

Dans un premier temps, nous avons procédé à des regroupements des différentes évaluations et des différents affects exprimés par les parti-

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[9] **Alpha de Cronbach** : Il s'agit d'un indice de fiabilité. S'il n'y a aucun véritable résultat, mais uniquement de l'erreur dans les questions du questionnaire expérimental, le coefficient alpha sera égal à zéro. Si toutes les questions sont parfaitement fiables et mesurent la même chose, le coefficient alpha sera égal à 1.

cipants, en nous appuyant sur les résultats d'analyses multidimensionnelles réalisées sur l'ensemble des données. Dans un second temps, sur la base de cette structure générale des dimensions évaluatives et affectives, nous étudions les positions respectives des différents participants en fonction de leur familiarité avec la surdité, en procédant à des analyses de variance et en considérant les résultats significatifs si $p<0{,}05$[10]. Cette étude permet de définir les dimensions cognitives et affectives pertinentes à soumettre aux tests statistiques.

- Les limites de l'étude

Toutefois, comme tout outillage quantitatif issu des sciences humaines et sociales, nos analyses donnent des chiffres discutables, car « la quantité, réduite à elle-même, n'est qu'une "présupposition" » (Guénon, 1945, p. 25). De plus, toute question est orientée par des chercheurs qui sont eux-mêmes des sujets, travaillant sur les dires d'autres sujets rencontrés et interrogés, et avec lesquels il n'est pas possible de monter des expériences qui vérifient, expliquent et aboutissent à des découvertes absolues. Chaque chercheur a son lot de stéréotypes qu'il utilise pour observer une sphère de vie sociale (Becker, 2002, p. 39). En outre, certains termes de notre questionnaire peuvent induire un biais : un jugement négatif à l'endroit des personnes sourdes à qui aucune « agentivité » ne serait reconnue (communication personnelle de Charles Gaucher, février 2017). Enfin, comment sont définis les sourds sur lesquels sont interrogées les personnes rencontrées? La représentation vis-à-vis la surdité varie en fonction de son degré, mais aussi de la langue pratiquée. Cette représentation dépend également d'une histoire, d'un récit qui a eu lieu à un moment donné et qui peut changer en fonction des situations de la vie : « Rien ne reste identique à soi-même » (Becker, 2002, p. 152).

Analyses

- Analyses du jugement social

Les dimensions soumises aux différentes analyses sont : être intelligent, ouvert, attentif, chaleureux, avoir de l'humour, être consciencieux, serein, autonome, sûr de soi, prudent, volontaire, entreprenant, créatif et optimiste. Nous réalisons une analyse en composantes principales (ACP) avec rotation Varimax Normalisée considérant comme variables actives les quatorze items de l'échelle de jugement. L'analyse fait apparaître deux facteurs principaux. Le premier facteur regroupe les items : autonome (0,80), entreprenant (0,78), volontaire (0,77), sûr de soi (0,73), créatif (0,62) et consciencieux (0,60); ceux-ci peuvent être définis par la dimension du « dynamisme ». Le second facteur rassemble les items : chaleureux (0,80), attentif (0,73), ouvert (0,68) et plein d'humour (0,65); ces derniers expriment la « sociabilité ». Nous effectuons des analyses de variance sur les scores factoriels. Nous observons que les groupes se différencient principalement sur le premier facteur ($F(2{,}74) = 4$; $p<0{,}02$)[11], à savoir le dynamisme. Le groupe « contacts épisodiques » semble s'opposer aux deux autres groupes et particulièrement au groupe « contacts réguliers », d'après le test de Newman-Keuls ($p<0{,}01$)[12]. Les personnes sourdes sont jugées dynamiques par le groupe aux « con-

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[10] **P (Niveau)** : La significativité statistique d'un résultat est une mesure estimée du degré auquel il est représentatif de la population. La valeur du niveau p représente un indice décroissant de la fiabilité d'un résultat. Plus le niveau p est élevé, moins on peut croire que la relation observée entre les variables dans l'échantillon est un indicateur fiable de la relation entre les variables correspondantes dans la population. Plus précisément, le niveau p représente la probabilité d'erreur associée à l'acceptation du résultat observé comme valide, c'est-à-dire comme représentatif de la population. Par exemple, un niveau p de 0,05 indique qu'il existe une probabilité de 5 % que la relation entre les variables trouvées dans notre échantillon soit due au hasard. Dans de nombreux domaines de recherche, le niveau p de 0,05 est considéré selon l'usage comme une « limite acceptable » d'erreur.

[11] **F (Distribution)** : La distribution de F a une fonction de densité de probabilité. La valeur du F et la valeur p (cette dernière est calculée à partir de la valeur de la variable aléatoire et des degrés de liberté spécifiés) induites sont utilisées comme un test F général de la relation entre la variable dépendante et l'ensemble des variables indépendantes.

[12] **Test de Newman-Keuls** : Ce test de comparaisons *post-hoc* est basé sur la statistique d'étendue *studentisée.* Il teste la significativité des intervalles, étant donné le nombre d'échantillons respectifs.

tacts épisodiques » (m = 5,05; σ = 0,98), moins dynamiques par les « sans contact » (m = 4,59; σ = 0,75) et encore moins dynamiques par les « contacts réguliers » (m = 4,35; σ = 0,94) (figure 1).

Une analyse des effets spécifiques de chaque item confirme ce que l'on observe pour le facteur « dynamisme ». Les personnes sourdes sont considérées comme autonomes, volontaires et créatives par le groupe aux « contacts épisodiques » (m = 4,77; σ = 1,6 / m = 5,73; σ = 1,22 / m = 5,23; σ = 1,1), de façon moindre par le groupe « sans contact » (m = 4,69; σ = 1,22 / m = 4,84; σ = 1,04 / m = 4,54; σ = 0,86) et moindre encore par les « contacts réguliers » (m = 3,72; σ = 1,54 / m = 5,16; σ = 1,18 / m = 4,24; σ = 1,53).

Pour l'item « volontaire » cependant, le groupe « sans contact » (m = 4,84; σ = 1,04) juge les sourds moins volontaires par rapport au groupe « contacts réguliers » (m = 5,16; σ = 1,18) (figure 2).

FIGURE 1. MOYENNES SUR LE FACTEUR 1 « DYNAMISME », SELON LA FAMILIARITE

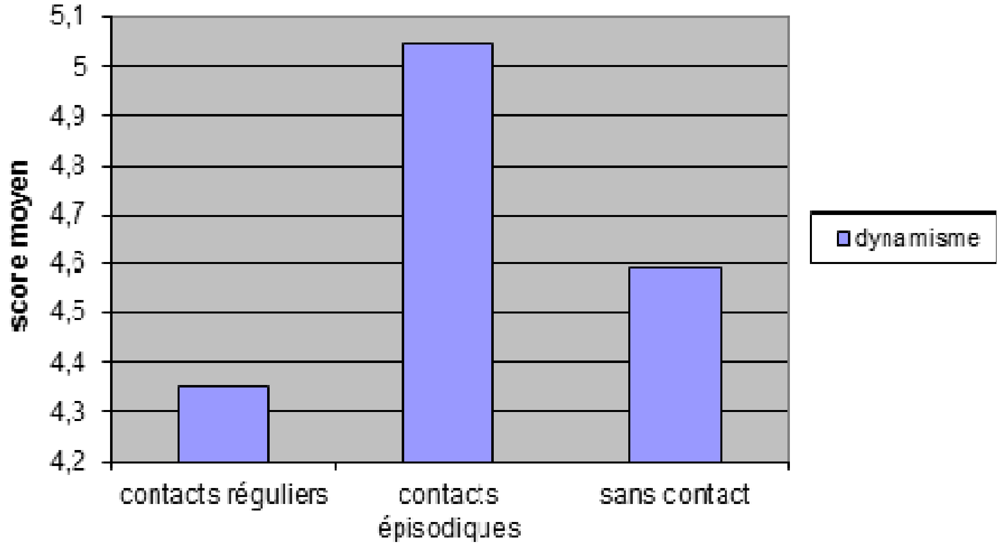
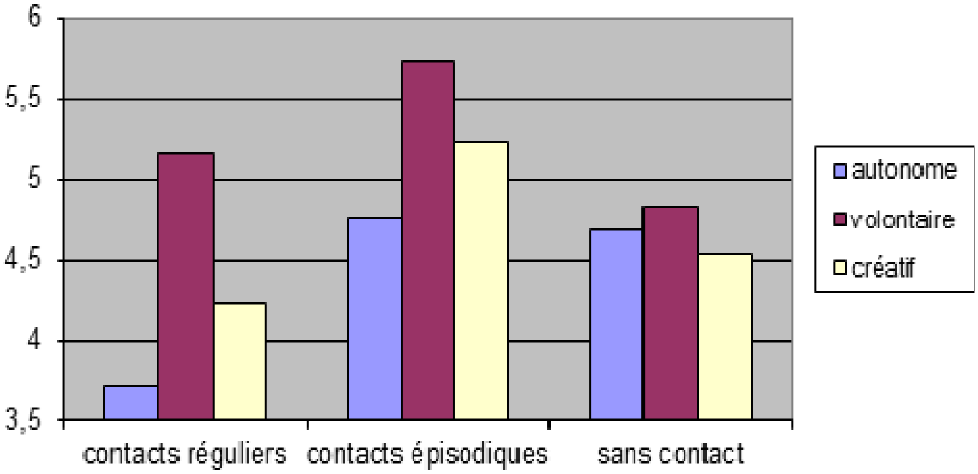


FIGURE 2. : MOYENNES SUR LES ITEMS « AUTONOME », « VOLONTAIRE » ET « CRÉATIF », SELON LA FAMILIARITÉ



Quant au facteur « sociabilité », on observe un effet spécifique sur l'item « humour » (F(2,74 = 4,75; p<0,01) (figure 2). Lorsque les participants ont des contacts avec des personnes sourdes, qu'ils soient réguliers (m = 4,92; σ = 1,11) ou épisodiques (m = 4,92; σ = 1,23), ils les trouvent pleines d'humour. Par contre, lorsqu'ils n'ont aucun contact avec les sourds, ils les imaginent avoir moins d'humour (m = 4,15; σ = 0,67) (figure 3).

On relève de plus un effet spécifique sur l'item « prudent » (F (2,74) = 9,51; p<0,01), qui ne contribue à aucun des deux facteurs (figure 4). Pour ce trait de caractère, les groupes « contacts réguliers » (m = 3,28; σ = 1,24) et « contacts épisodiques » (m = 3,92; σ = 1,49) jugent les sourds comme peu prudents par rapport aux « sans contact » (m = 4,8; σ = 0,98) (test de Newman-Keuls, respectivement : p<0,01 et p<0,01). Ainsi, les « sans contact » jugent les sourds significativement plus prudents que ceux qui ont des contacts (réguliers ou épisodiques). Ils ne les trouvent pas très « drôles » (n'ayant pas d'humour), mais les jugent prudents. Et inversement, les groupes ayant des contacts avec les personnes sourdes les trouvent pleines d'humour, mais pas très prudentes par rapport aux autres participants.

FIGURE 3. MOYENNES SUR L'ITEM « HUMOUR », SELON LA FAMILIARITE

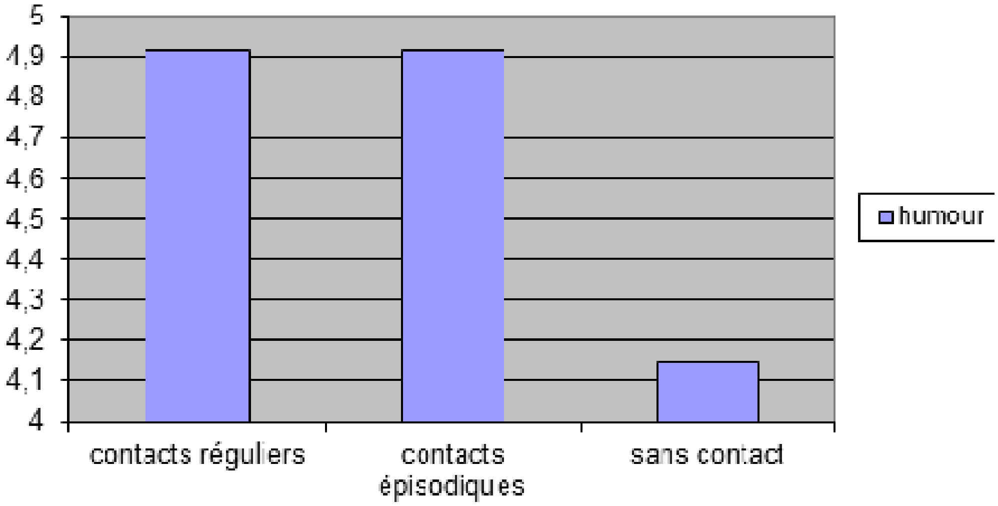
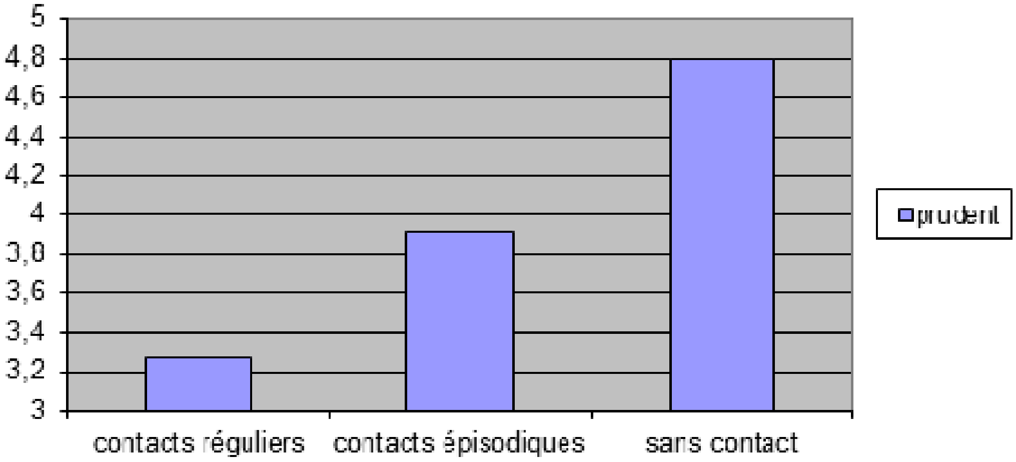


FIGURE 4. MOYENNES SUR L'ITEM « PRUDENT », SELON LA FAMILIARITE



En bref, les personnes ayant des contacts épisodiques jugent assez positivement la population sourde par rapport aux autres groupes. À l'inverse, le groupe « contacts réguliers » juge les personnes sourdes assez négativement : il les décrit comme n'étant globalement pas très dynamiques. L'humour et le caractère « volontaire » par contre sont des traits qui semblent fortement caractériser la population sourde, selon les personnes qui les côtoient (tableau 2).

Nous séparons l'échantillon des « contacts réguliers » en « familles » et en « professionnels » et effectuons une ACP avec rotation Varimax Normalisée. L'analyse fait apparaître deux facteurs principaux. Le premier facteur rassemble les items : entreprenant (0,83), volontaire (0,76), créatif (0,74), intelligent (0,66), sûr (0,66) et autonome (0,65). Il s'agit de la dimension « dynamisme ». Le second facteur regroupe les items : ouvert (0,82), chaleureux (0,80), attentif (0,71) et plein d'humour (0,69). À partir des analyses de variance sur les scores factoriels, nous remarquons que les deux sous-groupes se différencient principalement sur le premier facteur ($F(1,23) = 5{,}4$; $p<0{,}02$) : les personnes sourdes sont jugées plus dynamiques par les familles ($m = 4{,}73$; $\sigma = 1{,}07$) que par les professionnels ($m = 3{,}90$; $\sigma = 0{,}62$).

- *Les réactions affectives*

Les dimensions affectives soumises aux différentes analyses sont : l'angoisse, la compassion, la gêne, le dégoût, la révolte, l'inquiétude, la pitié et la déprime. Nous réalisons une ACP avec rotation Varimax Normalisée considérant comme variables actives les réactions affectives des participants. L'analyse fait apparaître trois facteurs principaux. Le premier facteur regroupe la compassion (coefficient de saturation = 0,78), l'angoisse (0,77), la révolte (0,60) et l'inquiétude (0,59). Ce sont des affects que l'on peut définir de « relationnels positifs ». Le second facteur regroupe la pitié (0,92) et la déprime (0,91), qui sont des affects « intrinsèques négatifs », que l'on ressent en songeant aux personnes sourdes. Notons que la pitié et la compassion se positionnent sur des dimensions indépendantes : la pitié traduit un sentiment négatif, alors que la compassion est plutôt liée au sentiment d'altruisme et au désir d'aller vers l'autre déprime (revoir ci-dessus la section « les limites de l'étude »). Enfin, le troisième facteur regroupe le dégoût (0,87) et la gêne (0,72); ce sont des affects « relationnels négatifs ». En effectuant des analyses de variance sur les scores factoriels, nous observons que les groupes se différencient principalement sur le dernier facteur ($F(2,74) = 3{,}27$; $p<0{,}04$) : les affects relationnels négatifs comme la gêne et le dégoût caractérisent surtout les participants n'ayant aucun contact avec des personnes sourdes (moyenne $m = 3{,}82$; écart-type $\sigma = 0{,}86$) (figure 5). Ces sujets sans contact avec les sourds s'opposent au groupe « contacts réguliers » ($m = 3{,}28$; $\sigma = 0{,}75$), d'après le test de comparaison des moyennes de Newman-Keuls ($p<0{,}035$).

Une analyse des effets spécifiques de chaque item révèle un statut particulier du sentiment de dégoût ($F\ (2,74) = 3{,}15$; $p<0{,}04$) : les « sans contact » ($m = 3{,}61$; $\sigma = 0{,}8$) éprouvent le plus de dégoût et par conséquent, le moins d'attirance vis-à-vis des personnes sourdes, comparé au groupe « contacts épisodiques » ($m = 2{,}96$; $\sigma = 1{,}15$) (figure 6). Un test de comparaison des moyennes (test de Newman-Keuls) confirme cette tendance ($p<0{,}045$). Les « contacts réguliers » ($m = 3{,}16$; $\sigma = 0{,}89$) ressentent plus d'attirance pour les personnes sourdes que les « sans contact », mais moins que les « contacts épisodiques ».

En résumé, selon les résultats de nos analyses, les affects relationnels négatifs, comme les sentiments de gêne et de dégoût, caractérisent essentiellement les personnes ne côtoyant pas de personnes sourdes. Ces sentiments s'estompent avec les contacts (réguliers ou épisodiques). Le groupe des « contacts épisodiques » ressent le moins d'affects négatifs et donc le plus d'affects positifs vis-à-vis des personnes sourdes en comparaison aux autres groupes (tableau 2).

FIGURE 5. MOYENNES SUR LE FACTEUR 3 « AFFECTS RELATIONNELS NEGATIFS », SELON LA FAMILIARITE

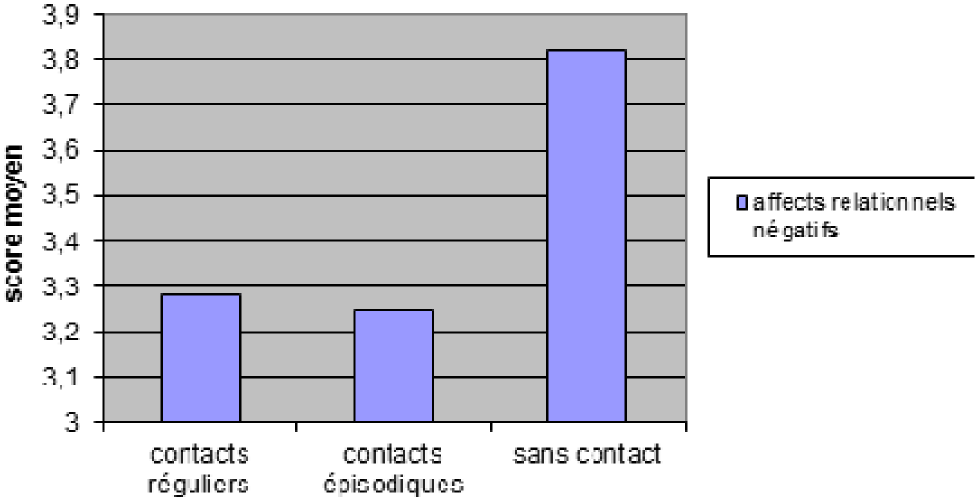
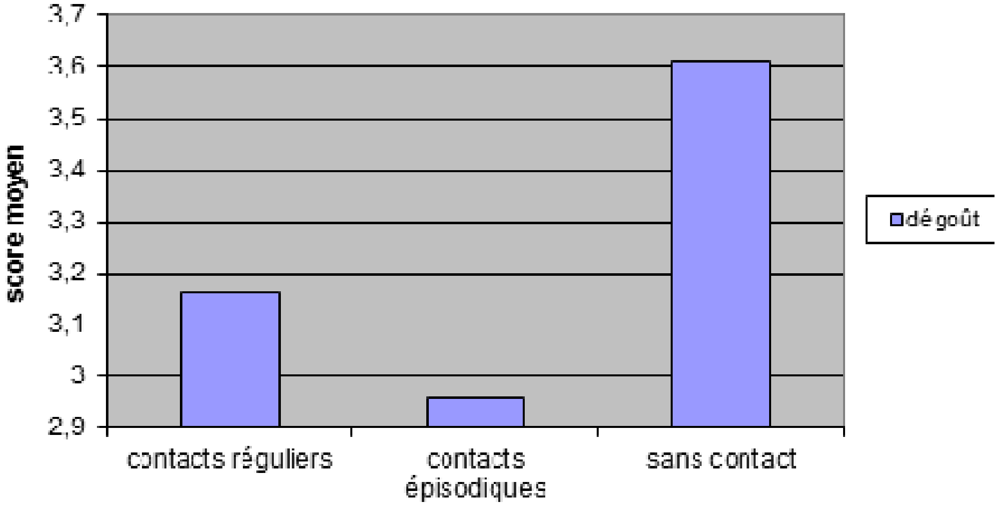


FIGURE 6. : MOYENNES SUR L'ITEM « DEGOUT », SELON LA FAMILIARITE



Notre groupe des « contacts réguliers » contient treize personnes ayant un proche sourd (conjoints, enfants, frères) et douze professionnels (interprètes en langue des signes, médecins ORL, éducateurs et enseignants spécialisés). Cet échantillon est séparé en deux sous-groupes : d'une part les « professionnels », d'autre part les « familles » aux contacts intimes avec un proche sourd. Ayant plus de dix observations par sous-groupe, nous procédons par les mêmes analyses statistiques que précédemment. L'ACP avec rotation Varimax Normalisée fait apparaître deux facteurs principaux. Le premier facteur regroupe l'angoisse (coefficient de saturation = 0,87), la compassion (0,78), la gêne (0,64) et la révolte (0,63); ce sont les affects « relationnels positifs ». Le second facteur regroupe la pitié (-0,92) et la déprime (-0,94), plus précisément, les affects « intrinsèques négatifs ». Nous accomplissons des analyses de variance sur les scores factoriels et observons que les deux sous-groupes se différencient principalement sur le premier facteur (F(1,23) = 5,98; p<0,02) : les affects relationnels positifs caractérisent principalement les participants ayant un contact intime avec des personnes sourdes (m = 4,67; σ = 0,89) par rapport aux professionnels (m = 3,77; σ = 0,92). Une analyse des effets spécifiques de chaque item révèle un effet particulier du sentiment d'angoisse (F(1,23) = 7,61; p<0,01) et de la compassion (F(1,23) = 5,62; p<0,02) : les familles (m = 5,0; σ = 1,15 / m = 5,46; σ = 1,12) éprouvent plus d'angoisse et plus de compassion vis-à-vis des sourds comparativement aux professionnels (m = 3,83; σ = 0,93 / m = 4,25; σ = 1,35) (figure 2).

- *Relation entre les réactions affectives et le jugement social*

Des corrélations très significatives apparaissent entre les dimensions qui structurent les affects et celles qui modèlent le jugement social. Les affects intrinsèques négatifs sont inversement corrélés à la sociabilité (r = -0,26; p< 0,023) et au dynamisme (r = -0,38; p<0,001)[13]. Autrement dit, plus les participants éprouvent de la pitié et de la déprime face aux personnes sourdes, moins ils les jugent sociables et dynamiques. Quant aux affects relationnels négatifs, ils sont inversement corrélés à la sociabilité (r = -0,38; p<0,01). Par conséquent, selon nos analyses, plus les sujets ressentent de la gêne et du dégoût vis-à-vis des personnes sourdes, moins ils les jugent ouvertes, attentives, chaleureuses et pleines d'humour.

Considérations sur les résultats de l'enquête

Selon les résultats de nos analyses, les sujets qui ont les contacts les plus réguliers avec le monde des sourds, à savoir, les familles et les professionnels (interprètes en langue des signes, médecins ORL, éducateurs et enseignants spécialisés) perçoivent assez négativement la population sourde (tableau 2). Ils jugent les personnes sourdes peu dynamiques (figure 1) et peu prudentes (figure 4) par rapport aux autres participants. Concernant les réactions affectives des sujets, si le contact améliore l'affect, ce n'est cependant pas le groupe des « contacts réguliers », mais le groupe des « contacts épisodiques » qui éprouve le plus d'attirance pour les individus sourds (figure 5). Notons que lors du remplissage du questionnaire, les proches et les professionnels se sont souvent montrés indécis, sinon gênés face à certaines questions. Est-ce à cause de certains termes employés dans nos échelles bipolaires (voir la section « les limites de l'étude »)? Une interprète professionnelle en langue des signes française et une psychologue spécialisée des enfants sourds ont refusé de participer à l'enquête.

TABLEAU 2 : COMPARAISON DU JUGEMENT SOCIAL ET DES RÉACTIONS AFFECTIVES VIS-À-VIS DES PERSONNES SOURDES, SELON LA FAMILIARITÉ

	Jugement social	Réactions affectives
Contacts réguliers	-	+
Contacts épisodiques	++	++
Sans contact	+	-

- *Jugement social et réactions affectives des « contacts régulier »*

Dans le groupe ayant des contacts réguliers avec des individus sourds, la proportion des familles est à peu près égale à celle des professionnels. À moins qu'il n'y ait un déni de ce

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[13] **R (Coefficient de Corrélation de Pearson)** : Le coefficient de corrélation de Pearson mesure la relation linéaire (« la proportionnalité ») entre les valeurs de deux variables. Il détermine le degré auquel les valeurs des deux variables sont « proportionnelles » les unes aux autres. Le coefficient de corrélation ne dépend pas des unités de mesure spécifiques utilisées. « Proportionnel » signifie « lié linéairement »; c'est-à-dire que la corrélation sera forte si les points s'alignent bien sur une droite (de pente positive ou négative).

handicap de la part des familles (certains auteurs relatent beaucoup ce fait, voir par exemple Lane, 1991; Mottez, 1993/2006; Poizat, 1996; Delaporte, 2002), il est difficile d'imaginer que les proches ne voient guère mieux la catégorie sociale des personnes sourdes par rapport aux professionnels. Nous avons interrogé une mère et un père de deux enfants vivant avec une surdité profonde. Lors du remplissage du questionnaire, ils ont jugé bien plus négativement les personnes sourdes en général que le proche sourd, ce dernier, étant considéré comme une exception à sa catégorie d'appartenance. Les parents ont donné le brillant exemple de l'aînée, sourde profonde de naissance, qui a appris à jouer du piano et qui vit pratiquement comme une enfant sans handicap. Y a-t-il minimisation, voire déni du handicap, chez certains parents?

La plupart des évaluations relevées chez les personnes ayant des contacts réguliers avec la population sourde semblent être orientées vers la perception du handicap en tant que situation difficile à vivre. Les professionnels sont en effet confrontés à ce handicap, mais aussi à certaines difficultés qui y sont liées, comme le problème d'apprentissage de la lecture et de l'écriture (voir sur ce sujet une recension des travaux dans C. Dubuisson & D. Daigle, 1998 ou N. Niederberger & I. Berthoud-Papandropoulou, 2004), d'intégration professionnelle et d'insertion sociale (INSEE « Handicaps-Incapacités-Dépendance, HID, 1998-1999 »). Selon ce point de vue, on peut supposer que les professionnels jugent les sourds peu autonomes (figure 2), par exemple, parce que beaucoup d'entre eux rencontrent des difficultés à lire et à écrire (Hamm, 2008). Les professionnels semblent donc s'appuyer sur une observation des difficultés occasionnées par ce handicap : pour les médecins, les psychiatres et les psychologues, l'individu sourd est atteint d'une déficience qui nécessite des soins particuliers; pour les enseignants spécialisés, l'enfant sourd est souvent un enfant en situation d'échec scolaire; pour l'éducateur, il est une parole à rééduquer. Ils définissent ainsi les sourds en termes de manque. D'après cette perspective ou ce « paradigme déficitaire », il s'agit de « réparer » la surdité (Meynard, 2002). Ce désir de « réparation » n'existe-t-il pas depuis fort longtemps?

Les familles, quant à elles, sont encore davantage impliquées dans une situation complexe vis-à-vis du proche sourd et par la prise en charge de son handicap. Vu sous cet angle, l'individu sourd se situe en dehors du circuit habituel que suit la société; il lui faut une institution spécialisée avec un formateur et un éducateur particuliers, un orthophoniste, un oto-rhino-laryngologiste, un pédopsychiatre, un audioprothésiste et enfin, un interprète en langue des signes pour lui permettre de communiquer avec autrui. Dans ce cas, les sourds sont peut-être jugés peu autonomes par les familles (figure 2), parce qu'ils ont besoin d'une interface de communication pour toute démarche administrative de quelque importance. Selon les résultats de nos analyses, les familles ressentent beaucoup plus d'angoisse et de compassion vis-à-vis des personnes sourdes que les professionnels (figure 7). Elles sont, en outre, confrontées au regard d'autrui, ce qui touche sans doute moins les professionnels. Avoir un proche sourd, qui est en marge de la société, est-ce parfois se sentir soi-même marginalisé? « Je me suis parfois heurté à des lieux communs idiots ou des remarques blessantes par leur ineptie. Je me suis donc senti seul ou différent en vivant par procuration ce que d'autres ne soupçonnaient même pas », écrit ce papa d'une petite fille sourde de deux ans (communication personnelle, juillet 2015). 95 % des sourds naissent dans des familles entendantes et 95 % de ces sourds ont ou auront des enfants entendants (voir notamment les travaux de M. Renard, 2008, p. 49). Combien de parents interrogés dans notre étude connaissent la langue des signes française? La majorité d'entre eux avaient décidé de scolariser leur enfant sourd soit dans une école ordinaire (en « intégration sauvage », pour la plupart), soit dans une école spécialisée réputée « oraliste »[14]. Peu d'entre eux avaient appris les bases de la langue des signes. Selon une

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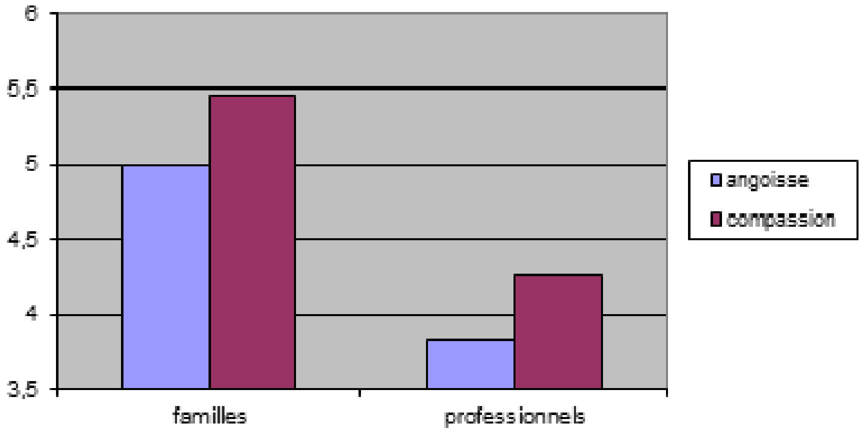
[14] Il existe deux écoles spécialisées pour enfants sourds à Strasbourg où l'enquête a été réalisée : l'une propose la langue des signes comme langue d'enseignement; l'autre la proscrit.

7. MOYENNES SUR LES ITEMS « ANGOISSE » ET « COMPASSION », SELON L'INTIMITÉ



ancienne étude menée par la psychosociologue Meadow (1966), les parents entendants seraient plus marqués par l'incapacité à parler – et donc à communiquer – de leur enfant sourd que par son inaptitude à entendre. Les familles de notre enquête rencontreraient-elles des problèmes de communication avec les personnes sourdes? « C'est à Tours que je me suis lancée plus longuement, dans cette formation [de langue des signes], sans Pierre [le papa], qui supportait mal le sentiment qu'il avait de devoir faire le clown », rapporte cette maman d'une petite fille sourde de deux ans (citée dans Croyère, 2007, p. 71). Bien entendu, tous les parents ne pensent pas qu'apprendre la langue des signes c'est « faire le clown ». Catherine Vella, par exemple, la maman de Vincent, un petit garçon sourd de sept ans, raconte :

> « Mon univers qui était son, qui était vibration, mes larmes à l'écoute d'un prélude de Bach ou au silence qui suit la dernière note de la mort d'**Isolde** de Wagner ont disparu d'un coup, emportés par ce tsunami qu'a été l'annonce : "votre enfant est sourd profond". Des jours de larmes amères, puis le choix à faire, lui ou moi! "Je continue? Je suis musique, je suis son, mais lui est visuel, lumière, soleil!". Mon choix : lui. J'ai quitté la planète musique classique pour entrer entièrement dans celle des sourds. J'y ai découvert un pays extraordinaire, totalement étranger pour moi, à l'opposé même de tout ce que j'avais vécu et ressenti depuis 45 ans! »[15].

Selon les dires des « contacts réguliers » de notre enquête, la sous-évaluation vis-à-vis des personnes sourdes semble liée à un problème de communication avec le monde des sourds.

- *Jugement social et réactions affectives des « contacts épisodiques »*

Les résultats de nos analyses font également apparaître que le groupe des « contacts épisodiques » a les jugements et les réactions affectives les plus positifs (tableau 2). Ce n'est donc pas la quantité des contacts qui compte. En ne côtoyant que de temps à autre le monde des sourds, ces personnes ne sont peut-être pas autant confrontées à la réalité des difficultés quotidiennes qu'occasionne ce handicap. Il s'agit de personnes sensibilisées aux problèmes de la surdité pour différentes raisons. Sans forcément bien connaître le milieu sourd, elles éprouvent des affects plus positifs que les proches qui côtoient régulièrement des personnes sourdes : elles attribuent aux personnes sourdes un dynamisme exceptionnel (figure 1),

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[15] Voir « Coup de tonnerre », article de Catherine Vella, publié le 15 octobre 2013, sur le blog : http://www.vincentmonamoursourd.com (consulté en juillet 2015). Ou voir : http://f.hypotheses.org/wp-content/blogs.dir/1593/files/2013/11/Catherine-VELLA-2013.-Coup-de-tonnerre.pdf.

les jugent pleines d'humour (figure 3) et éprouvent le plus d'attirance vis-à-vis d'elles par rapport aux autres participants (figure 5). Si le groupe des « contacts épisodiques » voit le handicap, il remarque peut-être davantage les aspects positifs de la surdité : la richesse visuospatiale et la beauté chorégraphique de la langue des signes, les représentations, les pratiques et les « rituels » du monde des sourds, et tout ce que les sourds ont su élaborer et se transmettre au fil des générations pour pallier la déficience (Delaporte, 2002, p. 3). Cette surévaluation est empreinte de préjugés, notamment de « l'exotisme produit par la première impression du contact avec une nouvelle langue ou culture qui contribue chez plusieurs personnes à "voir la vie en rose" ou à surévaluer positivement les traits d'un groupe en particulier » (communication personnelle de Charles Gaucher, décembre 2016). Toutefois, les « contacts épisodiques » de notre enquête semblent s'appuyer sur une approche globale de la surdité – et non pas partielle de l'audition – comme cela semble le cas chez de nombreux professionnels de l'audition, souvent à tort appelés « professionnels de la surdité ». Ce fut d'ailleurs bien plus facile d'obtenir la participation des « contacts épisodiques » que celle des autres participants. Le nombre des non-réponses est plus bas pour les « contacts épisodiques » par rapport au groupe des « contacts réguliers ». Il semble donc opportun de développer des contacts épisodiques entre les sourds et les entendants par le biais notamment de leçons de langue des signes française, de soirées d'échanges, de fêtes et de banquets annuels organisés au sein des associations des personnes sourdes et malentendantes.

Un autre aspect singulier révélé par nos résultats est l'humour souvent invoqué pour définir la communauté sourde. En effet, lorsqu'on a des contacts avec des personnes sourdes, qu'ils soient réguliers ou épisodiques, on les trouve pleines d'humour. C'est un trait de caractère qui marque et qui paraît stable. Il s'agit d'une caractéristique relationnelle notamment relatée dans des livres de maisons d'édition destinées à « faire entendre » la parole des sourds (voir par exemple Chalude & Delaporte, 2008; Renard, 1991 et 2008) et les ouvrages de sociologie analysant le milieu sourd (voir par exemple Delaporte, 2002). On y parle fréquemment de l'humour des sourds, vif, franc et « visuel », provenant sans doute de leur aptitude développée au mime. L'humour serait l'une des clés de la culture sourde. Les sourds aiment par exemple grossir les différences entre le milieu des sourds et celui des entendants pour produire des effets cocasses[16].

- Jugement social et réactions affectives des « sans contact »

Quant au groupe des « sans contact » de notre enquête, c'est au niveau des réactions affectives que les résultats sont les plus significatifs. Les analyses font apparaître que celles-ci se regroupent autour d'une dimension principale : les affects relationnels négatifs (figure 5). Les personnes non familiarisées avec la surdité éprouvent le plus d'affects relationnels négatifs face aux personnes sourdes. Ainsi, ce n'est pas parce que la surdité est une « infirmité » plus ou moins invisible que l'on ne retrouve pas les affects négatifs, tels que la gêne et le dégoût vis-à-vis des personnes ayant des incapacités observées dans plusieurs études (voir par exemple Louvet & Rohmer, 2000). Serait-ce lié à une trop grande frustration de ne pouvoir communiquer avec les sourds. Et les sourds? Que disent les sourds à ce sujet?

Presque tous les sujets sourds de notre population interrogée d'une autre enquête (Hamm, 2010) ont parlé d'une souffrance très vive, ancienne ou toujours actuelle, liée à un problème de communication avec leur environnement. Rapportons ce propos de Frédéric, dessinateur d'études, sourd de naissance, père de trois enfants dont une petite fille sourde :

> « Parfois, je me pose la question si les parents m'avaient accompagné dans mon apprentissage de la lecture et de l'écriture, est-ce que je lirais plus? Ils ne m'ont jamais accompagné dans

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[16] Voir par exemple le film « Sourds et Entendants » de P. Le Goff (2011), consultable sur https://www.youtube.com/watch?v=GA6PGHxeYiw

> mon parcours scolaire. Ma mère ne connaissait pas la langue des signes, elle était coincée quand elle essayait de communiquer avec moi. À table, on n'échangeait pas. Mon frère entendant et mes parents parlaient alsacien entre eux. Il n'y avait aucune communication avec moi, je prenais mon plat et me mettais devant la télévision. C'était déjà difficile d'apprendre le français, mais s'il avait fallu que j'apprenne encore l'alsacien! Je ne connais qu'une seule expression alsacienne : "Lass mich los" ["lâche-moi"] » (cité dans Hamm, 2010, p. 173).

Gérard Sanroma, quant à lui, formateur et comédien sourd, termine son livre par ces mots (2010, p. 88) :

> « Être sourd n'entraîne pas la souffrance. Mais l'absence de communication aisée, oui, une terrible. J'ai mis plus de quinze ans à enfouir la mienne, elle me colle à la peau, et refait surface à la moindre occasion. Mais grâce à elle, j'ai connu la résilience ».

Dans ce cas, comment ne pas s'étonner que les sourds cherchent le contact avec d'autres sourds? Les « sans contact » de notre étude jugent les personnes sourdes les moins volontaires ou persévérantes par rapport aux autres participants (figure 2), peut-être parce qu'ils pensent que les sourds restent entre eux et n'essayent pas de s'intégrer dans la société entendante. Ils les trouvent prudents (figure 4), mais peu humoristiques (figure 3). Si les réactions affectives des « sans contact » sont les plus négatives par rapport aux autres participants, leur jugement évaluatif est en revanche assez positif : il y a une plus grande proximité entre le jugement des « contacts épisodiques » et celui des « sans contact », qu'entre le jugement des « contacts épisodiques » et celui des « contacts réguliers ». Nous observons ainsi ce que d'autres expériences (voir par exemple Louvet & Rohmer, 2000) ont déjà mis en évidence : les personnes ayant des incapacités, qu'elles soient atteintes d'incapacités invisibles ou peu visibles, sont généralement considérées comme intelligentes, créatives, ouvertes aux autres, attentives et consciencieuses par l'homme de la rue. Cette surévaluation provient des règles sociales et du « politiquement correct » qui l'incitent à ne pas mal juger une catégorie « défavorisée ». « Le Sourd est en ce sens une figure identitaire exotique, mais d'un exotisme qui n'a pas été totalement colonisé par la rectitude politique, si ce n'est pour trouver des euphémismes servant à dire leur différence, euphémismes que les principaux intéressés rejettent généralement en bloc. La pudeur qui entoure la différence des Sourds fait qu'on la nomme avec précaution, mais on ne se gêne pas pour autant pour la juger, la fabuler, la fantasmer comme quelque chose de lointain qui se donne à voir, un objet paradoxal de distinction à proximité » (Gaucher, 2009, p. 3).

Les dernières analyses rappellent que la perception sociale implique de façon inhérente affect et cognition. On peut supposer que certains affects négatifs, tels que la gêne et le dégoût ressentis vis-à-vis des personnes sourdes empêchent une perception très positive envers la population touchée par ce handicap, comme dans le cas du groupe « sans contact ». On remarque en outre que l'on trouve moins de résultats pour les affects que pour les jugements. Il est en effet plus facile pour les « percevants » d'évaluer leurs propres jugements que leurs réactions affectives, qui sont plus intimes et plus secrètes. Aussi, cette recherche montre que la familiarité reposant sur l'habitude de rencontrer des personnes ayant des incapacités ne conduit pas nécessairement à une réduction des phénomènes discriminatoires face à cette catégorie d'individus.

Conclusion

Selon les résultats de notre enquête, les personnes sans contact avec la population sourde ont les réactions émotionnelles les plus négatives vis-à-vis des sourds. Toutefois, le jugement social des personnes familiarisées avec la surdité ou en contact régulier avec des personnes sourdes est assez négatif par rapport aux autres participants. Cette familiarité paraît reposer sur la connaissance de la surdité comme une déficience difficile à surmonter. Enfin, les individus ayant des contacts épisodiques avec les sourds ont les réactions affectives et le jugement évaluatif les plus positifs : ils semblent avoir une représentation de la surdité sans les problèmes qui y sont liés. Nos résultats montrent que certaines situations – comme des séances d'initiation à la langue des signes données par des enseignants sourds à des élèves entendants – constituent non seulement une expérience enrichissante, mais permettent également de réduire les préjugés et la discrimination à l'égard des personnes sourdes chez les entendants (sans doute aussi ceux des sourds à l'égard des entendants). Notre recherche ne serait complète que si nous faisions plusieurs études comparatives, notamment dans différents pays étrangers. De plus, à partir du même matériel d'investigation, il serait intéressant d'interroger une population de sourds sur leurs représentations vis-à-vis des entendants. Un sourd en contact régulier avec le monde entendant a-t-il les mêmes jugements et réactions affectives qu'un entendant en contact régulier avec le monde des sourds?

Notre enquête s'est enrichie de nombreux entretiens (Hamm, 2010 et 2014). D'un côté, il y a ceux qui disent : « Tu [ne] fais pas d'effort pour entendre » (parole d'une éducatrice d'un institut de jeunes sourds, Œil pour œil, 2012). Mais il y a aussi les personnes – le tout public – séduites par les langues des signes et « attendries », notamment par le film « La famille Bélier » (d'E. Lartigau, 2014). Ce film enregistre plus de 7 400 000 entrées en mai 2015; « c'est un excellent film grand public », écrit par exemple le sociolinguiste Jacky Simonin (communication personnelle, janvier 2015). Ce qui n'est pas l'avis de nombreux sourds ni de celui de ce père d'une petite fille sourde de deux ans : « Du point de vue de la surdité : ce film ne s'adresse pas aux sourds (même s'il a la prétention de le leur dédier dans le générique de fin), il donne une image ridicule des sourds, complètement exagérée et erronée » (communication personnelle, mai 2015). D'un autre côté, il y a ceux qui s'inquiètent et ont le souci d'être dans la norme : « Si je décidais de ne pas la faire implanter, je prendrais la décision de lui refuser la découverte de tant de saveurs auditives, alors même que l'implant aujourd'hui permet cela à un sourd profond. […] Je ne veux voir que le positif. Je veux croire que [ma fille] investira au mieux son implant et que cela lui ouvrira des voies qui lui étaient totalement fermées », écrit ce parent d'un enfant sourd d'un an (communication personnelle, juillet 2014). Tel est le rêve que propose aujourd'hui l'implant cochléaire. Rêve qui fait dire à cette maman d'une petite fille malentendante de neuf ans avec laquelle nous avons eu l'occasion d'échanger quelques mots dans le train en 2014 : « Malheureusement, elle entend trop pour un implant ». De nombreuses personnes sourdes non implantées, pourtant, disent être parvenues à grandir, non pas grâce à des appareils auditifs, ni grâce à des restes auditifs, et encore moins à la présence de médecins ou autres professionnels de l'audition, mais grâce à leurs ressources intérieures. Citons Marc Renard, ingénieur, écrivain et éditeur sourd (communication personnelle, septembre 2013) :

> « J'ai lu des (auto)biographies de personnes dites "handicapées", de divers pays (France, USA, Japon…) de diverses déficiences (mobilité, surdité, autisme, etc.) et toutes ces personnes, SANS exception, arrivent à la même conclusion : la vie mérite d'être vécue et je n'ai pas réussi "malgré", mais "parce que". Non pas "malgré que" je suis sourd, mais "parce que" je suis sourd. Au demeurant, c'est de la psychologie élémentaire, il faut s'accepter tel que l'on naît, tel que l'on est ou tel que l'on est devenu ».

Nous avons tenté de répondre à la question initiale : qu'entend-on par sourd? Quel pourrait être toutefois le regard du malentendant sur sa condition? Autrement dit, qu'entend-on par « être » sourd? Sacha Guitry (1885-1957) dans « Mon père avait raison » déclarait, non sans humour :

> « Quelle erreur! Une punition [d'être dur d'oreille]? Pour les autres, oui! C'est pour les autres que c'est fatigant… ce n'est pas pour moi! Pour moi, c'est délicieux! On ne me dit jamais que les choses essentielles.

> Comme on sait qu'il faut me crier dans l'oreille tout ce qu'on a à me dire, on réfléchit avant de parler… C'est excellent pour tout le monde… et moi ça ne m'empêche pas de parler… au contraire… et on est obligé de m'écouter… et on ne peut pas m'interrompre, moi! Je n'entends pas! » (cité dans Bernard, 1941, p. 104).

Ceux qui n'entendent pas ou mal ont sans doute encore beaucoup à dire, pour peu qu'on les questionne, leur donne la parole et les écoute. Qu'est-ce qu'un silence, un dialogue intérieur, un son, une musique pour un sourd? Que représente la langue des signes dans sa vie? Durant ces dernières années, la langue des signes s'est beaucoup médiatisée et de nombreuses expériences montrent ses vertus pédagogiques dans le développement cognitif des enfants et de certains adultes[17]. La formation du personnel soignant et enseignant tient-elle compte des apports de la langue de signes? Ne faut-il pas davantage souligner ses effets bénéfiques pour tout un chacun? Comment l'enseigner et avec quels moyens? Comment « fonctionne » cette langue? Quels sont ses « mécanismes »? Ne mérite-t-elle pas une véritable approche scientifique, voire épistémologique? La langue des signes n'appartient-elle pas au patrimoine intellectuel de l'humanité? Aujourd'hui encore, cette langue silencieuse constitue un champ d'exploration extrêmement stimulant. Elle est entre nos mains, et peut-être, au fond de nous.

Références

BECKER, H. S. (2002). *Les ficelles du métier. Comment conduire sa recherche en sciences sociales*. Paris : La Découverte.

BERNARD, R. (1941). *Surdité, surdi-mutité et mutisme dans le théâtre français*. Thèse de doctorat ès Lettres. France : Université de Rennes.

CAJAL, M. (2013). *Surdités, implants cochléaires et impasses relationnelles. Les enfants inouïs*. Toulouse : Éditions ERES.

CATTELL, R. B. (1974). *Test 16 PF de Cattell*. Paris : Éditions du centre de psychologie appliquée.

CHALUDE, J., & DELAPORTE, Y. (2008). *Gros signes*. Les Essarts-le-Roi : Éditions du Fox.

CORNEILLE, O. (1994). Le contact comme mode de résolution du conflit intergroupe : une hypothèse toujours bien vivante. *Les cahiers internationaux de psychologie sociale, 23*, 40-60.

CROYERE, N. (2007). La surdité : quelle(s) histoire(s)! Paris : L'Harmattan.

DELAPORTE, Y. (2015). *L'école des sourds. Encyclopédie historique des institutions française*. Les Essarts-le-Roi : Éditions du Fox.

DELAPORTE, Y. (2002). *Les sourds, c'est comme ça*. Paris : Éditions de la maison des sciences de l'homme.

DUBUISSON, C., & DAIGLE, D. (1998). *Lecture, écriture et surdité. Visions actuelles et nouvelles perspectives*. Québec : Les Éditions Logiques.

FISKE, S. T. (2008). *Psychologie sociale*. Traduction de V. Provost & S. Huyghues Despointes. Bruxelles : De Boeck.

FISKE, S. T., & NEUBERG, S. L. (1990). A continuum of impression formation from category based to individuating processes : influences of information and motivation on attention and interpretation. Dans M. P. Zanna, *Advances in experimental social psychology* (p. 1-74). New-York : Academic Press.

GAUCHER, C. (2009). L'altérité des Sourds : deux lieux communs pour interroger la liminalité des sociétés individualistes. *Monde Commun, 1*, 1-14.

GUENON, R. (1945). *Le règne de la quantité et les signes des temps*. Paris : Gallimard.

HAMM, M. (2008). L'apprentissage de la lecture chez les enfants sourds. Quels outils pédagogiques au service de quel apprentissage de la lecture? *Education-Formation*, *288*, 37-44.

HAMM, M. (2010). *L'apprentissage de l'écriture et la lecture chez les personnes sourdes et malentendantes*. Thèse de doctorat en sciences de l'éducation. France : Université de Strasbourg.

HAMM, M. (2014). L'alphabet chez les enfants sourds et malentendants. *Cahiers Pédagogiques*, *Réussir l'apprentissage de la lecture, de la maternelle à l'âge adulte, 516*, 49-50.

INSEE « HANDICAPS-INCAPACITES-DEPENDANCE, HID, 1998-1999 » (2007). *Le handicap auditif en France. Apports de l'enquête Handicaps, incapacités, dépendance – 1998-1999*. M.-S. Sander, F. Lelièvre & A. Tallec (Eds.). Avec la collaboration de J. Dubin, F. Legent, S. Danet & J.-B. Herbert. DREES, études et résultats, 589.

JAVEAU, C. (1990/1992). *L'enquête par questionnaire. Manuel à l'usage du praticien.* Bruxelles : Éditions de l'Université de Bruxelles.

JODELET, D. (2003). *Les représentations sociales*. Paris : Presses Universitaires de France.

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[17] Voir le cas du fils autiste de Marilyne et l'exemple de Jennifer dont la timidité et la dyslexie ont été atténuées grâce à ce mode de communication dans l'émission « Une langue en partage » d'O. Vinuesa (2015).

Kassin, S., Brehm, S. S., & Fein, S.(2005). *Social Psychology*. Boston : Houghton Mifflin.

Lane, H. (1991). *Quand l'esprit entend, histoire des sourds-muets*. Traduction de l'américain de C. Butel. Paris : Odile Jacob.

Louvet, E., & Rohmer, O. (2000). Le rôle des réactions affectives dans la perception sociale des personnes handicapées physiques selon la familiarité avec le handicap. *Les cahiers internationaux de psychologie sociale, 47 et 48*, 95-109.

Louvet, E., & Rohmer, O. (2004). Familiarité et réactions affectives à l'égard des personnes handicapées physiques. *Bulletin de psychologie, 470*, 165-170.

Louvet, E., & Rohmer, O. (2006). Le handicap physique : une catégorie de base? *Revue Internationale de Psychologie Sociale, 19*, 215-234.

Manrique, M. J., & Huarte, A. (2007). Hypoacousies. Surdités. Dans C. Chevrie-Muller et J. Narbona. *Le langage de l'enfant. Aspects normaux et pathologiques*. 3ème édition. Issy-les-Moulineaux : Elsevier Masson, 299-324. [Référence de la note de fin de page].

Meadow, K. P. (1966). *The effect of early manual communication and family climate on the deaf child's development*. Berkeley, University of California, Ph.D. dissertation.

Meynard, A. (2002). *Quand les mains prennent la parole. Dimension désirante et gestuel*. Toulouse : Éditions ERES.

Minguy, A. (2009). *Le réveil Sourd en France. Pour une perspective bilingue*. Paris : L'Harmattan.

Monahan, J. L., Murphy, S. T., & Zajonc, R. B. (2000). *Subliminal mere exposure: Specific, general, and diffuse effects. Psychological Science, 11*(6), 462-466.

Mottez, B. (1993/2006). Les Sourds existent-ils? Dans B. Mottez (2006). *Les Sourds existent-ils?* (p. 86-95). Présentation par Andrea Benvenuto. Paris : L'Harmattan.

Niederberger, N., & Bertoud-Papandropoulou, I. (2004). Utilisation des pronoms personnels en français écrit par des enfants sourds bilingues : un parcours spécifique d'apprentissage? *LIDIL, 30*, 27-38.

Œil pour œil (2012). *Contre les implants auditifs et la loi sur le dépistage ultra précoce de la surdité*. Repéré à https://infokiosques.net/spip.php?article1027

Poizat, M. (1996). *La voix sourde. La société face à la surdité*. Paris : Métailié.

Processus de production du handicap (1998). Les facteurs environnementaux. Repéré à http://www.ripph.qc.ca/mdh-pph/les-concepts-cles-du-mdh-pph/les-facteurs-environnementaux (consulté en décembre 2016).

Ravaud, J.-F., Beaufils, B., & Paicheler, H. (1986). Handicap et intégration scolaire : Inflation des stéréotypes et valse des étiquettes. *Sciences sociales et santé, 4*, 167-194.

Renard, M. (1991/1993). *Sourd, cent blagues*. Les Essarts-le-Roi : Éditions du Fox.

Renard, M. (1996/2008). *Les sourds dans la ville. Surdités et accessibilité*. Les Essarts-le-Roi : Éditions du Fox.

Rey, A., Rey-Debove, J., & Cottez, H. (1967/2001). *Le Petit Robert*. Dictionnaire alphabétique et analogique de la langue française [CD-ROM].

Sanroma, G. (2010). *L'amour au-delà du désert*. Avec la collaboration de J. Sanroma. Paris : Édilivre.

Zajonc, R. B. (1994). On the Primacy of Affect. *American Psychologist, 39*(2), 117-123.

Autres références

- Films et reportages télévisés :

Kaempfer, Louis, J. (2011). Sourds et fiers de l'être. Dans S. Brasey, *Signes*. Suisse : Radio Télévision Suisse. [Référence de la note de fin de page].

Lartigau, E., Bedos, V., & Carré de Malberg, S. (2014). *La famille Bélier*. France : Jerico Mars Film.

Le Goff, P. (2011). *Sourds et Entendants*, https://www.youtube.com/watch?v=GA6PGHxeYiw (consulté en septembre 2016). [Référence de la note de fin de page].

Vinuesa, O. **(2015).** Une langue en partage. Dans *L'œil et la main*. Paris : France 5. Repéré à http://www.france5.fr/emissions/l-oeil-et-la-main/diffusions/20-05-2013_63871. [Référence de la note de fin de page].

Voizeux, I. & Valo, L. (2009). On n'est pas que des sourds. Dans *L'œil et la main*. Paris : France 5. Repéré à http://www.france5.fr/emissions/l-oeil-et-la-main/on-n-est-pas-que-des-sourds_68274**.** [Référence de la note de fin de page].

- Communications personnelles :

Delaporte, Y. [courriel électronique]. Novembre 2016. [Référence de la note de fin de page].

Gaucher, C. [courriel électronique]. Décembre 2016 et février 2017/

Maman entendante anonyme [rencontre dans le train]. Mai 2014.

Père entendant anonyme [courrier électronique]. Juillet 2014.

Père entendant anonyme [courrier électronique]. Mai 2015.

Père entendant anonyme [courrier électronique]. Juillet 2015.

Renard, M. [courrier électronique]. Septembre 2013. Échange consultable sur http://f.hypotheses.org/wp-content/blogs.dir/1372/files/2013/09/Extrait-de-lentretien-avec-Marc-Renard-du-24.09.13.pdf.

Simonin, J. [courrier électronique]. Janvier 2015.

Vella, C. [courrier électronique]. Octobre 2013. Échange consultable sur http://implant.hypotheses.org/temoignages

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Social Representations of Persons with Learning Disability or Autism Spectrum Disorder Among Rehabilitation Professionals in Sweden

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Abstract

Individuals with disabilities are affected by their environment in different ways, and one important factor involves how these individuals are perceived by others. This article focuses on rehabilitation professionals and the social representations of people with learning disability or autism spectrum disorder, as this group's life situation is largely influenced by the professionals who work with them in their everyday lives. An association study, which is an established method in the theory of social representations, was carried out to gain more insight; in total, 121 rehabilitation professionals were included in the study. The results indicate that, when thinking about the target group, the respondents often associated the individuals in the group with work and the working process. A relational representation emerges where the individual is not perceived as someone with independent agency but rather as a person whose characterization is assigned in relation to the work tasks. Despite this, the respondents were sympathetic to the individuals and this work. The study also shows that the professionals' social representations of the target group differs depending on what organization they belong to and that the various denominations of the individuals used in the organizations are not appreciated by the professionals.

Keywords: Rehabilitation, social representations, professionals, learning disability, autism spectrum disorder

Résumé

Les individus avec des incapacités sont affectés par leur environnement de plusieurs façons, entre autres par la manière dont ils sont perçus des autres. Cet article se penche sur les représentations des professionnels de la réadaptation envers les gens vivant des difficultés d'apprentissage ou qui vivent avec le spectre de l'autisme, car les situations de vie de ces derniers sont grandement influencées par les professionnels avec lesquels ils travaillent au quotidien. Une étude par association, qui est une méthode établie dans la théorie des représentations sociales, fut entreprise afin d'approfondir les connaissances. Au total, 121 professionnels de la réadaptation ont participé au projet. Les résultats indiquent que, quand les professionnels pensent à leur clientèle, ils associent ce groupe au travail et au processus de travail. Une représentation de type relationnelle émerge où les personnes ne sont pas comme telle autonomes, mais plutôt associées aux tâches qu'elles réalisent. Malgré cela, les répondants avaient des attitudes sympathiques envers les individus et le travail. Cette étude montre aussi que les représentations sociales des professionnels envers les gens qu'ils aident diffèrent selon l'organisme auquel ils appartiennent et que les nombreuses dénominations par ces organismes à l'égard des individus ayant des incapacités ne sont pas appréciées par les professionnels.

Mots-clés : Réhabilitation, représentations sociales, professionnels, difficultés d'apprentissage, spectre de l'autisme

Introduction

Disability and its consequences for the individual are often discussed in various contexts. In the Nordic countries as well as in many other countries, an *environment-relative handicap model* is embraced. This model includes a social perspective and focuses on the impact of the surrounding society on the lives of individuals with disabilities. In contrast, the *medical model*, which involves a greater focus on diagnoses and individual difficulties, is seldom referenced in the public discourse. Research shows that individuals with disabilities are affected by their surroundings in different ways (Robey et al., 2006; Verdonschot et al., 2009; Vornholt et al., 2013). Negative aspects and consequences are often in focus, but in some cases, positive effects are also mentioned (Bell & Klein, 2001; Gouvier et al., 1994; Manchaiah et al., 2015). One important factor in the environment aspect relates to the perceptions people have about individuals with disabilities. Several studies have been conducted on this subject, and the results show that the negative attitudes of others toward people with disabilities leads to an increased risk of stigmatization and exclusion (e.g., Gilmore et al., 2003; Hall, 2004; Louvet, 2007).

The social psychological theory of social representations has been used in several studies of disease and disability (e.g., Herzlich, 1973; Zani, 1993; Morant, 2006; Linton et al., 2013). This theory suggests that our social representations – the everyday knowledge of phenomena or objects in our surroundings – affect our actions in various situations. Accordingly, this article focuses on rehabilitation professionals and their representations of people with learning disability or autism spectrum disorder (ASD). A learning disability affects a person's capability to learn new skills, understand complex information, communicate and act independently. ASD is a condition that affects social interaction, communication and behaviour, and often creates difficulties within these areas. The life situation for persons belonging to these groups is largely influenced by professionals that surround them in their everyday life (Ståhl et al., 2011; Stucki et al., 2007). Thus, the professionals' representations of these individuals are especially important, as their actions will affect the way in which these persons are treated and what rehabilitation measures are implemented. In line with this, the aim of the present study is to explore the social representations of persons with learning disability or autism spectrum disorder (ASD) among rehabilitation professionals in Sweden.

Theory and method

- Social representation theory

The theory of social representations (SRT) was developed by the social psychologist Serge Moscovici and was first formulated and published in the 1960s in his thesis "La psychanalyse, son image, son public" [*Psychoanalysis: Its image and its public*]. Moscovici defined a social representation as a system of values, ideas and practices which enables individuals to orientate themselves in their material and social world, and to communicate with members of a community by providing them with a code for social exchange and a code for naming various aspects of their world (Moscovici, 1973). Representations can be perceived as historically conditioned expressions of our contemporary culture, and the theory provides the possibility to describe and explain various groups' everyday knowledge, or in other words, their common mental images (Chaib & Orfali, 1995). It details how we, in social interaction with others, build our everyday knowledge and how this knowledge affects our worldview and subsequent actions[1].

- Data collection

To explore the professionals' perceptions and mental images of the target group, an *associa-*

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[1] For a more detailed presentation of the theory, see e.g., Germundsson, P. (2015) *Inclusive Education in Sweden and social representations* in Hensen, G. & Beck, A. (Eds.) Inclusive Education. Internationale Strategien und Entwicklungen Inklusiver Bildung (Beltz Juventa) or Chaib, M., Danermark, B. & Selander, S. (Eds.) (2011) *Education, Professionalization and Social Representations: On the Transformation of Social Knowledge* (Routledge).

tion study was carried out[2]. This is an established method in SRT. During the association study, free associations were gathered. The *free association method* involves respondents being asked to enter the word or expression that comes to mind from a presented stimulus word or word series. The method is expected to give spontaneous answers which are less elaborated and controlled than those which are developed and linguistically formulated during an interview, for example. (Abric, 1994). It is assumed that the person's response depends on the stimulus word or phrase as well as the knowledge and images the respondent has of the object (Wagner et al., 1996). By analyzing the associations, the opportunity to expose our partly subconscious mental images arises, which in turn, affects our often unreflected actions especially in situations where quick decisions are required (Kahneman, 2011; Ratinaud & Lac, 2011).

- *Participants*

The association study was conducted in the form of an online questionnaire to be answered by the respondents consisting of professionals working in daily activities[3] or assisted living facilities in a major city in Sweden or within the municipality or region's rehabilitation teams. From a list of all workplaces in the city with daily activities (*n* = 42) or assisted living facilities (*n* = 86), 25 % of the workplaces *(n* = 32) were randomly selected using the *Microsoft Excel* software. Within the selected workplaces and the two rehabilitation teams, all of the professionals with rehabilitative work tasks were contacted. The respondents were contacted via e-mail containing information about the study and a link to the questionnaire. In addition to demographic data such as age and gender, the respondents were asked to associate about the users. Up to five associations could be given by the respondents, and they were also asked to indicate if the association was positive or negative on a five-point scale of values (--, -, 0, +, or ++). The questionnaire was sent to 189 persons, of whom 121 responded (response rate 64 %). This study follows the ethical principles as stated in the Helsinki Declaration.

- *Data analysis*

A total of 323 associations were gathered, and the collected associations were divided into 13 categories (see Figure 1). The categorization process followed a step-by-step synonymy procedure: Association items considered to be synonymous (i.e., having the same meaning) were grouped together and specified categories were established. During the process, an external person with experience in social work was consulted to discuss the categorization, and corrections were made following the discussions. If the association consisted of several words or whole sentences, significant keywords were identified to place the association in the right category. The positive or negative connotations were helpful in efforts to place the associations in the correct category, with the aim of being as specific as possible for the items included. Eleven of the associations could not be interpreted (as *used*, *long*, *EU*, and *assistant*) or placed into any specific category resulting in 312 associations being included in the study. The number of categories varied by the respondents' affiliation (see Table 2), and the stimulus word was adapted to the denomination used in the respective organization (*inhabitant*, *patient*, or *user*).

To show the distribution of associations a *similarity analysis* was implemented, where the *co-occurrence* of associations among the respondents is studied. The analysis is based on the mathematical *graph theory*. During the analysis, *Iramuteq* (Ratinaud, 2015) software was utilized, which uses *R* statistical software (The R Foundation, 2015). The result is presented (see Figure 2) as a *maximum tree* graph through which the strongest link between different categories is shown in the form of lines. The tree consists of categories which are linked to each other thus showing the tendency of people to mention these categories together. The size of the text in the tree is in proportion to the size of the category.

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[2] The study is part of a research project in agreement for collaboration in the field of Rehabilitation for Individuals with Learning Disability or Autism Spectrum Disorder (ASD).

[3] Also referred to as 'regular educational–vocational activities'.

TABLE 1 : RESPONDENTS IN THE ASSOCIATION STUDY

	Number	Female/Male (%)	Age (average)	Post-Secondary Education (%)	Years in the Profession (average)
Daily Activities	52	83 / 17	45	68	13
Assisted Living	45	82 / 18	46	43	17
Rehab Team Region	14	86 / 14	42	100	14
Rehab Team Municipality	10	70 / 30	37	100	12
Total	121				

TABLE 2 : NUMBER OF ASSOCIATIONS AND CATEGORIES BASED ON THE RESPONDENTS' ORGANIZATIONAL AFFILIATION

	Associations	Categories
Daily Activities	142	12
Assisted Living	93	12
Rehab Team Region	43	13
Rehab Team Municipality	34	12

Results

1. The professionals' representations

1.1 Size and valance of categories

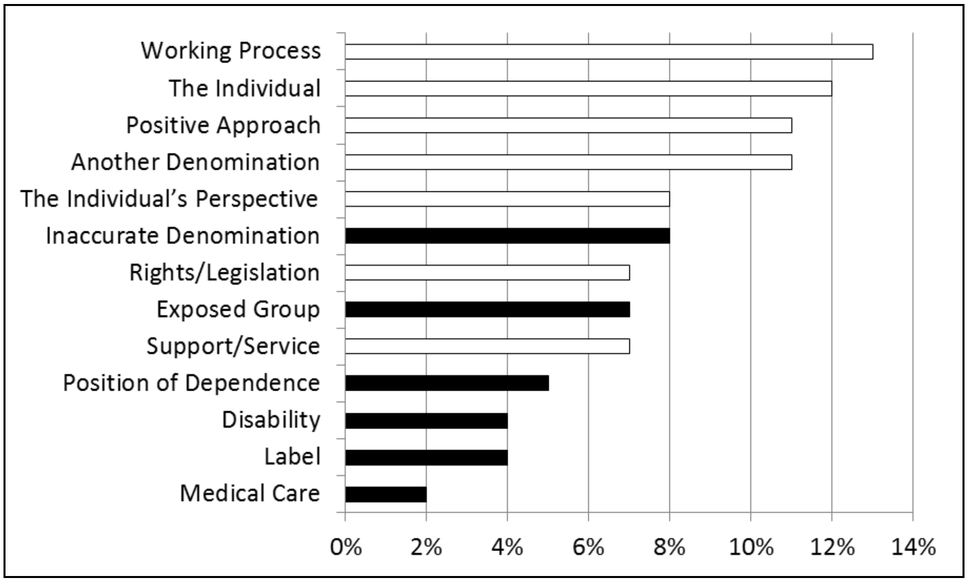
Figure 1 shows the categories and their size for all respondents. The figures indicate the percentage of the associations found in each category. The largest category (13 %) is 'Working Process', and contains associations such as *work*, *adapt*, *objectives*, *many meetings*, and *administration*. The second largest category, 'The Individual' (12 %), relates to the individual and individual characteristics, and includes associations such as *individual*, *personality*, and *fellow man*. Eleven percent of the associations are found in the category of 'Positive Approach' where, through their associations, the respondents expressed an overall positive attitude toward users (as *interest*, *joy*, and *consideration*).

Almost one fifth of the associations reflect references to the individual and that respondents give suggestions on 'Another Denomination'. In certain cases (8 %), the respondents expressed that the current denomination is inaccurate. Another four percent of the associations concern the same area; in this case, the respondents believed that the denomination is a label placed on the individual.

In addition to the 'Positive Approach' category, some associations (8 %) highlight the 'Individual's Perspective' (as *self-determination*, *independence*, *actor*, and *be like everyone else*). Overall, more than one in ten associations involve users being in an 'Exposed Group' (7 %) and in a 'Position of Dependence' (5 %).

In the collection of associations, the respondents were asked to state if the association was positively or negatively value-charged or had no charge (five values). In Figure 1, a black bar represents the categories containing predominantly negatively charged associations,

FIGUE 1 : CATEGORY SIZE AND PREDOMINANT VALENCE OF ASSOCIATIONS WITHIN EACH CATEGORY AMONG ALL RESPONDENTS



while the white bars indicate that the associations are predominantly positively charged based on a calculated average. The five largest categories are positively value-laden. Altogether, seven of the thirteen categories, containing 69 % of all associations, are predominantly positively charged. Among the six negatively charged categories 'Inaccurate Denomination' and 'Exposed Group' are the largest.

1.2 Similarity analysis

The result of the similarity analysis is presented in a maximum tree where the strongest link between the different categories is shown in the form of lines (see Figure 2). For instance, the number on the line connecting the two categories of 'Working Process' and the 'Individual's Perspective' indicates how many individuals mentioned both these categories. The conditions were thus created to determine how the associations are linked by studying the individuals' associations supplemented with information about what the persons *additionally* came to think of.

The tree clearly shows that 'Working Process' is the hub around which the other categories such as 'The Individual,' 'The Individual's Perspective,' and 'Positive Approach,' circuit. A strong link is also found between the categories of 'Working Process' and 'Rights/Legislation,' which in turn, is linked to the 'Position of Dependence' category. The tree also shows a link between 'Working Process' and the respondents' tendency to suggest 'Another Denomination' of the individual in this context.

2. Differences between professionals

2.1 Differences based on organizational affiliation

This section presents the categories based on organizational affiliation. The division is split into two groups based on the condition that the professionals working in daily activities and assisted living facilities meet the individual continually and regularly participate in everyday activities; in contrast, members of rehabilitation teams located in other premises meet the individual in specific cases and on more limited occasions. In Figure 4 the grey bar means that the associations within the category in total were neither positive nor negative.

FIGURE 2 : MAXIMUM TREE FOR ALL RESPONDENTS AND INDICATING NUMBER OF CO-OCCURRENCES

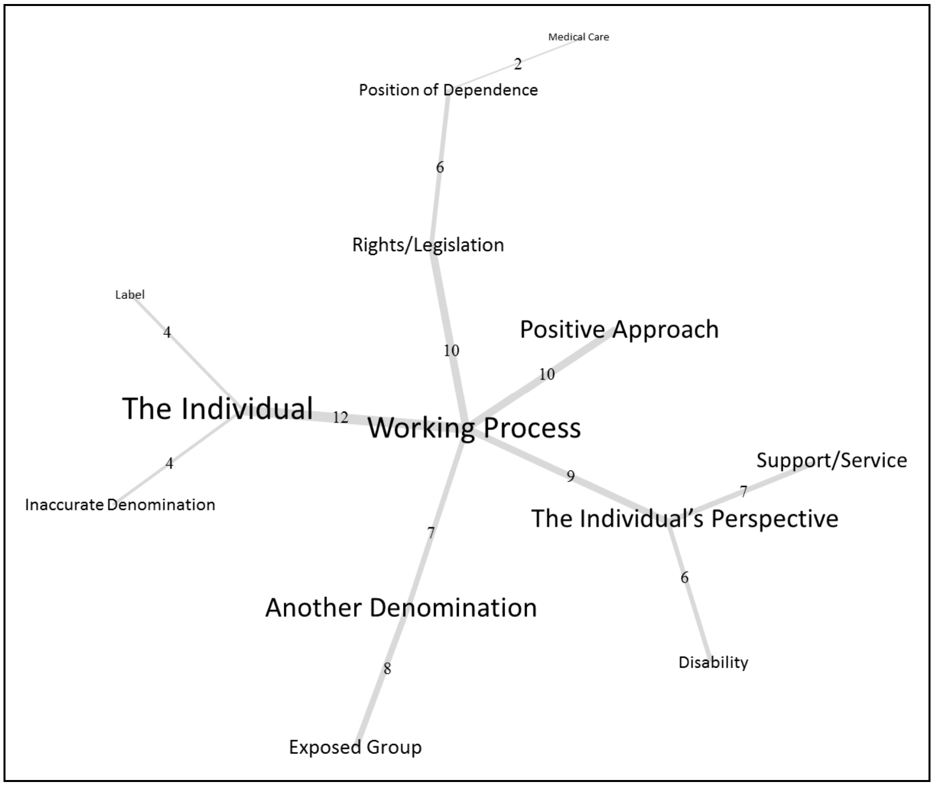


FIGURE 3 : CATEGORY SIZE AND PREDOMINANT VALENCE OF ASSOCIATIONS WITHIN EACH CATEGORY AMONG PROFESSIONALS IN DAILY ACTIVITIES AND ASSISTED LIVING FACILITIES

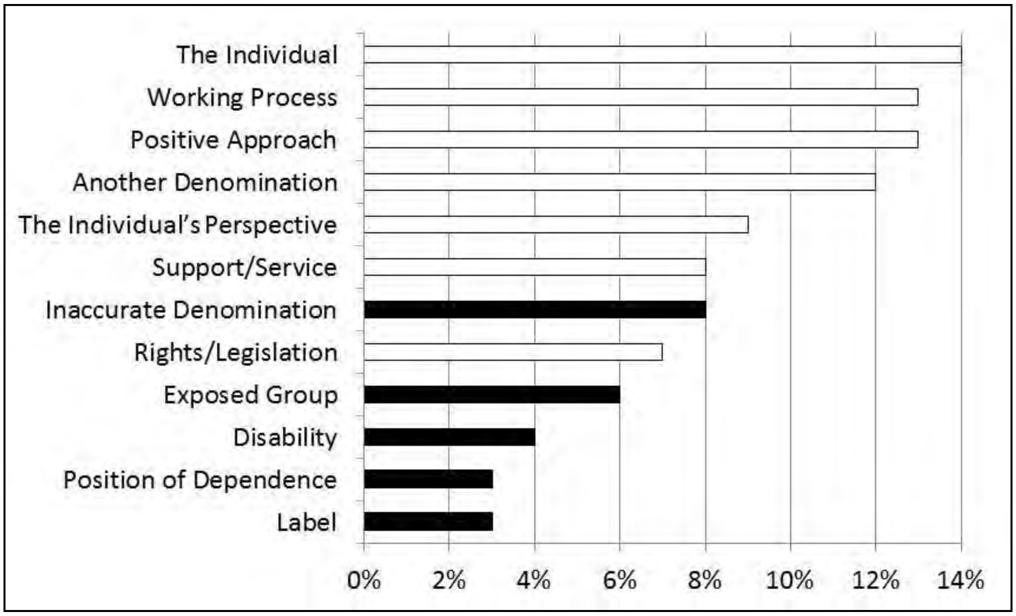


FIGURE 4 : CATEGORY SIZE AND PREDOMINANT VALENCE OF ASSOCIATIONS WITHIN EACH CATEGORY AMONG PROFESSIONALS IN REHABILITATION TEAMS

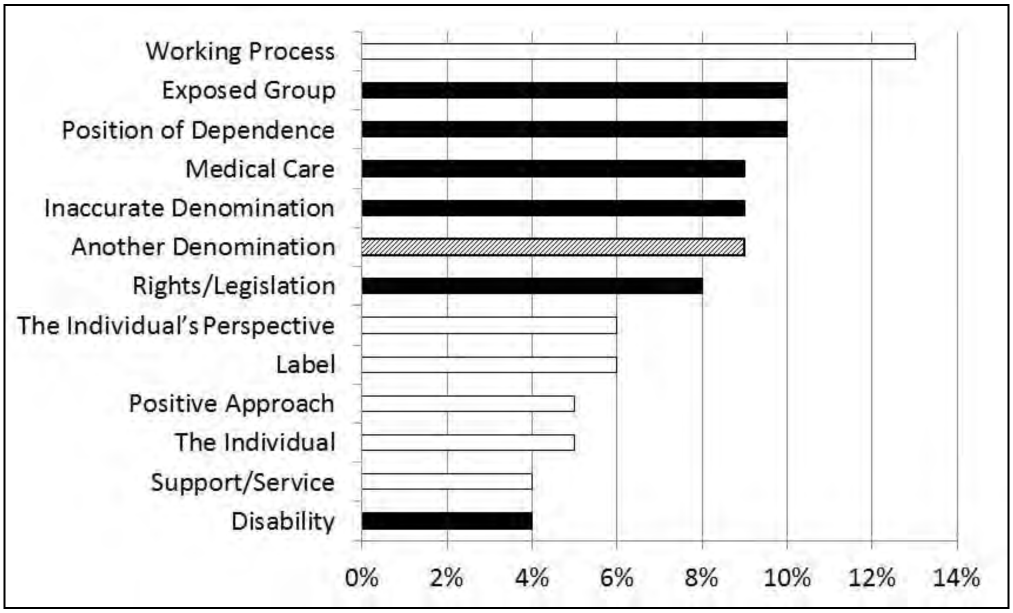


Figure 3 shows that the category which includes most associations among professionals in daily activities and assisted living facilities relates the user to an *individual*. This category is positively value-laden, which also applies to the next two categories, 'Working Process' and 'Positive Approach'. Overall, seven of the twelve categories which, when combined, contain 76 % of all associations, are predominantly positively charged. The largest negatively charged category is 'Inaccurate Denomination'.

Among the rehabilitation teams (see Figure 4), the distribution is different. The largest category is 'Working Process,' which is positively value-laden. Six of the other categories, which together contain 50 % of the associations, are predominantly negatively charged. The 'Another Denomination' category had neither a positive nor a negative response among respondents in the rehabilitation teams.

The denomination (*inhabitant*, *patient*, or *user*) varies between the organizations, and the stimulus word in the association study was adapted accordingly. In particular, this is reflected in the negatively value-loaded category of 'Medical Care' (stimulus word: *patient*) and is found only among the professionals who work in rehabilitation teams where this denomination is used. The figures show that the categories of 'Exposed Group' and 'Position of Dependence' are more prominent among the professionals in the rehabilitation teams. A difference in the value of the charge between the groups when it comes to the category 'Rights and Legislation' was also noted. The positively value-loaded category of 'Working Process' is proportionately equal in both groups, while the 'The Individual' and 'The Individual's Perspective' categories are more prominent among the professionals working in daily activities and assisted living facilities.

2.2 Significant differences between and within organizations

The difference between the groups is significant only within the category of 'Medical Care' (x^2 = 12.47, *p* < .01), which is not present in the group of respondents from daily activities and assisted living facilities. When testing significant differences, the calculations are made at the individual level, for example, if an individual has more than one association in the category of 'Working Process,' then they are only counted once. A significance level of .05 was used for interpretation.

Significant differences within the groups were tested based on demographic variables: gender, age, educational background, and number of years in the profession. The only significant difference was that the respondents with a higher level of education associated with the category ‘Rights and Legislation’ ($x^2 = 6.01$, $p < .05$)[4] more often than those without.

Discussion

The study indicates that the respondents largely associate with work and the working process when they think of the users and that they are sympathetic to this work. Many of the associations are linked to the individual and the individual’s perspective, and a positive picture emerges which is reinforced by a relatively large proportion of associations which more directly express a positive approach. From the SRT perspective, this may be interpreted as the professionals’ everyday knowledge of the users being positive, where both their own work and the individual are at the center. The variations within the groups are small; however, differences between occupational groups based on organizational affiliation do exist. Of the persons who work within the rehabilitation teams, a representation appears that is more influenced by the perception that the individuals belong to an exposed group who are in a dependent position. This image is reinforced by the negatively charged associations that come to mind when the members of the rehabilitation teams think of rights and legislation. The opposite is found with those who work in daily activities and assisted living facilities.

It should be noted that the results should not be interpreted as meaning that the professionals in the rehabilitation teams necessarily have a more negative perception of the individuals they care for compared to those working in daily activities and assisted living facilities but rather that the individual is often perceived to have a weaker position and is more dependent on others than the perceptions of those who work in daily activities and assisted living facilities. Within these organizations, the associations are more often linked to the individual and personal qualities, and these are often perceived as positive. This study cannot answer why this is the case, but one reason may be that these professionals, by the nature and organization of their working activities, will be more closely linked to the individual and this more personal relationship is reflected in the study’s results. Similarly, the professionals’ role in rehabilitation teams, one based on defined contributions to assist and facilitate for the individual, may cause the representation to be more colored by a sense of dependence and vulnerability.

The largest category is about the working process, which also forms the hub around which other categories are formed in the maximum tree. This is somewhat surprising, as the stimulus word was the denomination of the user that each organization uses. This indicates that when the professionals associate with the target group, the individual and the work are closely interlinked. A relational representation emerges where the individual is not perceived as an independent entity but as a person who is essentially characterized in relation to the working tasks. This relational approach could possibly be influenced by the environment-relative handicap model which emphasizes the role of the surrounding environment in the lives of persons with disabilities and is the dominant model in the public discourse in the Nordic countries. Also, very few associations are connected to medical or disease aspects. It can be assumed that the respondents included in the study adhere more often to the environment-relative model than to the medical model that focuses more on diagnoses and individual difficulties.

The association study shows that the different denominations of the individuals used in the organizations are not appreciated by the professionals. The way in which we term phenomena in our surroundings has been shown to affect how we perceive them (Philogène, 1999), and this study shows an example of

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[4] One expected value less than five.

this; in the organization that names the individuals as patients, the representation is linked to medical care while, in the other organizations, this link did not occur. Although it is not expressed in the form of representations by the respondents, this can be interpreted with the theory of social representations through which where one question arises: If we speak of individuals in what is perceived as negative terms, which in turn, affects the representation, how will that affect the way we perceive and respond to them? Although we are often unaware of our representations, they are the basis of how we interpret the world around us and treat others (Howarth, 2006; Moscovici, 2000). Social representations can be perceived as indicative of the professional when interacting with others (Jovchelovich, 2007). It is believed that these representations can affect the activity of the daily professional practice (where many quick decisions are often required) because, in such moments of quick decision-making, primarily unreflected thoughts and interpretations of the world affect one's behaviour (Kahneman, 2011).

Rehabilitation is an activity characterized by the need for collaboration between professionals and organizations; no single profession alone can respond to the needs of the individual, as these needs can be social, psychological, and medical in nature. Therefore, collaboration between professional groups is important for the rehabilitation process to work well. However, research shows that it is often difficult to establish well-functioning collaboration between various organizations and professions (Huxham & Vangen, 2005; Sullivan & Skelcher, 2002). For the collaboration process to be successful, a common view of whom (or what) you collaborate on (Danermark et al., 2013) is required, among other things. The partially differing perceptions of the individuals are likely to complicate the desired collaboration. Another aspect relevant to the collaboration process is linked to different organizations denominating the individuals in different ways. In the case of other organizations' denominations being perceived as improper or even disparaging, how does this affect the involved parties' views and understanding of each other? These questions are best discussed across organizational boundaries. If our representations (or our everyday knowledge of each other) have positive overtones, then this provides a good basis for good collaboration.

This study is not without its limitations. First, the sample was collected in only one city, so the results cannot be generalized to all professionals within the rehabilitation field. It should be noted that the categorization process could have led to alternative interpretations and categories if implemented by other researchers. Also, alternative methodological choices (e.g. to conduct focus groups) could have led to partly different results.

Conclusion

Overall, this study shows that, although few significant differences were found, the professionals' social representations of the target group differed depending on what organization they belonged to. Several factors may form the basis for these differences; in this study, the differences in working conditions and how the individual is denominated are especially focused on. Also, the study shows that the professionals' representations of the users are closely linked to the working process. From an organizational perspective, the representations are assumed to affect the activities, especially in matters related to collaboration with other parties. Continued and more in-depth studies are required to further understand and explain these differences and the impact they may have on rehabilitation work.

References

ABRIC, J. C. (1994). Méthodologie de recueil des représentations sociales [Methodology of miscellaneous social representations]. In J. C. Abric (Ed.), *Pratiques sociales et representations* [Social practices and representations] (pp. 59–82). Paris : P.U.F.

BELL, B. S., & KLEIN, K. J. (2001). Effects of Disability, Gender, and Job Level on Ratings of Job Applicants. *Rehabilitation Psychology, 46*,(3), 229–246. doi: 10.1037// 0090-5550.46.3.229

CHAIB, M., & ORFALI, B. (1995). *Sociala representationer. Om vardagsvetandets sociala fundament*. [Social representations. On the social founding of everyday knowledge.] Göteborg: Daidolos.

DANERMARK, B., GERMUNDSSON, P., & ENGLUND, U. (2013). Toward an instrument for measuring the performance of collaboration across organizational and professional boundaries. *Occasional Papers in Disability & Rehabilitation, 2013:1*. Malmö: Malmö University.

GILMORE, L., CAMPBELL, J., & CUSKELLY, M. (2003). Developmental Expectations, Personality Stereotypes, and Attitudes Towards Inclusive Education: community and teacher views of Down syndrome. *International Journal of Disability, Development and Education, 50*(1), 65-76. doi: 10.1080/1034912032000053340

GOUVIER, W. D., COON, R. C., TODD, M. E., & FULLER, K. H. (1994). Verbal Interactions With Individuals Presenting With and Without Physical Disability. *Rehabilitation Psychology*, 39(4), 263-268.

HALL, E. (2004). Social Geographies of Learning Disability: Narratives of Exclusion and Inclusion. *Area*, 36(3), 298-306.

HERZLICH, C. (1973). *Health and illness. A social psychological analysis*. London: Academic Press.

HOWARTH, C. (2006). A social representation is not a quiet thing: exploring the critical potential of social representations theory. *British Journal of Social Psychology, 45*(1), 65-86. doi:10.1348/014466605X43777

HUXHAM, C., & VANGEN, S. (2005). *Managing to collaborate. The theory and practice of collaborative advantage*. Oxon: Routledge.

JOVCHELOVITCH, S. (2007). *Knowledge in context. Representations, communication and culture*. Hove: Routledge.

KAHNEMAN, D. (2011). *Thinking, fast and slow*. New York: Farrar, Straus & Giroux.

LINTON, A.-C., GERMUNDSSON, P., HEIMANN, M., & DANERMARK, B. (2013). Teachers' social representation of students with Asperger diagnosis. *European Journal of Special Needs Education, 28*(4), 392-412. doi:10.1080/08856257.2013.812404

LOUVET, E. (2007). Social Judgment Toward Job Applicants With Disabilities: Perception of Personal Qualities and Competences. *Rehabilitation Psychology, 52*(3), 297-303. doi: 10.1037/0090-5550.52.3.297

MANCHAIAH, V., BAGULEY, D. M., PYYKKÖ, I., KENTALA, E., & LEVO, H. (2015). Positive experiences associated with acquired hearing loss, Ménière's disease, and tinnitus: A review. *International Journal of Audiology, 54*, 1-10. doi: 10.3109/14992027.2014.953217

MORANT, N. (2006). Social representations and professional knowledge: The representation of mental illness among mental health practitioners. *British Journal of Social Psychology, 45*, 817-838. doi:10.1348/014466605X81036

MOSCOVICI, S. (1973). Foreword. In C. Herzlich, *Health and illness. A social psychological analysis*. London: Academic Press.

MOSCOVICI, S. (2000). *Social representations. Explorations in Social Psychology*. Cambridge: Polity Press.

PHILOGÈNE, G. (1999). *From Black to African American: A New Social Representation*. Westport, CT: Praeger.

THE R FOUNDATION. (2015). *What is R?* Retrieved from https://www.r-project.org/about.html

RATINAUD, P., & LAC, M. (2011). Understanding professionalization as a representional process. In M. Chaib, B. Danermark & S. Selander (Eds.), *Education, professionalization and social representations: On the transformation of social knowledge* (pp. 55-67). New York: Routledge.

RATINAUD, P. (2015). *IRaMuTeQ: Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* [IRaMuTeQ: R interface for multidimensional analysis of texts and questionnaires]. Retrieved from http://www.iramuteq.org

ROBEY, K. L., BECKLEY, L., & KIRSCHNER, M. (2006). Implicit Infantilizing Attitudes About Disability. *Journal of Developmental and Physical Disabilities, 18*(4), 441-453. doi:10.1007/s10882-006-9027-3

SULLIVAN, H., & SKELCHER, C. (2002). *Working across boundaries. Collaboration in public services*. Hampshire: Palgrave, Macmillan.

STUCKI, G., CIEZA, A., & MELVIN, J. (2007). The international classification of functioning, disability and health: a unifying model for the conceptual description of the rehabilitation strategy. *Journal of Rehabilitation Medicine, 39*(4), 279-285.

STÅHL, C., SVENSSON, T., PETERSSON, G., & EKBERG, K. (2011). Swedish rehabilitation professionals' perspectives on work ability assessments in a changing sickness insurance system. *Disability and Rehabilitation, 33*(15-16), 1373-1382. doi:10.3109/09638288.2010.532282

VERDONSCHOT, M. M. L., DE WITTE, L. P., REICHRATH, E., BUNTINX, W. H. E., & CURFS, L. M. G. (2009). *Journal of Intellectual Disability Research, 53*(1), 54-64. doi: 10.1111/j.1365-2788.2008.01128.x

VORNHOLT, K., UITDEWILLIGEN, S., & NIJHUIS, F. J. N. (2013). Factors Affecting the Acceptance of People with Disabilities at Work: A Literature Review. *Journal of Occupational Rehabilitation, 23*, 463-475. doi: 10.1007/s10926-013-9426-0

WAGNER, W., VALENCIA, J., & ELEJABARRIETA, F. (1996). Relevance, Discourse and the "Hot" Stable Core of Social Representations – A Structural Analysis of Word Associations. *British Journal of Social Psychology, 35*, 331-351.

ZANI, B. (1993). Social representations of mental illness: lay and professional perspectives. In G.M. Breakwell & D.V. Canter (Eds.), *Empirical approaches to social representations* (pp.315-330). Oxford: Oxford University Press.

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Le paternalisme organisationnel et l'employabilité des personnes ayant des incapacités : les retombées paradoxales de l'autorité et de la bienveillance déplacées

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Résumé

Deux études ont été effectuées afin d'évaluer une mesure de paternalisme organisationnel (PO) à l'endroit des personnes ayant des incapacités. Dans la première étude, une échelle de PO a été élaborée, évaluant, à l'aide d'un sondage en ligne, deux composantes des représentations de 266 étudiants universitaires n'ayant pas d'incapacité : 1) l'autorité déplacée et 2) la bienveillance déplacée. Les résultats démontrent que ces deux sous-dimensions du PO sont actives chez la population étudiée. Elles permettent aux participants, dans le cas de l'autorité déplacée, d'exprimer leur supériorité par rapport aux personnes ayant des incapacités et, dans le cas de la bienveillance déplacée, de soutenir leur impression d'être respectueux du principe d'égalité envers ce groupe spécifique. La seconde étude avait pour objectif d'examiner le lien entre les deux composantes du PO retenues dans l'étude précédente et l'évaluation de la candidature d'une personne ayant une incapacité motrice. L'étude invitait de façon aléatoire les participants de la première recherche à évaluer cette candidature en fonction de deux offres d'emploi dont la seule variation dans la description était que le poste se situait dans un milieu intégré (n = 33) ou dans un milieu protégé (n = 28). Les résultats de cette deuxième étude démontrent que dans le cadre d'un poste menant à un emploi dans un milieu intégré, plus les participants avaient exprimé une *autorité déplacée*, moins ils accordaient une correspondance entre le profil du candidat et les exigences de l'emploi; le candidat est perçu comme moins compétent. Toujours dans le cadre d'une demande d'emploi dans un milieu intégré, les participants qui manifestaient une *bienveillance déplacée*, ont évalué le candidat comme davantage chaleureux; qualité n'ayant aucun lien avec les compétences visées par l'offre d'emploi. Or, le PO n'a pas été un enjeu dans l'évaluation de la candidature pour un poste dans un milieu protégé. Les retombées de ces résultats sur l'employabilité d'une personne ayant des incapacités seront abordées.

Mots-clés : paternalisme organisationnel, handicap et emploi

Abstract

Two studies were conducted to evaluate a measure of organisational paternalism (OP) directed toward people with disabilities. In the first study, a measure of OP was developed, designed to tap into two dimensions: 1) inappropriate authority; 2) inappropriate benevolence, and administered by an online survey to 266 university students. Results reveal that these two dimensions are relevant features for the sample under study. Both dimensions allow participants to express their superiority toward people with disabilities, in the case of inappropriate authority, and to maintain an impression of respecting the equality principle, as in the case of inappropriate benevolence. The object of the second study was to examine the link between the two dimensions of OP that were retained in the previous study and the evaluation of a candidate of a person with a physical disability. The study randomly placed participants in one of two job opportunities whereby both varied in terms of whether the employment was situated in an integrated (n = 33) or protected (n = 28) work environment. Results of this second study revealed that in an integrated employment situation, participants who reported high levels of inappropriate authority were less likely to report that the candidate was a good fit for the job and perceive the candidate as competent. Furthermore, in the integrated employment situation, participants who expressed inappropriate benevolence were more likely to evaluate the candidate as warm, a quality that was not associated with the job requirements. However, the OP was not an issue in the evaluation of the candidate when the job was situated in a protected work environment. Implications of these results for the employment of people with disabilities are discussed.

Keywords: organisational paternalism, disability and employment

Malgré les efforts visant à favoriser l'insertion professionnelle des personnes ayant des incapacités, elles demeurent désavantagées sur le marché de l'emploi. On remarque, entre autres, que le taux d'emploi des personnes ayant des incapacités au Canada se situe à 49 % et demeure inférieur à la proportion des individus qui sont disposés à contribuer au marché de l'emploi (Panel on Labour Market Opportunities for Persons with Disabilities, 2013; Turcotte, 2014). Plus particulièrement, au Nouveau-Brunswick, la sous-représentation et la sous-utilisation des personnes ayant des incapacités sont des réalités connues et documentées. Bien que la province présente la population avec le plus haut taux d'incapacités au Canada, leur participation au marché du travail est inférieure à la moyenne nationale (Gouvernement du Nouveau-Brunswick, 2012). Dans l'ensemble, l'exclusion des personnes ayant des incapacités de la population active canadienne prive ces individus d'une dimension importante de la participation sociale, source d'accomplissement de soi, d'intégration sociale et de revenu (Kabano & Beaton, 2011; Saunders & Nedelec, 2014).

Le regard des employeurs et des intervenants sociaux contribue significativement à l'inclusion professionnelle et au maintien en emploi des personnes ayant des incapacités (Fraser, Ajzen, Johnson, Hebert, & Chan, 2011; Vornholt, Uitdewilligen, & Nijhuis, 2013). En effet, les personnes ayant des incapacités jugent que les employeurs et les intervenants sociaux jouent un rôle déterminant dans leur embauche (Kabano & Beaton, 2011). Or, les auteurs concluent que les jugements à l'égard des personnes ayant des incapacités sur le marché de l'emploi sont équivoques et que les personnes ayant des incapacités sont mal comprises (Beaton, Kabano, & Léger, 2014; Colella & Stone, 2005; Conseil canadien de la réadaptation et le travail, 2005).

Selon Stiker (1982, 1997, 2005), la perception du handicap implique plusieurs difficultés concernant la reconnaissance de la contribution des personnes ayant des incapacités dans les différentes sphères sociales. Cette reconnaissance étriquée des personnes ayant des incapacités fait en sorte qu'elles sont parfois embauchées en fonction des critères qui ne relèvent pas des compétences propres à l'emploi postulé (ex. : l'image de l'entreprise) et sont cantonnées dans des emplois ne leur permettant pas de faire leurs preuves (Beaton et al., 2014; Luecking, 2008). De plus, selon les résultats de deux études nationales menées aux États-Unis, les intervenants sont plus enclins à diriger la personne ayant des incapacités vers un milieu de travail protégé plutôt qu'un milieu de travail intégré (Domin & Butterworth, 2013; Inge et al., 2009), tendance qui pourrait être attribuée par ce que certains auteurs du champ d'études sur le handicap appellent le paternalisme (Batavia, 2001; Colella & Stone, 2005; Jackman, 1994, 2005; Miller, Parker, & Gillinson, 2004). Le paternalisme correspond à une attitude condescendante envers les groupes minoritaires perçus comme incapables et donc, nécessitant protection et assistance (Jackman, 1994, 2005). Selon Jackman (1994), les attitudes paternalistes permettent la reproduction des mécanismes de justification de la discrimination systémique *non intentionnelle* à leur égard. Par exemple, l'inclinaison à la protection et à l'assistance des groupes désavantagés sont des moyens à justifier les jugements et les pratiques qui exacerbent leur marginalisation et leur isolement dans la société (Jackman, 1994, 2005).

Colella et Stone (2005) avancent que le paternalisme à l'égard des personnes ayant des incapacités répond à deux besoins. D'une part, les auteures expliquent que le paternalisme découle du besoin d'entretenir une image de soi positive. Ainsi, selon Colella et Stone (2005), les individus se comportent selon une norme sociale qui dicte le traitement bienveillant réservé aux membres des groupes moins fortunés. Cette attitude découlerait des normes sociales qui freinent les préjugés dégradants qui sont apprises dès le jeune âge (Monteiro, de França, & Rodrigues, 2009) et le besoin de se conformer à une image de soi positive, c'est-à-dire respectueuse du principe d'égalité par exemple (Beaton, Dovidio, & LeBlanc, 2011). D'autre part, Colella et Stone (2005) précisent que les attitudes paternalistes sont également tributaires du besoin d’exercer son autorité. Par exemple, Aycan (2006) explique qu’un leader paternaliste s’attribue un pouvoir déterminant les compétences essentielles et les standards requis dans un contexte donné. Cet individu exerce son autorité en entretenant l’idée qu’il est le mieux placé pour agir selon les intérêts du subordonné. En bref, deux besoins sont comblés par les attitudes paternalistes, soit le besoin de dominer (i.e., assumer son autorité en matière de l’emploi) et le besoin d’entretenir une image de soi positive (i.e., bienveillance) (Aycan, 2006; Colella & Stone, 2005).

Peu d’études ont évalué les attitudes paternalistes dans le contexte du travail. Deux exceptions notables méritent toutefois une attention, soit l’étude de Aycan (2006) et celle de Wagstaff, Colella, Triana, Smith et Watkins (2015). Ces auteurs ont élaboré et validé une mesure permettant aux employés d’évaluer le niveau de paternalisme manifesté par leur employeur. Ces recherches ont sans aucun doute permis de mettre en perspective les perceptions de l’employé quant à l’ampleur des attitudes paternalistes en démontrant que, dans le cas de l’étude de Wagstaff et al. (2015), le « contrôle » et la « bienveillance » constituent des dimensions significatives dans la façon que le paternalisme est conçu chez les employés.

Le présent article se propose de réfléchir aux attitudes paternalistes d’étudiants universitaires concernant l’employabilité et la présence sur le marché du travail des personnes ayant des incapacités. Pour ce faire, deux études sont présentées. Dans la première étude, une échelle de paternalisme organisationnel a été validée à l’aide d’un sondage en ligne, auprès de 266 étudiants universitaires n’ayant pas d’incapacité. Ces participants poursuivent leurs études dans un domaine susceptible de les mettre en contact avec des personnes ayant des incapacités qui sont dans une démarche de recherche d’emploi ou de maintien en emploi. La mesure était conçue de manière à évaluer deux composantes de la mesure du paternalisme organisationnel : 1) l’autorité déplacée et 2) la bienveillance déplacée. La seconde étude avait pour objectif d’examiner le lien entre les deux composantes du paternalisme organisationnel retenues dans l’étude précédente et l’évaluation de la candidature d’une personne ayant une incapacité motrice. L’étude invitait de façon aléatoire les participants de la première recherche à évaluer cette candidature en fonction de deux offres d’emploi, dont la seule variation dans la description était que le poste se situait dans un milieu intégré ou dans un milieu protégé. Les résultats de ces deux études révèlent que les composantes du paternalisme sont porteuses de comportements discriminatoires à l’endroit des personnes ayant des incapacités sur le marché de l’emploi.

Ces deux recherches ont été effectuées à une époque où les employeurs et les intervenants avouent ne pas se sentir bien préparés pour relever les défis de l’inclusion professionnelle des personnes ayant des incapacités (Beaton et al., 2014; Lindsay, McDougall, Menna-Dack, Sanford, & Adams, 2015). Par conséquent, le regard que posent les employeurs et les intervenants de demain sur les personnes ayant des incapacités en emploi est important à saisir pour mieux comprendre la façon dont ils se préparent pour faire face au défi de l’inclusion professionnelle.

Étude 1 : Le paternalisme organisationnel

Le but de cette première étude était de mesurer le paternalisme organisationnel (PO) à l’endroit des personnes ayant des incapacités qui se taillent une place sur le marché de l’emploi. Plus précisément, cette mesure a servi à élucider les composantes sous-jacentes du PO, notamment l’autorité et la bienveillance déplacées (Aycan, 2006; Colella & Stone, 2005; Wagstaff et al., 2015). Cette étude a été effectuée auprès des étudiants de l’Université de Moncton qui, une fois qu’ils seront diplômés, auront à se mettre en relation avec des personnes ayant des incapacités à la recherche d’emploi.

Méthode

- Élaboration de la mesure

Dans un premier temps, afin d’élaborer la mesure du PO, des entrevues semi-dirigées ont été effectuées auprès de trois personnes ayant des incapacités qui possédaient une expérience sur le marché de l'emploi et fréquentant un établissement postsecondaire. Ces consultations ont permis de jeter les bases des différents traitements réservés aux employés ayant des incapacités et qui correspondent, selon leur perspective, à un regard paternaliste de la part de leur employeur et/ou des intervenants sociaux avec lesquels ils ont eu des contacts soit dans le cadre de leur recherche d'emploi, soit une fois qu'ils ont eu un poste. Cette recherche exploratoire, jumelée aux réflexions de différents auteurs (e.g., Colella & Stone, 2005), a permis d'élaborer une mesure du PO, constituée de 25 énoncés et articulée sur deux dimensions, soit la bienveillance et l'autorité déplacées. Les énoncés portent sur différentes perceptions à l'endroit des personnes ayant des incapacités et qui œuvrent sur le marché du travail.

La mesure du PO a été complétée par 277 étudiants. Or, onze participants se sont identifiés en situation de handicap et ont été exclus de l'échantillon[1]. Ainsi, 266 complétions du sondage ont été retenues, portant l'échantillon de l'étude à 60 hommes et 206 femmes qui fréquentent l'Université de Moncton, dont l'âge varie entre 17 à 46 ans (M = 21,32, $ÉT$ = 4,09). La majorité de cet échantillon (82,3 %) est constituée d'étudiants inscrits à un programme de premier cycle. De plus, 61,6 % des participants sont issus des programmes menant à devenir de futurs employeurs (e.g., management) ou intervenants sociaux (e.g., psychologie, travail social, éducation).

- Mesure du paternalisme organisationnel (PO)

Les participants ont été invités à réagir à 25 énoncés mesurant les attitudes à l'endroit des personnes ayant des incapacités sur le marché du travail (voir tableau 1). Les énoncés ont été conçus afin de réagir aux énoncés du PO qui mesurent une autorité déplacée (ex. : « À mon avis, un employeur doit surveiller davantage le travail effectué par des employés handicapés plutôt que celui des employés sans handicap ») et une bienveillance déplacée (ex. : « J'admire le courage des personnes handicapées qui s'aventurent sur le marché du travail »). Plus le score est élevé, plus les répondants manifestent des attitudes paternalistes. Les participants étaient invités à partager leurs opinions en fonction d'une échelle de type Likert en cinq points où 1 correspond à *pas du tout d'accord* et 5 à *tout à fait d'accord*.

Résultats et discussion

Afin d'analyser les données recueillies par le sondage, la technique de l'analyse factorielle exploratoire a été effectuée en fonction de la méthode d'extraction de vraisemblance maximale. Le but de cette analyse est d'identifier une combinaison de variables qui sont fortement associées et qui se distinguent de d'autres ensembles de variables. Cette combinaison de variables formera un facteur. L'analyse fait également appel à la technique de la rotation oblique, permettant d'évaluer l'importance de l'association entre les facteurs.

Deux modèles ont été évalués, dont une analyse factorielle à deux et à trois facteurs. La solution à trois facteurs a été écartée, car un facteur était représenté par un doublet, c'est-à-dire un nombre insuffisant d'énoncés. Ainsi, la mesure du PO finale contient 20 énoncés évaluant deux facteurs. Le premier facteur intitulé *autorité déplacée* regroupe quinze énoncés (alpha = 0,90). Le deuxième facteur nommé *bienveillance déplacée* est constitué de cinq énoncés (alpha = 0,71). Selon les résultats, une corrélation positive et significative a été obtenue entre les deux facteurs (r = 0,31), de sorte que les individus qui appuient les énoncés évaluant

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[1] Les catégories des incapacités ont été puisées à partir du site des services d'accès et de soutien à l'apprentissage de l'Université de Moncton. Les répondants ont été invités à répondre aux questions suivantes : « Es-tu une personne ayant une condition telle que : une déficience auditive ou visuelle, une incapacité physique ou motrice, des troubles d'apprentissage, une condition médicale chronique, un trouble de santé mentale chronique, un trouble déficitaire de l'attention, un trouble envahissant du développement (autisme, syndrome d'Asperger)? Compte tenu de ce qui précède, est-ce que tu éprouves une ou plusieurs de ces problématiques? ». Le répondant devait indiquer « oui » ou « non ».

TABLEAU 1. POIDS FACTORIELS, COMMUNALITÉS (H^2) ET POURCENTAGE DE LA VARIANCE EXPLIQUÉE

Énoncés figurant dans la mesure de paternalisme organisationnel	Facteur 1	Facteur 2	h^2
1. C'est mieux pour l'employé handicapé si on lui accorde des tâches faciles et peu stressantes.	**0,77**	-0,07	0,56
2. À mon avis, un employeur doit surveiller davantage le travail effectué par des employés handicapés plutôt que celui des employés sans handicap.	**0,69**	-0,21	0,44
3. À mon avis, un bon employeur offre des tâches faciles aux employés handicapés.	**0,64**	0,05	0,43
4. C'est l'employeur qui connaît mieux ce qu'un employé handicapé peut et ne peut pas faire.	**0,62**	-0,08	0,36
5. Pour l'encourager, un bon employeur fournit un feedback plus positif à l'égard d'un employé handicapé qu'à l'égard d'un employé sans handicap.	**0,61**	0,09	0,41
6. C'est impressionnant lorsqu'un employé handicapé accomplit un travail de la même qualité qu'un employé sans handicap.	**0,59**	0,05	0,37
7. Il est important de féliciter un employé handicapé lorsqu'il accomplit un travail, peu importe la qualité de son ouvrage.	**0,59**	0,31	0,55
8. À mon avis, un bon employeur protège les employés handicapés contre le feedback négatif.	**0,57**	0,15	0,40
9. Les employés handicapés ont besoin de la protection des employeurs et des autres employés.	**0,56**	0,22	0,45
10. Les employeurs qui embauchent des personnes handicapées sont généreux.	**0,56**	0,18	0,41
11. Il faut faire attention de ne pas blesser les employés handicapés parce qu'ils ont eu une vie difficile.	**0,55**	0,22	0,43
12. L'employeur doit faire attention de ne pas surmener les employés handicapés.	**0,55**	0,08	0,33
13. Recevoir une promotion est plus stressant pour un employé handicapé que pour un employé sans handicap.	**0,48**	-0,05	0,22
14. La raison principale pour un employeur d'embaucher des personnes handicapées est pour assumer sa responsabilité sociale.	**0,46**	-0,08	0,19
15. Peu importe le rendement d'un employé handicapé, les employeurs doivent procurer un feedback positif vis-à-vis ce rendement.	**0,44**	0,29	0,36
16. Les personnes handicapées doivent être admirées.	-0,11	**0,67**	0,42
17. Les personnes handicapées doivent être protégées.	0,12	**0,56**	0,36
18. La société doit faire des sacrifices pour subvenir financièrement aux besoins des personnes handicapées.	0,06	**0,47**	0,24
19. Lors d'une catastrophe, les personnes handicapées doivent être sauvées avant les personnes n'ayant pas un handicap.	-0,07	**0,46**	0,19
20. J'admire le courage des personnes handicapées qui s'aventurent sur le marché du travail.	0,34	**0,35**	0,31
Énoncés ne figurant pas dans la mesure de paternalisme organisationnel			
1. Ce sont surtout les employeurs, plutôt que les employés handicapés qui savent comment rendre le milieu de travail accommodant.	0,33	-0,07	0,09
2. Les personnes handicapées devraient être reconnaissantes à l'endroit de leur employeur lorsqu'elles se décrochent un emploi.	0,33	-0,02	0,10
3. Malgré tout, le seul fait de vouloir travailler est un indicateur du courage des personnes handicapées.	0,31	0,28	0,23
4. Un employé handicapé ne devrait pas remettre en question les tâches et les responsabilités qui lui ont été assignées par l'employeur.	0,26	-0,05	0,06
5. Je crois que les employés handicapés peuvent donner de grandes leçons de détermination aux autres employés de l'organisation.	0,01	0,27	0,08
Pourcentage de la variance expliquée	26,49	5,55	

Note. Afin d'obtenir une solution simple, le critère de saturation retenue est de l'ordre de 0,35. Facteur 1 = Autorité déplacée; Facteur 2 = Bienveillance déplacée.

l'autorité déplacée, expriment également un accord aux énoncés qui mesurent la bienveillance déplacée. Les résultats de cette analyse factorielle exploratoire sont présentés au tableau 1.

Les résultats de l'analyse factorielle exploratoire appuient l'hypothèse voulant que le PO à l'endroit des personnes ayant des incapacités regroupe deux facteurs, dont l'autorité et la bienveillance déplacées. Selon les auteurs, ces deux dimensions répondent à des besoins spécifiques (Aycan, 2006; Colella & Stone, 2005). D'une part, l'autorité déplacée répond au besoin des employeurs ou d'autres agents sociaux, d'exercer un pouvoir absolu des conditions de travail réservées aux employés ayant une incapacité. Ce type d'attitude fait obstacle à une réelle inclusion des personnes ayant des incapacités sur le marché du travail. D'autre part, la bienveillance déplacée répond au besoin de projeter une image de soi nécessairement favorable et positive à l'égard des personnes ayant des incapacités. Les participants qui manifestent de la bienveillance déplacée s'accordent sur la nécessité d'un traitement indulgent des personnes ayant des incapacités; on leur doit protection et assistance. Ainsi, le PO repose sur un discours présupposant que la personne ayant des incapacités est en situation de grande dépendance en raison de sa vulnérabilité. Ensemble, les composantes du PO empêchent la reconnaissance du plein potentiel des personnes ayant des incapacités sur le marché du travail et, par conséquent, engendrent ce que Fougeyrollas (2010) nomme des situations de handicap (voir aussi Merzouk, 2008 pour d'autres exemples de ce processus).

Étude 2 : Paternalisme organisationnel et employabilité

Dans une deuxième étude, le lien entre les dimensions du PO (i.e., autorité et bienveillance déplacées) et l'évaluation d'une candidature d'une personne ayant une incapacité motrice a été évalué. Rappelons que le PO repose sur un traitement contraignant à l'égard les employés ayant des incapacités (i.e., autorité déplacée), ainsi qu'un traitement indulgent à leur endroit (i.e., bienveillance déplacée). Cette ambivalence se retrouve également dans l'évaluation des personnes ayant une incapacité sur le marché du travail. Par exemple, les travaux ont montré que les candidatures des personnes ayant des incapacités sont à la fois dépréciées et vénérées. Plus précisément, la candidature d'une personne ayant une incapacité est évaluée en fonction de deux critères, leur compétence (e.g., efficacité), qui correspond à leur capacité de relever les défis de l'emploi et leur chaleur humaine (e.g., aimabilité), c'est-à-dire les qualités morales et sociales qui leur sont attribuées (Louvet, 2007; Louvet, Rohmer, & Dubois, 2009; Rohmer & Louvet, 2016). Les recherches montrent que les candidatures des personnes ayant des incapacités sont perçues comme moins compétentes mais davantage chaleureuses que les candidats n'ayant pas d'incapacité. Ce résultat est obtenu, peu importe le type d'incapacités (Louvet et al., 2009; Rohmer & Louvet, 2011). Il est raisonnable de croire que les dimensions du PO sont associées à ces deux critères d'évaluation. Plus précisément, dans le cadre d'une évaluation d'embauche, il est prévu que plus une personne manifeste de l'autorité déplacée, plus elle percevra la candidature d'une personne ayant des incapacités comme incompétente. Par la même occasion, il est postulé que plus une personne entretient des propos qui relèvent de la bienveillance déplacée, plus elle jugera la candidature d'une personne ayant des incapacités comme chaleureuse. De cette façon, le PO permet à la fois de maintenir les inégalités sociales, tout en protégeant une image de soi nécessairement favorable et positive à l'égard des personnes ayant des incapacités dans une situation d'embauche.

La deuxième étude avait comme autre objectif d'examiner le lien entre les composantes du PO et l'évaluation de la candidature d'une personne ayant une incapacité motrice, selon deux contextes d'emploi. Plus précisément, certains répondants ont appris que l'emploi convoité était situé dans un milieu de travail intégré et soumis à la loi d'équité en matière d'emploi. D'autres répondants ont pris connaissance d'un contexte où l'emploi avait lieu dans un milieu de travail protégé où seules les personnes ayant des incapacités sont accueillies. Cette approche a permis d'examiner si les liens entre les dimensions du PO et les évaluations sont influencés par le contexte d'emploi. En effet, Colella et ses collaborateurs (Colella, De Nisi, & Varma, 1998) proposent que les évaluations des personnes ayant des incapacités varient selon la nature de l'emploi. Ces propos ont été vérifiés. Par exemple, dans un contexte d'emploi où la communication interpersonnelle est requise, les répondants ont évalué le candidat ayant une incapacité motrice moins favorablement que le candidat sans incapacité. Or, cette dépréciation du candidat ayant une incapacité n'a pas eu lieu dans un contexte d'emploi qui exigeait peu de communication interpersonnelle (Louvet, 2007). Ce résultat s'explique en fonction d'une incongruence entre la nature de l'emploi et les stéréotypes associés aux personnes ayant des incapacités (Colella et al., 1998; Lindsay et al., 2014). Les répondants ont écarté la candidature de la personne ayant une incapacité, car elle n'est pas perçue comme pouvant répondre aux exigences d'un emploi qui implique une pleine participation à la vie sociale et professionnelle (Louvet, 2007).

Il est postulé que les deux dimensions du PO seront des déterminants importants dans l'évaluation d'une candidature d'une personne ayant une incapacité dans un contexte d'emploi intégré, plutôt que protégé. Plus précisément, dans le contexte d'emploi intégré, plus le répondant manifeste une autorité déplacée, plus le candidat sera perçu comme incompétent et correspondant moins au profil de l'emploi. De plus, toujours dans un milieu de travail intégré, plus un répondant rapporte une bienveillance déplacée, plus il jugera le candidat comme chaleureux. En somme, cette stratégie empêche les personnes ayant des incapacités de faire leurs preuves dans un milieu de travail valorisant et répond à la norme sociale qui renvoie à l'équité.

Méthode

- *Participants*

En tout, 66 étudiants inscrits à l'Université de Moncton ont participé à cette étude. Cet échantillon était constitué de 16 hommes et 50 femmes, âgés de 17 à 37 ans (M = 21,77, $ÉT$ = 3,89). La majorité des étudiants fréquentaient un programme universitaire de premier cycle (75,80 %). Or, un répondant a indiqué avoir une incapacité. Ainsi, cet individu a été retiré des analyses et l'échantillon est constitué de 65 individus n'ayant pas d'incapacité.

- *Mesures*

Deux sondages en ligne ont été élaborés, évaluant différents aspects du jugement porté à l'endroit des employés ayant des incapacités. Le premier sondage a été conçu afin d'évaluer les perceptions à l'endroit des personnes ayant des incapacités, notamment le PO ainsi que des questions d'ordre sociodémographique (voir étude 1).

Le second sondage avait comme objectif d'inviter le répondant à prendre connaissance de l'offre d'emploi et de la candidature d'une personne ayant une incapacité motrice, nommée Claude Ouellette. L'emploi consistait en un poste de trieur pour un organisme de recyclage et de récupération des déchets. Deux différents sondages sont conçus afin de manipuler la description de l'entreprise et ont été administrés de façon aléatoire aux participants. Ainsi, certains répondants reçoivent un sondage décrivant une entreprise nommée RECOUVRE TECH où le contexte de l'emploi est « intégré » :

> « Notre entreprise recrute les personnes aptes sur le plan technique à exercer un métier dans le secteur du recyclage et récupération des déchets. Nous offrons un environnement de travail où les personnes peuvent œuvrer dans de bonnes conditions et où des mesures d'adaptation sont possibles. Notre but est d'offrir à nos clients un service complet de collecte et de gestion des matières résiduelles. RECOUVRE TECH comprend plusieurs services, dont : un centre de récupération, une compagnie de transport, un écocentre et un site de compostage. »

À la suite de la description de cette offre d'emploi, on avise le répondant que RECOUVRE TECH souscrit à l'équité en matière d'emploi et « … encourage les candidatures de toute personne qualifiée, femme et homme, y compris autochtones, les personnes handicapées et les membres de minorités visibles. »

D'autres répondants ont reçu un sondage où l'on présente une entreprise nommée RECOUVRE COOP, constituée d'un contexte d'emploi « protégé » :

> « Notre entreprise recrute exclusivement les personnes handicapées aptes sur le plan technique à exercer un métier de recyclage et récupération des déchets pour qui des mesures d'adaptation peuvent être prises. Nous offrons un environnement de travail protégé où les personnes ayant un handicap peuvent œuvrer dans de bonnes conditions qui sont adaptées selon leurs besoins. RECOUVRE COOP comprend plusieurs services, dont : un centre de récupération, une compagnie de transport, un éco-centre et un site de compostage. »

À la suite de la description de l'offre d'emploi et de l'entreprise, tous les répondants ont pris connaissance du profil du candidat, Claude Ouellette. D'abord, les répondants étaient invités à lire la lettre de présentation du candidat suivi de son curriculum vitae (CV). Afin d'assurer que le répondant a pris connaissance de l'incapacité motrice du candidat, deux mesures étaient prises : 1) une photo du candidat dans son fauteuil roulant est publiée au haut de son CV; 2) parmi ses intérêts, le candidat relate qu'il est membre de l'Association des personnes handicapées francophones du Nouveau-Brunswick.

À la suite de la description de l'offre d'emploi et du candidat, les répondants devaient répondre à une mesure d'évaluation de la candidature et du niveau de concordance entre le candidat et l'emploi. À moins d'avis contraire, les participants étaient invités à partager leurs opinions à l'aide d'une échelle de type Likert en sept points où 1 correspond à *pas du tout* et 7 correspond à *tout à fait*.

Paternalisme organisationnel (PO). La mesure du PO était constituée de vingt énoncés. Deux scores ont été calculés, de sorte à retenir les deux sous-dimensions, dont l'autorité déplacée (quinze énoncés, alpha = 0,88) et la bienveillance déplacée (cinq énoncés, alpha= 0,79). Les réactions à cette mesure étaient évaluées en fonction d'une échelle de type Likert en cinq points de sorte que 1 correspond à *pas du tout d'accord* et 5 correspond à *tout à fait d'accord*.

Manipulation du contexte d'emploi. Les deux sondages ont été élaborés afin de présenter deux conditions d'emploi distinctes, soit « intégré » ou « protégé ». Les répondants étaient invités à répondre « vrai » ou « faux » à l'énoncé suivant : « Le poste embauche exclusivement des personnes ayant un handicap ». Les participants ayant répondu « vrai » sont désignés le groupe « condition protégée » (*n* = 28) tandis que ceux ayant répondu « faux » sont désignés le groupe « condition intégrée » (*n* = 33)[2]. Quatre répondants n'ont pas complété cette question.

Correspondance entre le candidat et l'emploi. Une mesure de la correspondance entre le candidat et l'emploi a été conçue pour les fins de cette étude. Les répondants ont réagi aux cinq énoncés suivants : « Les exigences de l'emploi et les compétences du candidat correspondent bien. »; « Les habiletés et la formation du candidat correspondent bien aux exigences de l'emploi. »; « Les caractéristiques personnelles du candidat correspondent bien à ce que l'emploi exige d'un employé. »; « Le profil du candidat et l'environnement de travail correspondent bien. »; « Le candidat convient bien pour ce type d'emploi. » Les réactions aux énoncés ont été regroupées pour calculer un score global. Plus le score à cette mesure était élevé, plus cela signifiait que le répondant est

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[2] En raison des problèmes techniques, il n'a pas été possible de vérifier si leur réponse à cette question correspond effectivement au contexte d'emploi protégé ou intégré.

d'avis que le profil du candidat correspond à l'emploi (alpha = 0,90).

Évaluation du candidat. Le candidat a été évalué en fonction de neuf caractéristiques tirées des travaux de Louvet, Rohmer et Dubois (2009). Les répondants ont été invités à lire la consigne suivante : « Suite à la lecture du CV, quelle est ton impression immédiate de Claude Ouellette? Indique ton opinion à l'aide des étiquettes fournies. Il n'y a pas de bonne ou de mauvaise réponse, nous cherchons à connaître ton opinion. En quelle mesure penses-tu que Claude Ouellette peut être…? ». Le profil « compétent » est constitué des caractéristiques suivantes : capable, efficace, indépendant et compétent. Le profil « chaleureux » regroupe les caractéristiques suivantes : consciencieux, chaleureux, aimable et attentionné. Conformément aux travaux antérieurs (Louvet et al., 2009), ces deux scores sont calculés. Plus les scores étaient élevés, plus cela signifiait que les répondants jugent le candidat comme « chaleureux » (alpha = 0,93) et « compétent » (alpha = 0,84).

Déroulement

À la première étape de cette étude, un sondage (étude 1) a été transmis par voie électronique à deux occasions (novembre 2013 et septembre 2014), afin d'évaluer le PO auprès des étudiants inscrits à l'Université de Moncton. Les répondants étaient invités à inscrire leur adresse électronique afin de poursuivre leur participation à une deuxième étape de cette étude. Les répondants étaient avisés que la deuxième étape du projet de recherche consistait en la complétion d'un second sondage (étude 2) portant sur l'employabilité des personnes ayant une incapacité. Le deuxième sondage a été transmis en janvier 2015, par courriel, aux répondants ayant soumis leur adresse électronique. Les deux sondages ont été appariés en fonction d'un code arbitraire permettant de conserver l'anonymat et la confidentialité de la participation des répondants.

Résultats et discussion

Des analyses corrélationnelles ont été effectuées afin d'examiner le lien entre les dimensions du PO (i.e., bienveillance et autorité déplacées) et l'évaluation du candidat, c'est-à-dire la correspondance entre le profil du candidat et l'emploi ainsi que les profils « compétent » et « chaleureux ». Deux séries de corrélations ont été calculées selon le contexte de l'emploi (voir tableau 2). Conformément aux hypothèses, dans le contexte d'emploi intégré, le PO est associé à l'évaluation du candidat. Plus précisément, les répondants qui manifestent une autorité déplacée sont moins portés à juger le candidat « compétent » et perçoivent moins une concordance entre le candidat et l'emploi. Toujours dans le cadre de l'emploi intégré, plus les répondants manifestent une bienveillance déplacée à l'endroit des employés ayant des incapacités, plus ils accordent un profil « chaleureux » au candidat. Or, dans le contexte d'emploi protégé, les dimensions du PO ne sont pas associées à l'évaluation du candidat ni à la correspondance entre la nature de l'emploi et le profil du candidat.

Les résultats appuient les hypothèses. Selon cette étude, les dimensions du PO sont bel et bien présentes dans les représentations des étudiants rencontrés, surtout lorsque ceux-ci tentent d'imaginer la participation des personnes ayant des incapacités dans un milieu de travail intégré, plutôt que protégé. Chez les répondants qui rapportent un niveau élevé de PO, l'autorité déplacée écarte la candidature de la personne ayant une incapacité motrice en raison de son incompétence et de son incongruence avec les exigences du poste. Cette perception avilissante est accompagnée d'un regard bienveillant à l'endroit du candidat. Ensemble, ces résultats démontrent les différentes façons dont s'exprime et se justifie la dévalorisation du candidat.

TABLEAU 2
ANALYSES DESCRIPTIVES ET CORRÉLATIONS ENTRE LES DIMENSIONS DU PATERNALISME ORGANISATIONNEL ET L'ÉVALUATION DU CANDIDAT DANS LE CONTEXTE D'UN EMPLOI PROTÉGÉ ET INTÉGRÉ

Variables	1	2	3	4	5
Emploi protégé					
1. Bienveillance déplacée	-	0,55**	-0,07	0,15	0,02
2. Autorité déplacée		-	-0,24	0,06	-0,23
3. Profil compétent			-	0,64**	0,30
4. Profil chaleureux				-	0,34*
5. Correspondance					-
M	3,64	2,48	6,08	6,04	5,95
ÉT	0,79	0,64	0,74	0,83	0,73
Emploi intégré					
1. Bienveillance déplacée	-	0,46**	0,19	0,31*	-0,11
2. Autorité déplacée		-	-0,35*	-0,13	-0,51**
3. Profil compétent			-	0,60**	0,75**
4. Profil chaleureux				-	0,12
5. Correspondance					-
M	3,64	2,28	6,10	6,43	5,91
ÉT	0,80	0,73	0,80	0,82	1,02

Note. * *p* < 0,05; ** *p* < 0,01.

Discussion générale

Cette recherche avait comme objectif de valider une mesure de PO à l'endroit des personnes ayant des incapacités dans le milieu du travail. Les résultats révèlent que le PO est un moyen pour diminuer la contribution des personnes ayant des incapacités et de les écarter du marché du travail. Plus précisément, les résultats de la première étude appuient les hypothèses voulant que le PO est constitué de l'autorité et de la bienveillance déplacées. La deuxième étude a démontré que dans un contexte d'emploi intégré, plutôt que protégé, les répondants qui ont une attitude autoritaire déplacée évaluent la candidature de la personne ayant une incapacité motrice comme moins compétente et concluent que le profil ne correspond pas aux exigences de l'emploi. Quant à la bienveillance déplacée, plus les répondants adhèrent à ces attitudes, plus ils évaluent la candidature de la personne ayant une incapacité motrice comme chaleureuse. Tel que l'ont démontré d'autres études, les dimensions du PO font en sorte que la personne ayant des incapacités est perçue comme sympathique, mais incompétente; souhaitable, mais inutile (Louvet, 2007; Louvet et al., 2009; Miceli, Harvey, & Buckley, 2001; Wang, Barron, & Hebl, 2010).

Ces résultats permettent de s'interroger sur certaines représentations qui contribuent à la reproduction des conditions menant une grande proportion des personnes ayant des incapacités dans des emplois précaires, sans issue, avec une surveillance très étroite et peu d'occasions de suivre des formations professionnelles (Schur, Kruse, Blasi, & Blanck, 2009). Or, cette recherche contient certaines limites, notamment, la validité écologique des résultats. En effet, considérant que l'échantillon est composé d'étudiants inscrits à un établissement postsecondaire qui sont appelés à porter un jugement dans un contexte de travail fictif, les résultats obtenus doivent être validés auprès d'une population d'employeurs et d'intervenants sociaux. Bien qu'on reconnait les limites du choix de cette population, il faut quand même se rappeler que ce sont les perceptions des étudiants inscrits dans un programme d'études postsecondaires menant à une carrière en administration ou à une profession en intervention sociale qui sont particulièrement pertinentes à cette recherche. Ce sont ces individus qui auront le plus grand rôle à jouer dans l'insertion professionnelle des personnes ayant des incapacités.

Depuis plus d'une décennie, les Nations Unies ont adopté la Convention relative aux droits des personnes handicapées visant à accorder une plus grande visibilité aux personnes ayant des incapacités (Nations Unies, 2006). Ratifiée par la suite en 2010 par le Canada, la Convention souligne le besoin des mesures qui facilitent la pleine participation des personnes ayant des incapacités dans toutes les sphères de la société. En effet, l'article 27 de la Convention repose sur le postulat que les personnes ayant des incapacités devraient avoir accès à des emplois dans un milieu intégré, où elles se sentent reconnues et valorisées. Afin de réduire les obstacles à l'emploi, les mesures d'accompagnement étatiques ont surtout visé à préparer les personnes ayant des incapacités aux réalités de ce marché (Prince, 2016). Or, comme la présente recherche le démontre, les mentalités, notamment le paternalisme organisationnel, ont comme effet de rendre invisible la contribution des personnes ayant des incapacités sur le marché de l'emploi. Les résultats de la présente recherche appuient les propos de certains auteurs (Gilbride, Stensrud, Vandergoot, & Golden, 2003; Shier, Graham, & Jones, 2009; Stensrud, 2007); une approche centrée en grande partie sur l'augmentation du potentiel de l'individu aura des retombées modestes si les employeurs et les intervenants sociaux ne sont pas également préparés, c'est-à-dire capables de reconnaître leurs propres préjugés et outillés pour les dépasser. La présente recherche souligne le besoin de mettre en place des moyens pour préparer la prochaine génération des employés, employeurs et intervenants sociaux à l'inclusion professionnelle des personnes ayant des incapacités. Dans une étude menée auprès des employeurs récalcitrants, plus de la majorité a relaté leur besoin d'une formation visant à changer les mentalités (Kaye, Jans, & Jones, 2011). Une stratégie prometteuse est d'intégrer ces connaissances dans le cadre des cours de premier cycle universitaire qui sont beaucoup sollicités par les étudiants, notamment, les cours d'introduction à la psychologie. Or, selon les résultats, la question du handicap est en grande partie abordée en fonction du modèle médical et se limite aux conditions psychiatriques dans le cadre du curriculum des cours d'introduction en psychologie (Goldstein, Seigel, & Seaman, 2010; Rosa, Bogart, Bonnett, Estill, & Colton, 2016). Le changement des mentalités à l'endroit des personnes ayant des incapacités sur le marché de l'emploi doit reposer sur une formation qui relève du modèle du processus de production du handicap (Fougeyrollas, 2010) qui permet aux futurs acteurs sociaux de relever les défis de l'inclusion professionnelle des personnes handicapées dans le cadre d'une économie mondiale.

Références

AYCAN, Z. (2006). Paternalism: Towards conceptual refinement and operationalization. Dans U. Kim, K.-S. Yang et K.-K. Hwang (Dir.), *Indigenous and cultural psychology: Understanding people in context* (pp. 445-466). New York: Springer.

BATAVIA, A. I. (2001). The new paternalism: Portraying people with disabilities as an oppressed minority. *Journal of Disability Policy Studies, 12*, 107-113.

BEATON, A. M., DOVIDIO, J. F., & LEBLANC, J. (2011). Prejudice and intergroup discrimination: Does behavioural suppression moderate the relationship? *Personality and Individual Differences, 51*, 579-583.

BEATON, A. M., KABANO, J., & LÉGER, M. (2014). How do employers view people with disabilities in the labour market? *Développement humain, Handicap et Changement social, 20*, 25-39.

COLELLA, A., DE NISI, A. S., & VARMA, A. (1998). The impact of ratee's disabiliy on performance judgments and choice as partner. *Journal of Applied Psychology, 83*, 102-111.

COLELLA, A., & STONE, D. C. (2005). Workplace discrimination toward persons with disabilities: A call for some new research directions. Dans R. L. Dipboye, & A. Colella (Dir.), *Discrimination at work: The psychological and organizational bases* (pp. 227-254). Mahwah, NJ: Lawrence Erlbaum.

Conseil canadien de la réadaptation et le travail (2005). *Final report: Diversity planning for inclusive employment, employer survey*. Halifax Global, Halifax, NS. Retrieved from http://www.ccrw.org/userfiles/CCRW-DPIE-EN.pdf

Domin, D., & Butterworth, J. (2013). The role of community rehabilitation providers in employment for persons with intellectual and developmental disabilities: Results of the 2010-2011 National Survey. *Intellectual Development Disability, 51*, 215-225.

Fougeyrollas, P. (2010). *La funambule, le fil et la toile : transformations réciproques du sens du handicap*. Québec, QC : Les Presses de l'Université Laval.

Fraser, R., Ajzen, I., Johnson, K., Hebert, J., & Chan, F. (2011). Understanding employers' hiring intention in relation to qualified workers with disabilities. *Journal of Vocational Rehabilitation, 35*, 1-11.

Gilbride, D., Stensrud, R., Vandergoot, D., & Golden, K. (2003). Identification of the characteristics of work environments and employers open to hiring and accommodating people with disabilities. *Rehabilitation Counseling Bulletin, 46*, 130-137.

Goldstein, S. B., Seigel, D., & Seaman, J. (2010). Limited access: The status of disability in introductory psychology textbooks. *Teaching of Psychology, 37*, 21-27.

Gouvernement du Nouveau-Brunswick (2012). Plan d'action-emploi pour les personnes ayant un handicap au Nouveau-Brunswick. Repéré à http://www2.gnb.ca/content/dam/gnb/Departments/pcsdp-cpmcph/pdf/publications/EAPReport2012FR.pdf

Inge, K. J., Wehman, P., Revell, G., Erickson, D., Butterworth, J., & Gilmore, D. (2009). Survey results from a national survey of community rehabilitation providers holding special wage certificates. *Journal of Vocational Rehabilitation, 30*, 67-85.

Jackman, M. R. (1994). *The velvet glove: Paternalism and conflict in gender, class, and race relations*. Berkeley. CA: University of California Press.

Jackman, M. R. (2005). Rejection of inclusion of outgroups? Dans J. F. Dovidio, P. Glick, et L. A. Rudman (Dir.), *On the nature of prejudice: Fifty years after Allport* (pp. 89-105). Malden, MA: Blackwell.

Kabano, J., & Beaton, A. M. (2011). Le marché du travail vu par des personnes ayant des incapacités : une étude de leurs représentations sociales. *Développement humain, Handicap et Changement social, 19*, 109-126.

Kaye, H. S., Jans, L. H., & Jones, E. C. (2011). Why don't employers hire and retain workers with disabilities? *Journal of Occupational Rehabilitation, 21*, 526-536.

Lindsay, S., Adams, T., Sanford, R., McDougall, C., Kingsnorth, S., & Menna-Dack, D. (2014). Employers' and employment counselors' perceptions of desirable skills for entry-level positions for adolescents: How does it differ for youth with disabilities? *Disability & Society, 29*, 953-967.

Lindsay, S., McDougall, C., Menna-Dack, D., Sanford, R., & Adams, T. (2015). An ecological approach to understanding barriers to employment for youth with disabilities compared to their typically developing peers: View of youth, employers and job counselors. *Disability and Rehabilitation, 37*, 701-711.

Louvet, E. (2007). Social judgment toward job applicants with disabilities: Perception of personal qualities and competences. *Rehabilitation Psychology, 52*, 297-303.

Louvet, E., Rohmer, O., & Dubois, N. (2009). Social judgment of people with a disability in the workplace: How to make a good impression on employers. *Swiss Journal of Psychology, 68*, 153-159.

Luecking, R. G. (2008). Emerging employer views of people with disabilities and the future of job development. *Journal of Vocational Rehabilitation, 29*, 3-13.

Merzouk, R. (2008). Travail, handicap et discrimination : lorsque le travail devient aussi un espace de production du handicap. *Reflets : revue d'intervention sociale et communautaire, 14*, 155-181.

Monteiro, M. B., de França, D. X., & Rodrigues, R. (2009). The development of intergroup bias in childhood: How social norms can shape children's racial behaviours. *International Journal of Psychology, 44*, 29-39.

Miceli, N. S., Harvey, M., & Buckley, M. R. (2001). Potential discrimination in structured employment interviews. *Employee Responsibilities and Rights Journal, 13*, 15-38.

Miller, P., Parker, S., & Gillinson, S. (2004). *Disablism: How to tackle the last prejudice*. London, UK: Demos.

Monteiro, M. B., de França, D. X., & Rodrigues, R. (2009). The development of intergroup bias in childhood : How social norms can shape children's racial behaviours. *International Journal of Psychology, 44*, 29-39.

Nations Unis (2006). *Convention relative aux droits des personnes handicapées et protocol facultatif*. Repéré à http://www.un.org/disabilities/documents/convention/convoptprot-f.pdf

Panel on Labour Market Opportunities for Persons with Disabilities (2013). *Rethinking disability in the private sector: We all have abilities. Some are just more apparent than others*. Ottawa, ON. Retrouvé à https://familyworksbc.files.wordpress.com/2013/01/canada-federal-panel-report-on-labour-mkt-opps-for-pwds-jan13-copy.pdf

Prince, M. J. (2016). *Inclusive employment for Canadians with disabilities: Toward a new policy framework and agenda*. Institute for Research on Public Policy/Institut de recherche en politiques publiques. Retrouvé à http://irpp.org/wp-content/uploads/2016/08/study-no60.pdf

Rohmer, O., & Louvet, E. (2011). Le stéréotype des personnes handicapées en fonction de la nature de la déficience. Une application des modèles de la bi-dimensionnalité du jugement social. *L'Année Psychologique, 111*, 69-85.

ROHMER, O., & LOUVET, E. (2016). On dit qu'on les apprécie mais sommes-nous prêts à les côtoyer? Le cas particulier des personnes en situation de handicap. *Psihologia Sociala, 38*, 17-34.

ROSA, N. M., BOGART, K. R., BONNETT, A. K., ESTILL, M. C., & COLTON, C. E. (2016). Teaching about disability in psychology: An analysis of disability curricula in U.S. undergraduate psychology programs. *Teaching of Psychology, 43*, 59-62.

SAUNDERS, S. L., & NEDELEC, B. (2014). What work means to people with work disability: A scoping review. *Journal of Occupational Rehabilitation, 24*, 100-110.

SHIER, M., GRAHAM, J. R., & JONES, M. E. (2009). Barriers to employment as experienced by disabled people : A qualitative analysis in Calgary and Regina, Canada. *Disability & Society, 24*, 63-75.

SCHUR, L., KRUSE, D., BLASI, J., & BLANCK, P. (2009). Is disability disabling in all workplaces? Workplace disparities and corporate culture. *Industrial Relations: A Journal of Economy and Society, 48*, 381-410.

STENSRUD, R. (2007). Developing relationships with employers means considering the competitive business environment and the risks it produces. *Rehabilitation Counseling Bulletin, 50*, 226-237.

STIKER, H.-J. (1997) [1982, 2005]. *Corps infirmes et sociétés*. Paris, France : Dunod.

TURCOTTE, M. (2014). Persons with disabilities and employment. *Insights on Canadian Society*, Statistics Canada Catalogue no. 75-006-X. ISSN 2291-0859.

VORNHOLT, K., UITDEWILLIGEN, S., & NIJHUIS, F. J. N. (2013). Factors affecting the acceptance of people with disabilities at work: A literature review. *Journal of Occupational Rehabilitation, 23*, 463-475.

WAGSTAFF, M. A., COLELLA, A., TRIANA, M. D. C., SMITH, A. N., & WATKINS, M. B. (2015). Subordinates' perceptions of supervisor paternalism: A scale development. *Journal of Managerial Psychology, 30,* 659-674.

WANG, K., BARRON, L. G., & HEBL, M. R. (2010). Making those who cannot see look best: Effects of visual resume formatting on ratings of job applicants with blindness. *Rehabilitation Psychology, 55*, 68-73.

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Impact of Contextual Factors on the Social Representation of Disability Among Students in Inclusive Junior High Schools

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Abstract

This article explores the social representation of disability and the stereotypes held by nondisabled students. We were particularly interested in how these might change as a result of the interaction between contact, visibility and hindrance. We recruited 549 junior high students from schools that included pupils with disabilities. Results showed that social representation and disability stereotypes were indeed contingent upon the interaction of the three factors. The wheelchair, which was at the core of the student's social representation of handicap at the beginning of the year, eased out and was replaced by references to mental disability and/or other terms when there was direct contact with a disabled peer. In the case of indirect contact, the disability had to be visible to observe similar results. Concerning disability stereotypes, the majority of participants initially attributed negative personality traits to people with disabilities and expressed negative emotions towards them. There was a tendency for them to become less negative under certain conditions at the year's end. We discuss these results and their implications.

Keywords: disability, social representation, stereotypes, contact, visibility, hindrance

Résumé

Cet article porte sur l'évolution de la représentation sociale du handicap et des stéréotypes qui y sont liés auprès de 549 jeunes adolescents non handicapés, scolarisés dans un cadre inclusif lors d'une année scolaire. L'interaction des facteurs contact, visibilité et importunité du handicap est particulièrement étudiée. Les résultats montrent que l'évolution de la représentation sociale et les stéréotypes du handicap dépendent effectivement de l'interaction des trois facteurs. Le fauteuil roulant, élément central de la représentation sociale du handicap en début d'année, s'efface au profit de références à la déficience mentale ou à d'autres termes lorsque le contact est direct avec un pair handicapé. En revanche, le handicap doit être visible pour repérer un tel résultat en cas de contact indirect. En ce qui concerne les stéréotypes du handicap, la majorité des participants attribuent des traits de personnalité négatifs aux personnes handicapées et expriment des émotions négatives à leur égard. Ces stéréotypes évoluent peu, mais tendent à devenir moins négatifs dans certaines conditions en fin d'année. Ces résultats sont discutés ainsi que leurs implications.

Mots-clés : handicap, représentation sociale, stéréotypes, contact, visibilité, importunité

Introduction

Most Western nations have opted to encourage people with disabilities to play a full and active role in society, and have legislated accordingly (Ainscow & César, 2006). This new political will reflects changes in conceptions of disability: over three decades, we have moved away from a medical approach centred on the individual towards a multifactorial approach that takes account not just of the person's state of health but also of the environment in which he or she lives and operates (Fougeyrollas, 1997). Despite these legislative and conceptual advances, however, people with disabilities continue to face barriers to their participation in every sphere of social life.

In schools, this reticence can take a variety of forms. While teachers are generally favourable to the policy of inclusion *in principle*, their enthusiasm swiftly evaporates when a pupil with a disability arrives in their classroom (Avramidis, Bayliss, & Berben, 2000). Concerning the socialisation of pupils with disabilities, research has shown that they enjoy fewer social interactions and fewer reciprocal friendships than their nondisabled peers (Estell et al., 2008) do. They also lose the few friendships they have when they disclose their disability or when that disability worsens (Moses, 2010). Even when they do have friends, they often find themselves trapped in asymmetrical relationships and continue to be regarded as different from nondisabled pupils (Skar, 2003; Watson, 2002). Lastly, pupils with disabilities are more often the victims of jokes, insults, and cold-shouldering by nondisabled children (Sentenac et al., 2011). These observations clearly sit ill with the aspirations of recent legislation, and it is important that we identify the sociopsychological dimensions of resistance to the inclusion of pupils with disabilities in mainstream schools, as these institutions play a key role in secondary socialisation.

The explanation, in part, for this resistance could lie in the nature of the social representation of disability. Social representations are sets of beliefs, knowledge, opinions and stereotypes that shape attitudes and influence behaviour (Rouquette & Rateau, 1998), and French schools offer a prime opportunity for studying the representation of disability held by children. In less than a century, France's education system shifted from a segregationist model (1909-1975) to an integrationist one (1975-2005), and has slowly been moving towards inclusiveness since 2005, when the act on "equal rights and opportunities, participation and citizenship of persons with disabilities" was promulgated (Gillig, 2006). Increasing numbers of children with disabilities are therefore attending mainstream schools, especially at secondary level (French Ministry for Education, 2012).

Whichever form this schooling takes (full-time or part-time in a typical classroom, one-to-one support, etc.), a balance has to be struck between catering for the children's special educational needs (SENs) and favouring their social inclusion. On this particular point, French legislation urges nondisabled pupils to practise the values of tolerance and respect individual differences so that everyone can "live together"[1]. The aim is therefore to change their whole perception of disability, replacing the medical deficit representation of disability with one that is person-centred (Gardou, 1999). The present study therefore explored the social representation of disability held by French junior high students, seeking to detect possible changes.

- Social representation and transformation

A social representation is a "form of knowledge that is socially elaborated and shared with a practical aim, contributing to the construction of a reality shared by a given social group" (Jodelet, 1989, 36). According to the structural approach (Abric, 1994), social representations are made up of cognitive components organised in a hierarchical, two-tier system comprising a central core (stable part) and a peripheral area (flexible part). The central core is

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[1] Official Bulletins of National Education numbers 1995-125, 1999-187 and 2010-088, which are named Educational integration of preteens and teens with disabilities in middle and high school; Schooling of children and teenagers with disabilities; Schooling of the disabled pupils.

directly associated with the values and norms conveyed by society. The peripheral components, on the other hand, reflect the characteristics of individual members of that society and their immediate context. The peripheral area acts as a buffer zone, accommodating components informed by individual experiences and life stories, whilst shielding the central core from change.

Even though social representations are remarkable for their stability, they can and do change in order to remain relevant in the changing social world. According to Flament (2001), the introduction of new practices, resulting from modifications in the social environment, is the main reason for their transformation. This transformation (Guimelli, 1994) results in modifications to the central core.

- The social representation of disability

According to Morvan (1988), the social representation of people with disabilities can be broken down into five images. The *semiological* image defines disability in terms of deficiencies and pathologies (e.g., Down syndrome, paralysis). The *secondary* image tends to dwell on the disability's repercussions in terms of incapacity, reducing it to technical (e.g., assistive devices, wheelchair), human (e.g., physicians, psychologists), and institutional (special schools, etc.) forms of support. The *childlike* image likens people with disabilities to overgrown children who lack autonomy and need help. The *affective* image concerns the personality traits that are attributed to people with disabilities. The fifth image, *relational,* represents the affects (feelings and emotions) that are triggered by the able-bodied or able-minded by people with disabilities. The social representation of disability is dominated by semiological and secondary images.

Were we to apply a structural approach to these findings, we would probably conclude that the central core of the disability representation contains items referring to the medical dimension of disability. However, as far as we are aware, its organisation has only been explored on two occasions. The first study discovered that deficiency was one of the central components of the social representation of mental disability held by trainee specialist teachers (Lachal et al., 2005). The second, conducted among pupils of an inclusive junior high school, also found a reference to deficiency in the central core, this time in the shape of a wheelchair (Harma, Gombert, & Roussey, 2013). It further showed that the peripheral system varied according to the children's actual experience of integration (i.e., whether any of their classmates had a disability) and the visibility of the disability (i.e., whether or not there was a visible deficiency). Results indicated that the inclusion of a pupil with a visible disability prompted participants to refer more to the difficulties linked to disability. If the disability was not visible, participants referred more to the personality traits and physical attributes of people with disabilities. The fact that contextual factors (experience of integration, visibility of the disability) brought about a variation in the peripheral system suggests that it is possible for the social representation of disability to change. Although, as we said earlier, the peripheral system serves to protect the central core, it may reach a tipping point if the number of children with disabilities entering mainstream education rises beyond a certain point, resulting in the modification of the central core.

What makes this a particularly important area of research is the fact that contextual factors are known to influence attitudes, themselves a product of social representations. Several studies, for instance, have shown that pupils' attitudes towards disability vary according to the type of disability they encounter, and the degree of contact they have with it. There are divergent results as to the effects of the *contact* factor. Some researchers have suggested that children who come into regular and prolonged contact with people with disabilities (e.g., a classmate, friend or family member with a disability) do indeed develop more positive attitudes towards them, whether the deficits are intellectual and cognitive, or physical and sensory. Gottlieb, Cohen, and Goldstein (1974), however, found that it was young people who had never come into contact with pupils with disabilities at school who displayed the most positive behaviour towards them. In the same register, Vignes (2009) showed that the presence of a SEN class (*pedagogical integration unit*, UPI) in their school was associated with more negative attitudes among French fifth graders. Yet other studies have failed to find any significant effect of contact on the attitudes of nondisabled pupils.

Concerning the *type of disability*, researchers have shown that pupils have more positive attitudes towards physical disabilities than towards intellectual ones, citing visibility as a reason (Furnham & Gibbs, 1984; Magiati, Dockrell & Logotheti, 2002; Tringo, 1970; Wisely & Morgan, 1981). Their explanation is that physical deficiencies, such as paralysis, blindness and amputation, are immediately visible, unlike intellectual ones. Nevertheless, according to Goffman (1975)'s stigma theory, another factor could explain this finding: disturbances in the fluidity of social interaction can result in more negative attitudes towards individuals with disabilities. For example, people attending a meeting may well ignore a colleague's wheelchair because when they are all sitting round a table, his or her disability does not impede the smooth flow of proceedings. Were that colleague to have a stammer (i.e., a disability that is not immediately visible), the interaction would be disrupted as soon as he or she spoke. One person's disability may thus be visible, yet not at all disruptive, while another's may be invisible, but cause considerable disruption.

This is certainly the case for some forms of mental disability, such as intellectual deficiency, which can hinder social intercourse because the people concerned are assumed to have a poorer vocabulary and be slower, less focused, absent-minded or over-imaginative (Pace, Shin, & Rasmussen, 2010). It is therefore legitimate to ask whether the supposed hindrance from mental disability actually provides a better explanation for people's more negative attitudes towards mental, as opposed to physical, disability. To our knowledge, however, the effect of this factor has never specifically been investigated. Research focusing exclusively on attitudes towards mental disability, which is popularly assumed to hinder social interaction, has shown that they are less favourable towards mental illness than they are towards intellectual disability (Schwartz & Armony-Sivan, 2001; Walker et al., 2008). One possible explanation for this is that intellectual disability, unlike mental illness, is represented by a visible disability (i.e., Down syndrome). Instead of focusing exclusively on the characteristics of a given disability, we should therefore investigate the *interaction* of contextual factors if we want to explore variations in social representations and attitudes.

Taken together, these various theories and approaches suggest that the expansion of mainstreaming in France will eventually bring about a shift in the current social representation of disability. How and when it does will, however, depend on a range of contextual factors, including the extent of contact, the visibility of the disability, and the hindrance it is thought to cause.

- *Objective of the present study and hypotheses*

Our study had a twofold objective. First of all, we set out to probe the social representation of disability and the (positive or negative) disability stereotypes held by junior high students attending inclusive schools. Second, we looked for possible changes in them as a result of the interaction of three factors: Contact, Visibility and Hindrance. In the light of the research findings outlined above, we decided to test four hypotheses. Our first hypothesis was that deficiency is the main component of the social representation of disability held by junior high students, just as it is for adults (Morvan, 1988) and adolescents (Harma et al., 2013) (H1). We also hypothesised that, just as perceptions of disability are negative (Goffman, 1975) so, too, are disability stereotypes, which we explored via the personality traits our participants attributed to people with disabilities and the emotions they expressed towards them (H2). Third, as new practices tend to modify social representations (Flament, 2001), we hypothesised that mainstreaming leads to changes in nondisabled children's social representation and stereotypes of disability (H3). Fourth and last, in the light of research on the factors liable to influence the social representation of disability and attendant attitudes (Allport, 1954; Goffman, 1975), we formed the hypothesis that change is contingent upon the interaction between contact, visibility and hindrance (H4).

Method

- *Operationalised factors*

The *contact* factor corresponded to contact with a peer with a disability at school. This factor was divided into two modalities: direct contact and indirect contact. We selected junior high schools where pupils with disabilities were present for the full school day, and included in ordinary classes for at least half that time. Within these schools, pupils belonging to inclusive classes formed the direct contact group, and those who belonged to noninclusive classes formed the indirect contact group.

Concerning the characteristics of the disability, if the disability was easily observable because of a physical stigma that was impossible to conceal or because of the use of an assistive device, it was said to be *visible*. In all other cases, the disability was deemed to be *nonvisible*.

Hindrance was the term we used to refer to disabilities that disrupt social interactions between disabled persons and those who are not (radical break in Goffman's "rites of interaction"). This disruption must lead nondisabled people to adapt to restore the rites of interaction. Goffman (1975) gives the example of a person who reaches out his right hand to greet a person whose right arm has been amputated. In this situation, the interaction is broken and to restore it, the two individuals have to extend their left hands. Some forms of disability, such as deafness, elocution disorders, and intellectual disabilities… can be a hindrance to the interaction. For instance, they can lead the person who is speaking to a disabled individual, to speak more slowly or to accompany his or her language with gestures (eating, drinking, listening…), to make the partner repeat, to ask him to communicate through a different way, or to use simple vocabulary to be understood. In this study, the operationalization of the hindrance factor is limited to intellectual disability because it impedes communication and the fluidity of the interaction (Goffman, 1975; Marcellini, 2005) between pupils in the classroom, the schoolyard or off school grounds. Thus, pupils with intellectual disability were considered to have a "hindering" disability.

These three factors were found to interact in five junior high schools in Southeast France, which we therefore selected as the setting for our research. The first school included five pupils with Down syndrome (hindering and visible; Hin+ V+), the second included four pupils with motor disorders[2] (nonhindering and visible; Hin- V+) and the third included six pupils with learning disabilities (nonhindering and nonvisible; Hin- V-). The fourth and fifth schools included a total of ten pupils with an intellectual disability but no physical stigma (hindering and nonvisible; Hin+ V-).

- *Participants*

We recruited nondisabled pupils in their first or second year of junior high school. Participants from 17 inclusive classes, who therefore had direct experience of integration, formed our direct contact group. They were matched with participants from 16[3] noninclusive classes, based on three criteria: same junior high school, same school year (i.e., first or second year), and equivalent academic performances. These participants formed our indirect contact group.

A total of 620 students schooled in 33 identified classes were authorised by their parents to take part in the experiment, but only the

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[2] Cerebral palsy of these pupils is not accompanied by problems of elocution. Moreover, they are schooled in a completely accessible school (elevator, ramp, automatic doors…). So, the interactions between disabled and nondisabled pupils should not be disrupted.

[3] 17 noninclusive classes had been selected but one theme did not hand over the parental consents within the set deadlines. So, the number of noninclusive classes was reduced to 16.

549 students who participated in both data collection sessions were included in the final sample, which contained 285 girls (51.9 %) and 264 boys (48.1 %), aged 10.2-15 years (*M* = 12.6 years).

For ethical reasons, we took several steps to minimise the stigmatising effects of our study on the pupils with disabilities. Their parents were informed of the research and its objectives, and with their agreement, their children took part in the study, completing the same questionnaire as their nondisabled peers. They sometimes took part in a semi-structured interview. This material was not processed in the present study.

- Procedure

The first session was held in October/November 2009 (T1) and the second in April/May 2010 (T2). Participants answered the questionnaire during their study periods, which is when pupils with disabilities usually return to their special classes to consolidate their learning. The latter therefore completed the questionnaire or underwent the interview in a classroom that had been specially set aside for them, so that the experimenter could support them more effectively. The same protocol was followed in both sessions. After he described briefly the study, the experimenter emphasised that all the responses would be analysed anonymously. The students were then asked to fill out the questionnaire on their own.

- Material

We used a free-association question to probe the content of the participants' social representation of disability. Participants first had to provide five words or expressions that came to mind when they thought about someone with a disability. They then had to list them in order of importance. We looked at two indicators: frequency of occurrence and importance ranking.
To study the stereotypes linked to disability, participants had to answer two descriptive questions. One concerned the personality traits they attributed to people with disabilities, the other the affects they felt towards them. In the first one, participants were given a list of 12 traits and asked to select the four they felt best described people with disabilities. They then had to select the four least characteristic traits. The remaining terms were deemed to be neutral. To answer the second question, they were shown a list of 12 emotions and asked to select them in the same way. All the items were then incorporated into clauses that would be easily understandable to young junior high pupils. Their order was randomised in each list.

- Data collection and analysis

We analysed 1098 questionnaires filled out at the two sessions by 549 participants. We ran two analyses on the free-association data to explore the social representation of disability and one analysis on the descriptive data to explore disability stereotypes.

TABLE 1 : DISTRIBUTION OF PARTICIPANTS ACROSS THE EIGHT EXPERIMENTAL CONDITIONS

	Direct Contact		**Indirect Contact**	
	High-visibility disability V+	Nonvisible disability V-	High-visibility disability V+	Nonvisible disability V-
Hindrance+	78	116	33	101
Hindrance-	67	40	76	38
Total	145	156	109	139

A content analysis of all the words produced in response to the free-association question revealed that the typology of the social representation of disability (Harma, Gombert, & Roussey, 2013) consisted of seven categories[4]: pathologies or symbol (paralyzed, blind, Down syndrome, wheelchair…), personality traits and physical attributes (nice, funny, naughty, courageous…), norms (different, as us, bizarre…), feelings/emotions (sadness, sorrow, compassion…), disease (disease, health problems, asthma, hospital…), difficulty (his has difficulties, it's difficult) and the causes of disability (accident, genetics…). In line with Bardin (1989)'s five recommendations, these categories were exhaustive, exclusive, methodical, objective, and quantifiable. The coding had to be approved by two judges, who were tasked with checking that the words were correctly classified and were only placed in one category. When both judges considered that a term had been misclassified, but could not agree on the right category, a third judge was brought in. After discussion between the three judges, the statement was reclassified either unanimously or by a majority. When multiple occurrences were excluded, participants were found to have produced a total of 709 different terms. Of these, 26 were reclassified by the judges, 32 required the intervention of a third judge. Interrater agreement was above 90 %. A total of 2514 words were produced and classified at T1 and 2545 words at T2.

A second analysis crossing ranking with frequency allowed us to identity those terms that made up the central core and those that belonged on the periphery. More specifically, a high-frequency term with a high importance ranking was deemed to belong to the central core, whereas a term with, say, a low frequency and a low or moderate ranking was relegated to the peripheral system (Vergès, 1994). This analysis was carried out with Evoc 2005 software, which was designed specifically for this type of analysis. We further compared the items that were in the central core at T1 with those that were in it at T2, in order to see if the representation had changed and to measure the effect of the Contact x Visibility x Hindrance interaction.

The third analysis concerned the items that were chosen to describe the personality of people with disabilities and the emotions felt towards them. Items were classified according to their polarity, after which we counted the number of occurrences.

For all three content analyses, we used the χ^2 test to observe the effect of the Contact x Visibility x Hindrance interaction, using Outils. Stat freeware (Dauvier & Arciszewski, 2009). The significance threshold was set at $p = .05$.

Results

To study the effect of the interaction between Contact, Visibility and Hindrance on changes in the social representation of disability, we looked at the Visibility x Hindrance interaction in each of the two Contact modalities. After providing the results on the *content* of the social representation of disability, we set out the results on its *organisation*, and the results on the disability stereotypes.

- *Changes to the content of the social representation of disability*

Our young junior high pupils mainly cited different types of disability and symbolic objects when referring to disability (pathologies category, TI: 1542 words; T2: 1379 words). They made far fewer references to either feelings/ emotions or personality traits and physical attributes. In the direct contact modality, changes in the content of the social representation depended on the nature of the disability the participants encountered. When their schoolmates had a Hin+ V+ disability, participants referred less to their feelings/emotions, and to the causes of disability at the end of the year. There was a comparable shift when the disability was V-, regardless of whether it was Hin+ or Hin-. More specifically, pupils made fewer references to pathologies and deficiencies to evoke disability, and more references to personality traits and physical attributes. No significant change was observed among partici-

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[4] More eighth unclassifiable category.

pants who had a classmate with a Hin- V+ disability.

When participants had only indirect contact with a pupil with a Hin+ V- disability, they evoked more personality traits and physical attributes at the end of school year, and were less prone to express their feelings/emotions towards disability. Those who had indirect contact with pupils with a Hin- disability, whether it was V+ or V-, referred less to deficiencies at the end of the year and more to personality traits and physical attributes. However, Visibility did affect the frequency of terms belonging to the other categories. When the disability was V+, pupils used more terms evoking difficulty and feelings/emotions, whereas when it was V-, they referred more to norms. No change was observed among participants who had indirect contact with pupils with a Hin+ V+ disability.

- *Changes in the organisation of the social representation of disability*

By calculating the frequency and mean ranking of each word or expression in the corpus, we were able to access the social representation's central core. The term most often cited by the participants was *wheelchair* (169 out of 549). At the beginning of the year, the participants shared more or less the same social representation of disability, as the central core consistently featured a single component (*wheelchair*). However, depending on the nature of the interaction, this representation then changed in the course of the school year.

The social representation of disability held by participants who came into *direct contact* with a classmate with a disability changed regardless of the nature of that disability. In every single case, the term *wheelchair* moved out of the central core, to be replaced by at least one term referring to mental deficiency, either generically (*mental disability*), specifically (*Down syndrome*) or both. In two of the conditions, one other term appeared in the central core: *ill* (Hin+ V-) and *nice* (Hin- V+). The terms making up the central core therefore varied according to the interaction of our three contextual factors.

TABLE 2

DISTRIBUTION OF THE TERMS PROVIDED BY THE PARTICIPANTS IN DIRECT CONTACT WITH A CLASSMATE WITH A DISABILITY ACROSS THE SEVEN CATEGORIES ACCORDING TO THE VISIBILITY X HINDRANCE INTERACTION AT THE BEGINNING (T1) AND END (T2) OF THE SCHOOL YEAR

	V+			V-			V+			V-		
	Hin+			Hin+			Hin-			Hin-		
Categories	T1	T2	*p*	T1	T2	*p*	T1	T2	*p*	T1	T2	*p*
Pathologies	224	253	*ns*	342	292	.001	182	168		135	102	.01
Personality/Physical	36	52	*ns*	38	90	.001	31	45		9	33	.001
Norms	26	21	*ns*	31	42	*ns*	13	16		11	10	*ns*
Feelings & emotions	43	28	.05	85	74	*ns*	39	52		18	14	*ns*
Disease	18	14	*ns*	23	31	*ns*	7	12		15	14	*ns*
Difficulty	10	6	*ns*	11	8	*ns*	3	3		4	5	*ns*
Causes of disability	9	1	.01	6	6	*ns*	10	3		0	3	*ns*
Total	366	375	.02	536	543	.001	285	299	*ns*	192	181	.005

TABLE 3

DISTRIBUTION OF THE TERMS PROVIDED BY THE PARTICIPANTS IN INDIRECT CONTACT WITH A PEER WITH A DISABILITY ACROSS THE SEVEN CATEGORIES ACCORDING TO THE VISIBILITY X HINDRANCE INTERACTION AT THE BEGINNING (T1) AND END (T2) OF THE SCHOOL YEAR

	V+ Hin+			V- Hin+			V+ Hin-			V- Hin-		
Categories	T1	T2	*p*	T1	T2	*p*	T1	T2	*p*	T1	T2	*p*
Pathologies	87	81		235	262	*ns*	223	151	.001	114	67	.001
Personality/Physical	20	27		32	50	.05	26	54	.005	13	26	.02
Norms	17	16		29	37	*ns*	11	17	*ns*	5	16	.02
Feelings & emotions	16	19		116	71	.001	48	93	.001	39	51	*ns*
Disease	12	4		30	31	*ns*	15	14	*ns*	10	9	*ns*
Difficulty	4	5		11	8	*ns*	4	20	.005	3	9	*ns*
Causes of disability	4	1		6	4	*ns*	5	4	*ns*	0	0	
Total	160	153	*ns*	459	463	.01	332	353	.001	184	178	.001

TABLE 4

CENTRAL CORE OF THE DISABILITY REPRESENTATION HELD BY PARTICIPANTS IN DIRECT CONTACT WITH A CLASSMATE WITH A DISABILITY ACCORDING TO THE VISIBILITY X HINDRANCE INTERACTION AT THE BEGINNING (T1) AND END (T2) OF THE SCHOOL YEAR

V+ Hin+		V- Hin+		V+ Hin-		V- Hin–	
T1	T2	T1	T2	T1	T2	T1	T2
Wheel-chair (43/2.0)	Mental disability (12/2.0) Down syndrome (24/1.7)	Wheel-chair (60/2.1)	Mental disability (15/1.9) Ill (14/2.3) Down syndrome (17/2.4)	Wheel-chair (41/2.1)	Mental disability (9/1.8) Nice (9/2.4)	Wheel-chair (25/2.2)	Down syndrome (10/2.2)

NB: In parentheses, the first number corresponds to the frequency of occurrence and the second at importance ranking.

As for the participants who only came into *indirect contact* with a pupil with a disability, their social representation of disability only changed if that disability was V+. The nature of this change then depended on whether the disability was Hin+ or Hin-. If the disability was Hin+ V+, the central core contained the term *Down's syndrome*, but if it was Hin- V+, it contained terms *like us* and *poor guy*.

- Changes in the stereotypes linked to disability

At both T1 and T2, participants mainly used negative personality traits to describe disability, except for those who came into direct contact with a peer whose disability was Hin- V+. Nonetheless, in one condition (direct contact, Hin- V-), participants used more positive traits to describe disability at T2.

At T1, participants used primarily negative emotions to describe their feelings towards disability in six of the eight conditions we studied. These were students who came into either direct or indirect contact with a peer whose disability was V- (either Hin- or Hin+), those who came into direct contact with a pupil with a Hin+ V+ disability and those who came into indirect contact with a pupil with a Hin- V+ disability. At T2, changes were only observed in when participants came into direct contact with a pupil with a Hin+ V- or Hin- V+ disability. In these two conditions, participants felt more positive emotions at T2 than at T1. Indeed, in the Hin- V+ condition, most of the emotions expressed at T2 were positive.

TABLE 5

CENTRAL CORE OF THE DISABILITY REPRESENTATION HELD BY PARTICIPANTS IN INDIRECT CONTACT WITH A PEER WITH A DISABILITY ACCORDING TO THE VISIBILITY X HINDRANCE INTERACTION AT THE BEGINNING (T1) AND END (T2) OF THE SCHOOL YEAR

V+ Hin+		V- Hin+		V+ Hin-		V- Hin-	
T1	T2	T1	T2	T1	T2	T1	T2
Wheelchair (15/2.2)	Down syndrome (14/1.6)	Wheelchair (41/2.2)	Wheelchair (44/1.4)	Wheelchair (49/2.2)	Like us (9/2.4) Poor guy (13/2.1)	Wheelchair (20/1.9)	Wheelchair (11/1.3)

NB: In parentheses, the first number corresponds to the frequency of occurrence and the second at importance ranking.

TABLE 6

DISTRIBUTION OF PERSONALITY TRAITS SELECTED AT THE BEGINNING (T1) AND END (T2) OF THE SCHOOL YEAR BY PARTICIPANTS IN DIRECT OR INDIRECT CONTACT WITH A PEER WITH A DISABILITY TO DESCRIBE DISABILITY, ACCORDING TO POLARITY AND THE VISIBILITY X HINDRANCE INTERACTION

	Direct Contact								Indirect Contact							
	V+ Hin+		V- Hin+		V+ Hin-		V- Hin-		V+ Hin+		V- Hin+		V+ Hin-		V- Hin-	
Traits	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
Positive	86	90	110	123	125	141	39	48	40	38	105	115	104	119	41	53
Negative	226	222	341	341	143	127	119	112	90	94	299	289	198	185	110	99
Total	312	312	451	464	268	268	158	160	130	132	404	404	302	304	151	152

TABLE 7

DISTRIBUTION OF EMOTIONS SELECTED AT THE BEGINNING (T1) AND END (T2) OF THE SCHOOL YEAR BY PARTICIPANTS IN DIRECT OR INDIRECT CONTACT WITH A PEER WITH A DISABILITY TO DESCRIBE WHAT THEY FELT TOWARD DISABILITY, ACCORDING TO POLARITY AND THE VISIBILITY X HINDRANCE INTERACTION

	Direct Contact								Indirect Contact							
	V+ Hin+		V- Hin+		V+ Hin-		V- Hin-		V+ Hin+		V- Hin+		V+ Hin-		V- Hin-	
Emotions	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
Positive	135	150	133	158	148	173	44	54	65	57	124	132	123	134	51	54
Negative	176	162	322	306	120	94	114	106	64	75	277	272	179	167	101	98
Total	311	312	455	464	268	267	158	160	129	132	401	404	302	301	152	152

Discussion

The aim of the present study was to explore the social representation of disability held by junior high students attending inclusive schools, and to find out if and how it changed as a result of the interaction between contact, visibility and hindrance. We also looked at disability stereotypes, again in order to pick up possible changes and to observe the effect of the Contact x Visibility x Hindrance interaction.

First of all, results showed that our participants' social representation of disability was dominated by references to different types of deficiency. This was reminiscent of Morvan (1988)'s findings for adults more than two decades earlier. At T1, the central core contained just one component (*wheelchair*). To explain why it is that the wheelchair has come to symbolise disability, we need to look at the modern history of disability. In the second half of the twentieth century, invalids and disabled servicemen (amputations, paralysis, etc.) made up a sizeable proportion of the population, leading to a strong increase in wheelchair production. Wheelchairs allowed their users to continue to participate in social life and thus became increasingly visible in public places.

In the sixties, the now familiar blue-and-white pictogram featuring a wheelchair was selected to become the international symbol of disability (Marcellini, De Leseleuc, & Le Roux, 2008; Saillant & Fougeyrollas, 2007). This pictogram is apparently too firmly rooted in the minds of ordinary citizens to be dethroned by other pictograms created to symbolise specific types of disability (deaf, mute, blind) and today it is even used to indicate accessibility for people with mobility problems that are not directly linked to a deficiency (e.g., a person with a stroller or a pregnant woman). This pictogram is therefore used to refer to a wide diversity of disabling situations encountered by individuals and not just to one specific type of disability.

Throughout the school year, the participants' social representation of disability changed in six of the eight conditions we studied. Whereas *wheelchair* had been the sole component of the central core at T1, by T2 it had largely vanished, making way for other terms. This change was observed among all the participants who came directly into contact with a classmate who had a disability, regardless of its nature. By contrast, for those who were only in indirect contact, a change was only observed when the disability was visible. Direct contact with a peer with a disability therefore sufficed to change our participants' social representation of disability, whereas that disability had to be visible for the same result to be seen in the indirect contact condition. It is legitimate to wonder whether the pupils who had only indirect contact with pupils with V- disabilities were actually aware of the fact, as these pupils had either dyslexia or a minor intellectual disability, neither of which matches the two prevailing disability archetypes, namely the *wheelchair* and *Down syndrome* (Giami et al., 1988). Future studies will therefore need to check that participants who do not share a classroom with pupils with disabilities actually realise that theirs is an inclusive school, by asking them, for instance, what they know about the local inclusive schooling unit (known as *ULIS* in France) programme in their school.

In the six conditions where we observed changes in the social representation of disability, the new items making up the central core differed according to the interaction between the contact, visibility and hindrance factors. In the direct contact condition, if the disability was Hin- V- or Hin+ V+, the change consisted solely in the arrival of one or two terms referring to mental deficiency. In the two other direct conditions, however, new arrivals included not just terms referring to mental deficiency, but also terms referring to pathologies (Hin+ V-) and to personality traits (Hin- V+). Thus, whatever the characteristics of the disability that was directly encountered, the change consisted in the entry of at least one term referring to mental disability. This could be either generic (*mental disability*) or specific (*Down syndrome*). This result can be interpreted in the light of the participants' daily experiences in their inclusive classrooms. Some of them probably had to adjust their level of language to suit their classmates, repeat what they said to them, and focus on the reality of who they were in order to interact with them. By contrast, others doubtless discovered that, despite the disability label, their peers still met most of the prevailing social and academic norms (pupils with paralysis or dyslexia). Direct contact therefore makes pupils realise that different deficiencies can have different degrees of repercussions, and leads them to conceive of physical disability as being less disabling than mental disability. As a result, they reject the symbol of the wheelchair in favour of mental disability as the fundamental figure of disability (Giami et al., 1988).

When participants had indirect contact with a V+ disability, results showed that the hindrance caused by the disability affected the nature of the changes in the social representation. When the disability was Hin+, the central core contained *Down syndrome*, because this was precisely the sort of disability they saw in the schoolyard, the canteen or the corridor between lessons. When it was Hin-, the central component was *poor guy*, for as Rohmer and Louvet (2009) have shown, able-bodied people see individuals with this type of disability (i.e., motor problems) as distorted images of themselves. These images may take part into the reorganisation of the social representation of disability, prompting participants to perceive their peers with disabilities as both their equals and as people who were unlucky and suffering.

More generally, these results lead to two methodological observations. The first one concerns analyses by which it becomes possible to distinguish the central elements from the peripheral elements. The results on the evolution of social representations should be complemented and deepened with other techniques of validation of the core components. Indeed, the questions of evocation classically used to identify the elements susceptible to belong to central core (Abric, 2003) could be validated using the Ambiguous Scenario Induction method (ASI, Moliner, 1993, 2002), or the Calling Into Question technique (CIQ, Moliner, 1989) or else the Test of Context Independence (TCI, Lo Monaco et al., 2008). For example, the use of the ASI method for studying social representation of disability could be developed according the three phases: a) after collecting the elements belonging to the social representation of the object via a question of evocation, a text presenting this object without ever naming it and without using the collected elements would be produced. It would be about a description of a person with a disability in which the types of disability, symbols or the term handicap would not be mentioned. This text would be submitted to the participants who would have the task of identifying if the person is disabled, sick person, in difficulty, vulnerable... If fewer than half of the participants identified a person with a disability (shared identification), the scenario would be considered ambiguous and could be used to identify the central elements; b) then, this ambiguous scenario would be submitted to two groups of participants with an additional sentence each: one indicating the social object studied "one person with a disability (scenario conform), the other indicating the opposite "It is not a person with a disability (contradictory scenario); c) lastly, on a Likert scale the participants would answer a questionnaire in which they would indicate their degree of adhesion to the characteristics related to disability and identified during pre-investigation : this person is in a wheelchair, this person is courageous... These characteristics should register a high adherence score when the scenario is "conform" and low when the scenario is "contradictory". Thus, this method makes it possible to discriminate, which characteristics are or are not central to the social representation.

The second methodological observation concerns that it would be worthwhile to define familiarity with disability in even more detail in future studies by looking for other criteria by which to gauge contact at school. The Level of Contact Report (Holmes et al., 1999) could be used to measure each participant's intimacy of contact with disability (low, medium or high). It would, however, have to be adapted to use with adolescents encountering a wide range of disabilities, as it was originally intended to measure adults' familiarity with mental disability. Regarding contact at school, it would be interesting to take account of the attitudes of the participants' teachers and parents, as Stewart (1990) and Robertson, Chamberlain and Kasari (2003) have shown that they can influence children's attitudes. We should also take classroom teaching practices into consideration, as they can promote contact between pupils with and without disabilities (peer mentoring, mutual assistance, working in groups, etc.). Lastly, it is important to scrutinise the way in which the inclusive policy is implemented by individual schools, as some of them actively strive to support inclusion, not least by encouraging teachers to seek extra training, raising disability awareness and making sure that SEN classes are located in the main building. All these initiatives can dispel negative disability stereotypes within the school community.

Although the social representation of disability changed for the majority of our participants, the stereotypes remained stable. The only change we observed was in the descriptions of people with disabilities provided by participants who had indirect contact with a Hin- V- disability, who used more positive personality traits at the end of the year. Despite this, they continued to supply mostly negative terms, as did their peers in the other conditions, except for those in direct contact with a Hin- V+ disability, who supplied positive and negative traits in equal measure at both T1 and T2. These results show that inclusive schooling did not lead students to develop more negative perceptions of people with disabilities, and that direct contact with pupils with a Hin- V+ disability seems to be the best way of getting children to view people with disabilities in equally positive and negative ways. This is not a particularly surprising result, as this particular condition was exemplified by pupils with motor problems (paralysis), a deficiency that attracts ambivalent stereotypes. People with paralysis are perceived of as having a will to live and an ability to adapt. They are attentive to others, but remain trapped in their suffering (Rohmer & Louvet, 2011). This may have been the image that came to mind when participants had classmates with paralysis, leading them to attribute equal numbers of negative and positive personality traits during the year.

Finally, among the elements composing the social representation of disability, some are stereotypes related to disability: "different", "slow" or "courageous" (Ravaud, Beaufils, & Paicheler, 1986). Therefore, we can wonder about the link between social representation and stereotypes. The last notion cited is defined as « a set of shared beliefs about personal characteristics, usually personality traits, but also behaviors specific to a group of people » (Leyens, Yzerbyt, & Schadron, 1996, p. 129). This definition is similar to this central core because he gathered the beliefs, values and norms concerning an object and making consensus in a social group. From then on, we can wonder if the central elements of a social representation are systematically stereotypes. Moliner and Vidal (2003) worked this question by studying the central elements of the social representation of the older people and their stereotypes. Their results show that the stereotypy and centrality test scores are correlated for 19 of the

20 items tested. An item for which there is not significant correlation is an element belonging to the core of the social representation of the old person. So, the central elements cannot be stereotypes. However, the comparison of the score of stereotypy for the items belonging to the central core (68.4 %) with that of the items belonging to the peripheral system (32.4 %) indicates that the first are more stereotypic than the seconds are. In other words, the central elements identified are in the majority of cases conform to stereotypes but not automatically. These results could lead to think that elements which are at the same time central and stereotypic are most resistant to change. When these components have a negative valence, we can imagine their effects on the social interactions. For example, there was a time when people with disabilities were excluded because of mistaken beliefs that disability was an incarnation of the devil or a contagious disease. Thus, aiming for a change in the perception of disability passes also and necessarily by work on the processes of social categorization which are founded on the stereotypes and which should be deconstructed, in particular by exposure to information that counters the stereotypes (Weber & Crocker, 1983).

Regarding the emotions felt towards disabilities, they were predominantly negative in six of the eight conditions at the start of the school year. By the end of the school year, this figure had fallen to four. More specifically, participants attending schools that included pupils with visible disabilities stated that they felt both positive and negative emotions by the end of the year, whether their contact was direct or indirect. Moreover, in the case of direct contact with a Hin- V+ disability, emotions became mostly positive. These results suggest that the visibility of the disability led participants to feel fewer negative emotions towards disability. This interpretation must, however, be viewed with caution, as our results could also be explained by the stereotypes that are associated with the sorts of deficiencies participants encountered. Paralysis (Rohmer & Louvet, 2011) and Down syndrome (Carlier & Ayoun, 2007; Enea-Drapeau, Carlier, & Huguet, 2012) attract a mixture of positive and negative emotions, including feelings of compassion, sympathy, guilt and unease. These affects were probably present before among our junior high students, predisposing them to feel fewer negative emotions towards disability by the end of the school year. It is therefore legitimate to question whether results would have been the same for other visible deficiencies, such as multiple disabilities or cleft lip, that have different associated stereotypes. We believe that far more studies need to be conducted to ensure that visibility is indeed the factor responsible for positive change in the emotions expressed by individuals towards disability.

The change in our participants' social representation of disability raises the question of the attitudes that this representation shapes. We would expect a modification of the central core to be accompanied by modified attitudes and behaviour (Rateau, 2000; Tafani & Souchet, 2001). However, although the change was real enough, the central core remained rooted in disability, as its main new component was mental disability. Even if this type of change were to lead to a shift in attitude, what would be the direction of that shift, given society's negative perception of metal disability? In addition, if there were no such shift, would this mean that the central core needs to include items that do not refer exclusively to disability before a change is observed in students' attitudes?

Before we start to try and answer these question, the present study's findings need to be taken one step further. Our results confirmed the usefulness of exploring changes in the social representation of disability by looking at the interaction between contact, visibility and hindrance, rather than examining each factor separately. We therefore need to ascertain now whether the changes we observed can be replicated in other conditions and using other methodologies. For example, a longitudinal study could be conducted of students who come into contact with peers with other deficiencies that correspond to the interaction between visibility and hindrance, such as multiple disabilities (Hin+ V+), blindness or dwarfism (Hin- V+), autism spectrum disorder or dysphasia (Hin+ V-), or depression (Hin- V-).

Conclusion

The inclusive practices introduced in France as a result of the 2005 Act were intended to engineer changes in students' social representation of disability through exposure to an inclusive setting. Although the precise direction of these changes depends on how the contact, visibility and hindrance factors interact, the social representation of disability appears to remain firmly anchored in the medical model of disability (Jamet, 2003). This outcome may seem to run counter to the Act's objectives, as the aim was to modify the way people look at disability, such that they consider the person and not just his or her deficiency. However, the results of the present study showed both that personality trait components could enter the central core, and that working alongside classmates with disabilities for a year does not increase the number of negative characteristics attributed to people with disabilities. The variations we observed suggest that with time and the development of inclusive practices, the Act's objectives may be met. This raises the question of how to change the social representation of disability according to these objectives. There are several avenues worth exploring, including the introduction of programmes designed to remove stigma from disability. Although programmes along these lines have yielded promising results in the past (Holtz & Tessman, 2007; Reina et al., 2011), they have primarily involved providing information about deficiencies, thus affording few opportunities for people with disabilities to be perceived of other than from a medical perspective. This is a problem that all such initiatives need to address.

As well as providing both general and more specific information about disability to all the players in the education system, it would be useful to raise awareness of disability by highlighting not just differences but also, and more importantly, similarities. The aim would not be to deny the difference linked to the disability, nor to overstate similarities with able-bodied people, but rather to put similarity on the same par as difference, the aim being to get people with disabilities to be perceived of as men/women, mothers/fathers and employees, such that they are no longer viewed solely through the lens of deficiency. In sum, de-stigmatisation programmes should seek to improve the environment in which pupils with disabilities operate and construct their identity, so that they are regarded as regular members of the school community.

References

ABRIC, J.-C. (1994). *Pratiques sociales et representations* [Social Practices and Representations]. Paris : PUF.

ABRIC, J.-C. (2003). La recherche du noyau central et de la zone muette des représentations sociales. In *Méthodes d'étude des représentations sociales* [Methods for Studying Social Representations], edited by J.-C. Abric, 59-80, Ramonville Saint-Agne: Erès.

AINSCOW, M., & CÉSAR, M. (2006). Inclusive Education Ten Years after Salamanca: Setting the Agenda. *European Journal of Psychology of Education, 21,* 231-238.

ALLPORT, G. W. (1954). *The Nature of Prejudice.* Reading, MA: Addison-Wesley.

AVRAMIDIS, E., BAYLISS, P., & BURDEN, R. (2000). Student Teachers' Attitudes towards the Inclusion of Children with Special Educational Needs in the Ordinary School. *Teaching and Teacher Education, 16,* 277-293.

BARDIN, L. (1989). *L'analyse de contenu* [Content Analysis]. Paris : PUF.

CARLIER, M., & AYOUN, C. (2007). *Déficience intellectuelle et intégration sociale* [Intellectual Deficiency and Social Integration]. Liège : Mardaga.

DAUVIER, B., & ARCISZEWSKI, T. (2009). Outils-STATS. Repéré à http://outils.stat.free.fr

ENEA-DRAPEAU, C., CARLIER, M., & HUGUET, P. (2012). Tracking Subtle Stereotypes of Children with Trisomy 21: From Facial-Feature-Based to Implicit Stereotyping. *PLoS ONE* 7 (4): e34369. doi:10.1371/journal.pone.0034369

ESTELL, D. B., JONES, M. H., PEARL, R., VAN ACKER, R., FARMER, T. W., & RODKIN, P. C. (2008). Peer Groups, Popularity, and Social Preference: Trajectories of Social Functioning Among Students With and Without Learning Disabilities. *Journal of Learning Disabilities, 41,* 5-14. Doi:10.1177/0022219407310993

FLAMENT, C. (2001). Pratiques sociales et dynamique des représentations [Social Practices and Representational Dynamics]. In *Dynamique des représentations sociales* [Dynamics of Social Representations], edited by P. Moliner, 43-58. Grenoble: PUG.

FOUGEYROLLAS, P. (1997). Les déterminants environnementaux de la participation sociale des personnes ayant des incapacités : Le défi sociopolitique de la révision de la CIDIH [The Environmental Determinants of Social Participation by Persons with Disabilities: The Sociopolitical Challenge of Revising the CIDIH]. *Canadian Journal of Rehabilitation, 10,* 147-160.

French Ministry of Education (2012). *Repères et références statistiques sur les enseignements et la recherche* [Statistical Benchmarks and References on Teaching, Training and Research**]**. France : DEPP.

Furnham, A., & Gibbs, M. (1984). School children's attitudes towards the handicapped. *Journal of Adolescence, 7*, 99-117.

Gardou, C. (1999). *Connaître le handicap, reconnaître la personne* [Knowing the Disability, Recognising the Person]. Toulouse : Erès.

Giami, A., Assouly-Piquet, C., & Berthier, F. (1988). *La figure fondamentale du handicap : Représentations et figures fantasmatiques* [The Fundamental Figure of Disability: Fantasmal Representations and Figures]. Paris : MIRE-GERAL.

Gillig, J.-M. (2006). *Intégrer l'enfant handicapé à l'école* [Integration of Children with Disabilities in Primary School]. Paris : Dunod.

Goffman, E. (1975). *Stigmate, les usages sociaux du handicap* [Stigma: The Social Usages of Disability]. Paris : Éditions de Minuit.

Gottlieb, J., Cohen, L., & Goldstein, L. (1974). Social Contact and Personal Adjustment as Variables Relating to Attitudes toward EMR Children. *Training School Bulletin, 71,* 9-16.

Guimelli, C. (1994). *Structures et transformations des représentations sociales* [Structures and Transformations of Social Representations]. Neuchâtel-Paris : Delachaux et Niestlé.

Harma, K., Gombert, A., & Roussey, J.-Y. (2013). Impacts of Mainstreaming and Disability Visibility on Social Representations of Disability and Otherness Held by Junior High School Pupils. *International Journal of Disability, Development, & Education, 60,* 312-321.

Holmes, E. P., Corrigan, P. W., Williams, P., Canar, J., & Kubiak, A. M. (1999). Changing Attitudes about Schizophrenia. *Schizophrenia Bulletin, 25,* 447-456.

Holtz, K. D., & Tessman, G. K. (2007). An Evaluation of a Peer-Focused Intervention to Increase Knowledge and Foster Positive Attitudes toward Children with Tourette Syndrome. *Journal of Developmental and Physical Disabilities, 1,* 531-542.

Jamet, F. (2003). De la Classification internationale du handicap (CIH) à la Classification internationale du fonctionnement de la santé et du handicap (CIF) [From the International Classification of Handicaps (ICIDH) to the International Classification of Functioning, Disability and Health (ICF)]. *La nouvelle revue de l'AIS, 22,* 163-171.

Jodelet, D. (1989). Représentations sociales : Un domaine en expansion [Social Representations: An Expanding Field]. In *Les représentations sociales* [Social Representations], edited by D. Jodelet, 47-78, Paris : PUF.

Lachal, M., Urban, E., Favier, C., Marchois, A., Roye, L., Delbeke, M.-P., Gaillet, F., Mucha-Scheibling, L., & Talon, V. (2005). Handicap mental : Évolution des représentations de futurs enseignants spécialisés au cours d'une première année de formation [Mental Disability: Changes in the Representations of Future Specialist Teachers During Their First Year of Training]. *La nouvelle revue de l'AIS, 31,* 111-127.

Leyens, J.-P., Yzerbyt, V. Y., & Schadron, G. (1996). *Stéréotypes et cognition sociale* [Stereotypes and social cognition]. Bruxelles : Mardaga.

Lo Monaco, G., Lheureux, F., & Halimi-Falkowicz, S. (2008). Test d'Indépendance au Contexte (TIC) et Structure des Représentations Sociales. *Swiss Journal of Psychology, 67,* 119-123.

Magiati, I., Dockrell, J., & Logotheti, A. (2002). Young children's understanding of disabilities: The influence of development, context, and cognition. *Journal of Applied Developmental Psychology, 23,* 409-430.

Marcellini, A. (2005). Déficiences et ritualité de l'interaction. Du corps exclu à l'éducation corporelle [Deficiencies and the Rituality of Interaction: From the Excluded Body to Bodily Education]. *Revue Eduquer-Binet Simon* 11: 47-60. Retrieved 6 February 2013 from http://rechercheseducations.revues.org/index387.html

Marcellini, A., De Lesceleuc, E., & Le Roux, N. (2008). Vivre en fauteuil roulant : Aspects symboliques [Living in a Wheelchair: Symbolic Aspects]. In *Le fauteuil roulant* [The Wheelchair], edited by J.-F. Ravaud, F. Lofaso, and F.-X. Lepoutre, 123-133. Paris : Frison-Roche.

Moliner, P. (1989). Validation expérimentale de l'hypothèse du noyau central des représentations sociales. *Bulletin de psychologie, 41,* 759-762.

Moliner, P. (1993). L'induction par scenario ambigu. Une méthode pour l'étude des représentations sociales [Induction by Ambiguous Scenario. A Method for Studying Social Representations]. *Revue internationale de psychologie sociale, 2,* 7-21.

Moliner, P. (2002). Ambiguous scenario and attribute challenge techniques. Social Representations of "The Firm" and "The nurse". *European Revue of Applied Psychology,* 3-4, 273-280.

Moliner, P., & Vidal, J. (2003). Stéréotype de la catégorisation et noyau de la représentation. *Revue Internationale de Psychologie Sociale, 1,* 157-176.

Morvan, J.-S. (1988). *Représentations des situations de handicap et d'inadaptations chez les éducateurs spécialisés, les assistants de service social et les enseignants spécialisés en formation* [Representations of Situations of Disability and Inadaptation Among Specialist Youth Workers, Social Workers and Trainee Specialist Teachers]. Paris : CTNERHI-MIRE.

Moses, T. (2010). Being Treated Differently: Stigma Experiences With Family, Peers, and School Staff among

Adolescents with Mental Health Disorders. *Social Science & Medicine, 70,* 985-993.

PACE, J. E., SHIN, M., & RASMUSSEN, S. A. (2010). Understanding Attitudes toward People with Down Syndrome. *American Journal of Medical Genetics, 152*(A), 2185-2192. doi:10.1002/ajmg.a.33595

RATEAU, P. (2000). Idéologie, représentation sociale et attitude : Étude expérimentale de leur hiérarchie [Ideology, Social Representation and Attitude: Experimental Study of their Hierarchy]. *Revue Internationale de Psychologie Sociale, 13*(1), 29-57.

RAVAUD, J.-F., BEAUFILS, B., & PAICHELER, H. (1986). Handicap et intégration scolaire : inflation des stéréotypes et valse des étiquettes. *Sciences Sociales et Santé, 4,*167-194.

REINA, R., LÓPEZ, V., JIMÉNEZ, M., GARCÍA-CALVO, T., & HUTZLER, Y. (2011). Effects of Awareness Interventions on Children's Attitudes toward Peers with a Visual Impairment. *International Journal of Rehabilitation Research, 34,* 243-248.

ROBERTSON, K., CHAMBERLAIN, B., & KASARI, C. (2003). General Education Teachers' Relationship with Included Students with Autism. *Journal of Autism and Developmental Disorders, 33,* 123-130.

ROHMER, O., & LOUVET, E. (2009). Describing Persons with Disability: Salience of Disability, Gender and Ethnicity. *Rehabilitation Psychology, 54,* 76-82. Doi:10.1037/a0014 445

ROHMER, O., & LOUVET, E. (2011). Le stéréotype des personnes handicapées en fonction de la nature de la déficience. Une application des modèles de la bi-dimensionnalité du jugement social [Stereotypes of Persons with Disabilities According to the Nature of the Deficiency. An Application of Social Judgment Bidimensionality Models]. *L'année psychologique, 111,* 69-85. Doi:10.4074/S0003 503311001035

ROUQUETTE, M. L., & RATEAU, P. (1998). *Introduction à l'étude des représentations sociales* [Introduction to the Study of Social Representations]. Grenoble : PUG.

SAILLANT, F., & FOUGEYROLLAS, P. (2007). L'icône du handicap [The Disability Icon]. *Reliance, 25,* 81-87. doi:10.39 17/reli.025.0081

SCHWARTZ, C., & ARMONY-SIVAN, R. (2001). Students' Attitudes to the Inclusion of People with Disabilities in the Community. *Disability & Society, 16,* 403-413. Doi:10.10 80/09687590120045978

SENTENAC, M., GAVIN, A., ARNAUD, C., MOLCHO, M., GODEAU, E., & GABHAINN, S. (2011). Victims of Bullying Among Students With a Disability or Chronic Illness and Their Peers: A Cross-National Study Between Ireland and France. *Journal of Adolescent Health, 48,* 461-466.

SKAR, L. (2003). Peer and Adult Relationships of Adolescents with Disabilities. *Journal of Adolescence, 26,* 635-649.

STEWART, C. 1990. Effect of Practice Types in Preservice Adapted Physical Education Curriculum on Attitudes toward Disabled Populations. *Journal of Teaching in Physical Education, 10,* 76-83.

TAFANI, E., & SOUCHET, L. (2001). Changement d'attitude et dynamique représentationnelle [Attitude Change and Representational Dynamics]. In *La dynamique des représentations sociales* [The Dynamics of Social Representations], edited by P. Moliner, 59-88. Grenoble : PUG.

TRINGO, J. L. (1970). The hierarchy of preference toward disability groups. *Journal of Special Education, 4 ,* 295-306.

VERGÈS, P. (1994). Approche du noyau central : Propriétés quantitatives et structurales [Approaching the Central Core: Quantitative and Structural Properties]. In *Structures et transformations des représentations sociales* [Structures and Transformations of Social Representations], edited by C. Guimelli, 233-254. Paris : Delachaux et Niestlé.

VIGNES, C. (2009). *CREATIVE : Étude d'intervention sur les attitudes des élèves envers leurs pairs en situation de handicap* [Study of an Intervention on Pupils' Attitudes Towards Peers With Disabilities]. Doctoral thesis. Paul Sabatier University, Toulouse.

WALKER, J. S., COLEMAN, D., LEE, J., SQUIRE, P. N., & FRIESEN, B. J. (2008). Children's Stigmatization of Childhood Depression and ADHD: Magnitude and Demographic Variation in a National Sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47,* 912-920.

WATSON, N. (2002). Well, I Know This is going to Sound Very Strange to You, But I Don't See Myself as a Disabled Person: Identity and Disability. *Disability & Society 17,* 509-527. Doi: 10.1080/09687590220148496

WEBER, R., & CROCKER, J. (1983). Cognitive processes in the revision of stereotypic beliefs. *Journal of Personality and Social Psychology, 45,* 961-977.

WISELY, D. W., & MORGAN, S. B. (1981). Children's ratings of peers presented as mentally retarded and physically handicapped. *American Journal of Mental Deficiency, 86,* 281-286.

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Active Involvement of People with Disabilities in Education: A Literature Review*

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Abstract

In recent years, a growing number of educational initiatives designed for current and future professionals have sought the active involvement of patients and users. Recent reviews have explored different aspects of these initiatives. However, they do not distinguish between the involvement of people with disabilities and that of other users. This review describes the main features of educational initiatives in the fields of education, health and social sciences that actively seek the involvement of people with disabilities. Our systematic approach identified 20 projects. We analyzed their nature, the actors involved, and their documented outcomes. This review shows that to improve professional practice and the quality of services given to people with disabilities, it is important to seek their active participation in educational initiatives targeting learners from a range of disciplines and to use a diversity of teaching strategies. Recommendations to consider when implementing such initiatives are also discussed.

Keywords: disability, education, service user involvement, patient involvement, participation

Résumé

Au cours des dernières années, un nombre grandissant d'initiatives de formation destinées à des professionnels actuels et futurs ont misé sur l'engagement actif des patients ou des usagers. Les recensions des écrits publiées dans les dernières années décrivent différentes composantes de ces initiatives. Or, elles ne permettent pas d'établir de distinctions entre l'engagement de personnes présentant des incapacités et celui d'individus vivant avec une autre condition. Cette recension met en exergue les principales composantes d'initiatives de formation dans le domaine de l'éducation, de la santé et des sciences sociales, qui ont recours à l'engagement actif de personnes présentant des incapacités. Notre approche systémique a favorisé l'identification de 20 projets. Nos analyses nous ont permis de circonscrire leur nature, les acteurs impliqués et leurs retombées. Cette recension met en lumière que l'engagement des personnes ayant des incapacités dans la formation doit se faire en utilisant une diversité de stratégies pédagogiques et viser des apprenants de plusieurs disciplines pour contribuer au développement de pratiques et de services de meilleure qualité. Des recommandations pour implanter de telles initiatives sont aussi proposées.

Mots-clés : incapacité, éducation, formation engagement actif, participation

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Introduction

A growing number of student training and professional development initiatives have sought to have people receiving care and services play a role than the one traditionally ascribed to them: that of passive actor (e.g., simulated patient) or absent witness (e.g., in written case studies or video reports). Today, they now serve as experts who are actively engaged in teaching, curriculum development and assessment (Jha, Quinton, Bekker, & Roberts, 2009; Towle et al., 2010; Towle & Godolphin, 2011, 2013). The popularity of this new form of partnership in education is based on a recognition of their unique expertise, acquired through their experiences of health, illness, disability, or the effects of the social determinants of health (Towle et al., 2010). Recent reviews have explored aspects of patient[1] involvement (ex. practical, theorical) mainly in healthcare professional education (Jha et al., 2009; Morgan & Jones, 2009; Repper & Breeze, 2004; Spencer et al., 2000; Towle et al., 2010; Wykurz & Kelly, 2002). These reviews do not distinguish between the involvement of people with disabilities and other patients. While there are certainly commonalities between these two groups of service users, there are also important differences: people with disabilities often cope with social stigma; they usually require treatments and services throughout their lives; transitions they go through can be challenging; barriers to communication and social interaction can hinder their relationships in various contexts; etc. (World Health Organization [WHO], 2011). Since their needs and experiences are distinct, current and future practitioners have much to learn from them (Iezzoni & Long-Bellil, 2012).

To understand educational initiatives involving people with intellectual, developmental, sensory or physical disabilities, we have conducted a literature review.

Methods

- Design: Literature review method

We conducted a literature review of educational initiatives involving people with disabilities in order to draw useful lessons for guiding similar projects.

- Identification of the research question

The literature review was designed to answer one main question: What are the characteristics of educational initiatives that actively involve people with disabilities and that are intended for current or future professionals in the fields of education, health and social sciences?

- Systematic search of the literature

The papers upon which this review is based were systematically collected as in figure 1. They were found following a comprehensive search in relevant databases in education (ERIC, FRANCIS), social sciences (Social Sciences Full Texts, PsycINFO) and medicine (MEDLINE). We used various combinations of keywords and thesaurus search terms, which have been validated by a research synthesis expert. They were used alone and in combination, and referred to four themes (1) education/teaching/learning; (2) service users/patients; (3) disability; (4) involvement/partnership.

- Systematic selection of relevant articles: Inclusion and exclusion criteria

We prioritised the papers that referred to any educational initiative that sought active involvement of people with disabilities, as reported in peer-reviewed scholarly papers and grey literature. The following criteria, presented at Table 1, were applied to identify papers in scope.

- Collection and mapping of the data

The data was extracted from 19 texts and organized in a table. The extraction criteria were

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[1] Some authors use the term ‘patient’, for the sake of brevity, to include people receiving healthcare, their carers (including parents and families) and healthy people (eg: community members, lay people, etc.). Towle et al. (2010) believe that the term “patient” may seem controversial, but no single alternative seems more acceptable.

broken down into three main categories: (A) educational initiatives, (B) people actively engaged, and (C) outcomes. Subcategories are presented in Table 2 below.

FIGURE 1: SYSTEMATIC SEARCH OF THE LITERATURE

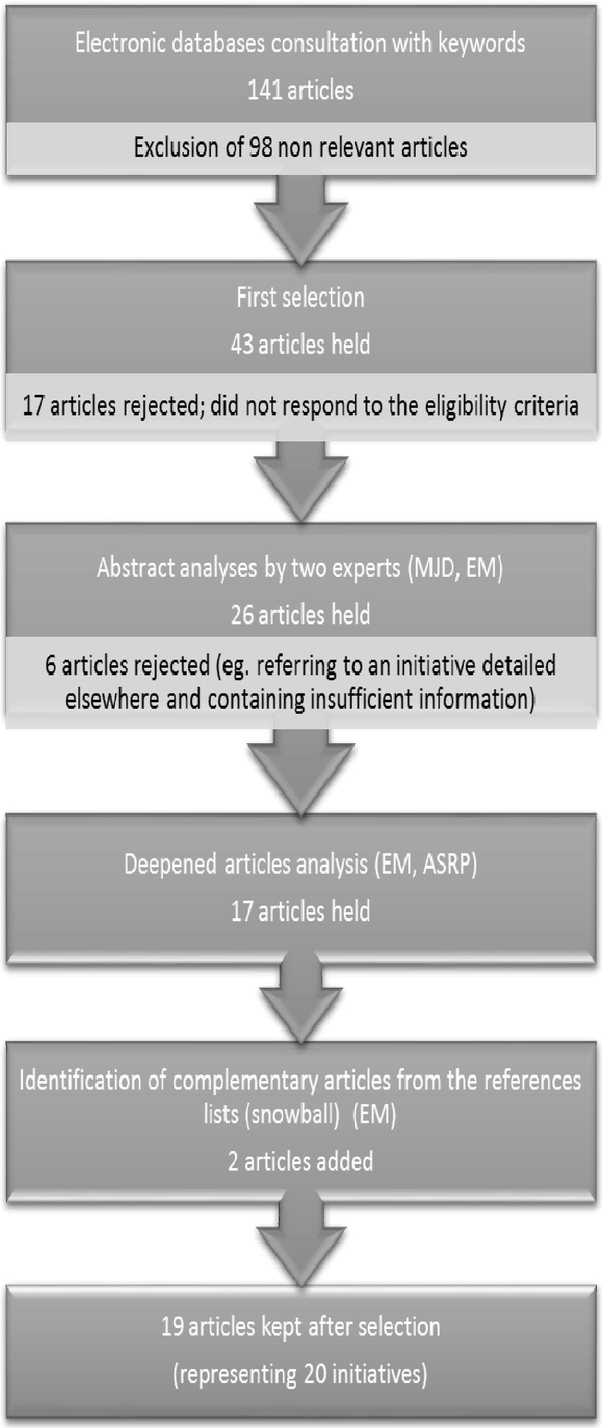

TABLE 1: INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria	**Papers must:** • Refer to people with disabilities actively engaged in teaching or in an educational role; • Refer to undergraduate or graduate learners or practitioners of any educational, social or healthcare professions; • Have been published since 2000; • Are written in English or French.
Exclusion criteria	**Papers must not:** • Refer to mental health service users actively engaged in teaching or in an educational role; • Refer to a discussion on the topic (ex. opinion paper); • Be a conference abstract.

- Collating, summarizing, and reporting results

The educational initiative itself is the unit of analysis. In the case of the text describing three initiatives (Jorgenson, Bates, Frechette, Sonnenmeier, & Curtin, 2011), each one was analyzed separately. Only the initiative involving people with disabilities in the article by Novak, Murray, Scheuermann, & Curran (2009) was examined. Fifteen other texts each described a single initiative, and the last text (Towle et al., 2014) described an activity as part of an an overall report (The Social Planning and Research Council of BC [TSPRCBC], 2011). Therefore, we referred mainly to the text by Towle et al. (2014) to understand this initiative.

The results are presented in three parts, based on the extraction criteria above. The first part, discusses the initiatives' distinctive characteristics, learners, objectives, reference frameworks, and teaching strategies. The second part, concerns the people with disabilities, their characteristics, the recruitment methods, their preparatory training, and the distinctive aspects of their involvement. The third part concerns the initiatives' outcomes, the obstacles encountered, the facilitators, and the recommendations proposed by the authors of the texts.

TABLE 2: EXTRACTION CRITERIA

Criteria	Subcategory
(A) Educational initiatives	A.1) Format (e.g., number of hours, session frequency, etc.) A.2) Learners targeted A.3) Objectives of the educational initiative A.4) Reference framework(s) underlying the initiative A.5) Teaching or learning strategies used
(B) People actively engaged	B.1) Characteristics of the population involved (e.g.: age, number, types of disabilities, etc.) B.2) Criteria used to select participants B.3) Recruitment methods B.4) Participants' degree of involvement
(C) Outcomes	B.1) Outcomes B.2) Obstacles encountered B.3) Recommendations

Results

1. Educational initiatives

1.1 An overview

Four **large-scale interventions** include the creation of a national framework for nurse education (Mathieson, 2002), an undergraduate intellectual disabilities[2] nursing program (Bollard, Lahiff, & Parkes, 2012), and two extended interdisciplinary learning experiences (Doucet, Andrews, Godden-Webster, Lauckner, & Nasser, 2012; Towle et al., 2014).

In five other initiatives, people with disabilities were involved in **university courses** of a semester or more. Two were integrated within an undergraduate program (Muwana & Gaffney, 2010; Sadao & Robinson, 2002) and another, within a graduate program (Jorgensen et al., 2011). Two others were offered within the context of an advanced certification (Jorgensen et al., 2011). While four of these initiatives used interactive and innovative in-class co-teaching methods, the fifth relied heavily on partnerships with four community disability agencies (Muwana & Gaffney, 2010). Students were called upon to collaborate with these partners on and off campus.

Finally, eleven initiatives consisted of **brief interventions** (e.g., workshops) within a larger educational or professional setting. Of these, seven involved a single, interactive on-campus session within an undergraduate, (Maestri-Banks, 2013; McClimens & Scott, 2007; Tracy & Iacono, 2008; Zirkle et al., 2008) graduate (Terry, 2012) or postgraduate professional development program (Heneage, Morris, & Dhanjal, 2010; Martin & Hoy, 2013; Terry, 2012). Four other initiatives were spread out over two or more sessions on campus (Kroll, Groah, Gilmore, & Neri, 2008) or off-campus (Novak et al., 2009; Siebens et al., 2004; Smith, Anderson, & Thorpe, 2006). Community groups (e.g., a theatre group comprising people with disabilities) or agencies (e.g., local clinics, hospitals) were directly involved in three of these initiatives (McClimens & Scott, 2007; Novak et al., 2009; Smith et al., 2006), while pairing of students with a person with disabilities took place within two of them (Siebens et al., 2004; Smith et al., 2006).

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[2] The terms "learning disabilities," used mainly in the United Kingdom, and "intellectual disabilities" were both chosen by the authors of the selected texts to refer to the same condition. For the sake of consistency, we used the term "intellectual disabilities" in this article.

1.2 Learners targeted

The learners targeted were varied and spanned all levels of post-secondary education. Unfortunately, the number of learners reached is not always specified and varies from one initiative to another.

Ten single discipline designs were aimed at nursing (Bollard et al., 2012; Kroll et al., 2008; Maestri-Banks, 2013; Martin & Hoy, 2013; Mathieson, 2002; McClimens & Scott, 2007; Terry, 2012) or medical (Siebens et al., 2004; Tracy et al., 2008; Zirkle et al., 2008) students or professionals. Most of these were conducted in the United Kingdom. Four other initiatives targeted students or professionals in education (Jorgensen et al., 2011; Muwana & Gaffney, 2010; Novak et al., 2009), while another initiative was geared towards students in rehabilitation/communication (i.e., future speech pathologists) (Jorgensen et al., 2011). All of these were run in the United States. The five remaining initiatives were interdisciplinary (Doucet et al., 2012; Heneage et al., 2010; Sadao & Robinson, 2002; Towle et al., 2014; Smith et al., 2006), including both Canadian initiatives.

1.3 Objectives

All the initiatives had a common objective—to improve professional practice with people with disabilities, and by extension, the quality of care and services offered. However, more specific objectives were also listed or implied by the choice of teaching activities and assessment methods. These objectives, which concern the training environment, knowledge, skills, and learner dispositions, are described in Table 3 below.

1.4 Reference frameworks and teaching or learning strategies

Three primary frameworks emerge from our analysis: person- or community-focused, experiential and interprofessional education. In addition, three secondary frameworks have been identified: service learning, intergroup contact theory, and reflective practice. Teaching strategies are chosen in light of these frameworks.

Sixteen initiatives referred to **person- or community-focused learning** and/or practice. The most prevalent person-focused teaching strategies include collaborative teaching (an educator and a person with disabilities teach conjointly) (Heneage et al., 2010; Jorgensen et al., 2011; Kroll et al., 2008; Martin & Hoy, 2013), mentoring (pairing of students with a person with disabilities) (Doucet et al., 2012; Siebens et al., 2004; Smith et al., 2006; TSPRCBC, 2011), and inviting guest speakers to share their experiences and knowledge (Terry, 2012; TSPRCBC, 2011; Zirkle et al., 2008).

Among the four remaining initiatives, two of them make extensive use of the **service learning** approach, which combines community service with academic studies (Muwana & Gaffney, 2010; Novak et al, 2009). While **experiential learning** is extensively implied in these two service learning initiatives, it is alluded to in three others (Kroll et al., 2008; Tracy et al., 2008; Siebens et al., 2004). Experiential learning is based on the assumption that students learn through personal experience. In addition to mentoring and community service learning, project-based learning (Sadao & Robinson, 2002; Smith et al., 2006), as well as action learning (Kroll et al., 2008; McClimens & Scott, 2007; Tracy & Iacono, 2008) are popular experiential learning/teaching strategies. Much like service learning, **intergroup contact theory**, which postulates that learning occurs when different groups interact with one another, is mentioned in two initiatives (Heneage et al., 2010; Tracy & Iacono, 2008). Furthermore, **interprofessional education**, which promotes learning through collaboration between students from various fields of study, is discussed in three initiatives (Doucet et al., 2012; Smith et al., 2006; TSPRCBC, 2011). Lastly, while only two initiatives wove **reflective practice** theory into their framework (Doucet et al., 2012; McClimens & Scott, 2007), a total of five incorporated an explicit self-reflection component (e.g., journaling), which encourages students to examine their experiences, attitudes, and behaviours (Doucet et al., 2012; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Towle et al., 2014). Similarly, implicit self-reflection opportunities (e.g., oral debrief

TABLE 3: OBJECTIVES

Type of objective	Description	Number of Initiatives
Training environment	General objectives related mainly to the explicit desire to improve the quality and relevance of the training provided, especially by establishing durable partnerships and conducting learning activities to prepare students for practice	5[3]
Knowledge development	Concern the acquisition of evidence-based theoretical and factual knowledge (definitions, diagnostics, etiology, and assessment methods)	14[4]
Skills development	Refer to the acquisition of practical knowledge (e.g., mastering person-focused interprofessional team work, adopting a reflective approach, etc.)	15[5]
Dispositions	Aim to shape learners' attitudes through awareness activities to help them develop new insights and challenge their own attitudes (e.g., foster empathy)	15[6]

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[3] (Bollard et al., 2012; Mathieson, 2002; McClimens & Scott, 2007; Terry, 2012; TSPRCBC, 2011)

[4] (Bollard et al., 2012; Doucet et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Kroll et al., 2008; Muwana & Gaffney, 2010; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; Tracy et al., 2008; Towle et al., 2014; Zirkle et al., 2008)

[5] (Bollard et al., 2012; Doucet et al., 2012; Jorgensen et al., 2011; Kroll et al., 2008; Martin & Hoy, 2013; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; Tracy & Ianoco, 2008; Towle et al., 2014)

[6] (Bollard et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Kroll et al., 2008; Maestri-Banks, 2013; Martin & Hoy, 2013; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Smith et al., 2006; Siebens et al., 2004; Terry, 2012; Towle et al., 2014; Tracy & Ianoco, 2008; Zirkle et al., 2008).

ing sessions or ongoing post-intervention online conversation) were built into two other initiatives (Martin & Hoy, 2013; Terry, 2012).

2. Actors Involved

2.1 Characteristics

Fifteen of twenty initiatives sought the active involvement of people with disabilities.[7] Only one project involved high school students (Novak et al., 2009). In the other five the active participation of individuals with knowledge of particular disabilities (e.g., representatives of community organizations) were also used, although the focus was on the expertise of the individuals with disabilities.

Of the initiatives where the type of disability is mentioned, five referred to people with physical disabilities (Jorgensen et al., 2011; Kroll et al., 2008; Sieben et al., 2004; Terry, 2012; Zirkle et al., 2008) and five sought the participation of people with intellectual disabilities (Bollard et al., 2012; Heneage et al., 2010; Maestri-Banks, 2013; Mathieson, 2002; Tracy & Iacono, 2008) or autism spectrum disorder (Jorgensen et al., 2011).

Of the five initiatives that sought the involvement of individuals with knowledge of specific disabilities, three referred to family members (Jorgensen et al., 2011; Muwana & Gaffney, 2010; Sadao & Robinson, 2002) and two to informal caregivers (Martin & Hoy, 2013; Smith et al., 2006). The initiative of Muwana and Gaffney (2010) also refers to the participation of six representatives of community organizations, including two with disabilities, as well as that of professionals and family members.

2.2 Recruitment and selection

Nine of twenty initiatives synthesized discussed how people with disabilities were recruited and selected, which depended mainly on the training environment (e.g., type of institution, number of learners). They also described the type of disability sought (e.g., physical vs. intellectual), which varied according to the learners' needs. In five initiatives, people with disabilities were selected based on their community involvement or membership in a community organization (Heneage et al., 2010; Siebens et al., 2004; Towle et al., 2004; Tracy & Iacono, 2008; Zirke et al., 2008). They were described as having knowledge about their condition or a certain expertise acquired through contact with health professionals. In three initiatives (Kroll et al., 2008; Terry, 2012; Towle et al., 2004), the people recruited had to be able to articulately convey their expertise and experience in public. Selecting these participants involved judgement and an aptitude for the type of teaching/communication required.

2.3 Preparation and training

Five of the twenty initiatives that involved people with disabilities mentioned that tangible resources (e.g., technological support, training manual) (Jorgensen et al., 2011; Kroll et al., 2008) or training was offered to make sure they develop the skills needed to fulfill their roles (Bollard et al., 2012; Jorgensen et al., 2011; Kroll et al., 2008).

2.4 Type of involvement

Six types of involvement are described: personal accounts of real life situations, consultation, course development, formal teaching, informal teaching, and assessment (formative or summative).

Personal accounts by individuals with experiential expertise were mainly a matter of sharing personal experiences, particularly with regard to their disabilities, to the adaptations they

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[7] The article by Jorgensen, Bates, Frechette, Sonnenmeier, & Curtin (2011) briefly mentions the involvement of other specially invited people with disabilities, families, or professionals, without describing the nature of their participation (e.g.,active or passive). Since in the case of three initiatives the authors focused mainly on the active participation of four people, we limited our analysis to their contribution. The articles by Mathieson (2002) and Zirkle et al. (2008) also examined the involvement of people with disabilities in initiatives in which other players participated. Since the articles focus on the involvement of people with disabilities, we analyzed only their contribution to the initiatives concerned.

need and to social, educational and medical services they require. In eighteen initiatives, one or more people with disabilities or representatives helped draw up, develop, plan, or organize a project, program, strategy, curriculum, or training environment. Of all the forms of active participation in local initiatives (apart from personal accounts), teaching was the most common: 18 initiatives involved one or more people with disabilities in formal or informal teaching (i.e., arising from interaction with learners). Apart from these types of involvement, the initiative conducted by Bollard et al. (2012) also sought the participation of people with disabilities in marketing and publicizing the training program and hiring teaching staff (recruitment and admission).

3. Outcomes

According to the 17 texts listing outcomes[8], 18 initiatives had positive ones, not only from the learners' perspective, but also in the eyes of people with disabilities, community partners, the proponents of the initiatives, and the authors. They relate to the training environment, acquired knowledge and skills, dispositions, and identity.

The outcomes related to the **training environment** mainly consisted of participant satisfaction with their learning or teaching experience and the scope of the methods used.

With regard to learners, the acquisition of durable **knowledge** is implied or mentioned in 14 of the 17 texts discussing outcomes (Bollard et al., 2012; Doucet et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Martin & Hoy, 2013; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; TSPRCBC, 2011; Towle et al., 2014; Tracy & Iacono, 2008; Zirkle et al., 2008). The knowledge acquired concerned: (a) people with disabilities and their needs; (b) the power relations they must deal with; (c) required adaptations and support; (d) the roles of informal and professional caregivers, (e) available community resources, (f) person-focused practice, (g) the disabilities themselves, and (i) related concepts and theories. In one initiative, representatives of community organizations mentioned having learned more about other community programs (TSPRCBC, 2011). A number of learners acquired new **skills** in the areas of person-focused interprofessional collaboration, partnerships with people with disabilities, teamwork, individual intervention, and reflective practice (Doucet et al., 2012; Heneage et al., 2010; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Smith et al., 2006; Terry, 2012; Towle et al., 2014). Other texts referred to the ability of learners to apply what they learned to their practice (Bollard et al., 2012). With regard to people with disabilities, the authors indicated an improvement in their teaching skills (Jorgensen et al., 2011; TSPRCBC, 2011). The initiative involving teens with disabilities enabled the latter to acquire professional experience and job search skills (Novak et al., 2009).

Outcomes regarding learners' **dispositions** refer more specifically to their values, perceptions, and attitudes. Some authors indicate that when the initiatives came to an end, learners were more aware and respectful of people with disabilities' expertise and conscious and critical of their own assumptions and stereotypes. The same authors also observed greater empathy, compassion, and openness to others and greater ease in their interactions with people with disabilities (Bollard et al., 2012; Martin & Hoy, 2013; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; Terry, 2012; TSPRCBC, 2011; Towle et al., 2014; Tracy & Iacono, 2008; Zirkle et al., 2008).

Impacts on **identity**, or how participants felt about themselves, are also measured as outcomes. This included of a feeling of confidence and professional competence (Heneage et al., 2010; Novak et al., 2009; Towle et al., 2014; Zirkle et al., 2008). In participants with disabilities, they refer to a greater sense of confi-

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[8] Outcomes were not listed in the texts by Maestri-Banks (2013) and Mathieson (2002).

dence, pride, self-worth, liberation, empowerment and accomplishment (Bollard et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Smith et al., 2006; Terry, 2012; Towle et al., 2014; TSPRCBC, 2011).

4. Obstacles

Eight initiatives listed the obstacles encountered, including individual, logistical and financial. The **individual** obstacles concerned mainly people with disabilities, especially with regard to their selection (e.g., ensuring that a range of disabilities was represented, finding people who were articulate and available, etc.) (Terry, 2012) or to their level of confidence (e.g., first encounter with learners, insecurities about the quality and benefits of their involvement, etc.) (Towle et al., 2014).

The main **logistical** obstacles related to transportation (e.g., travel time and cost), technology (e.g., people unfamiliar with technology), time management (e.g., heavy workload outside class time, preparation of clinical sites, etc.), and scheduling (Jorgensen et al., 2011; Muwana & Gaffney, 2010; Smith et al., 2006; Terry, 2012).

The active involvement of people with disabilities requires prior consultation, ongoing collaboration with external resources, and a longer preparation period, which increases costs and the necessary organizational investment, thus potentially undermining the feasibility of this type of initiative (Bollard et al., 2012).

5. Facilitating factors and recommendations

The texts identified facilitating factors and recommendations in favour of conducting similar initiatives. They mainly refer to the active involvement of people with disabilities, reference frameworks and teaching/ learning strategies.

5.1 Involvement of people with disabilities

It is generally recommended that people with disabilities be involved, or more involved, in training of current or future professionals, in order to enrich the learning experience. This approach tends to involve learners emotionally and spur their interest in issues and resources that can affect the quality of care and services available to people with disabilities (Zirkle et al., 2008). However, to maximize the impact of this involvement and ensure a positive experience for all, certain conditions must be met. For example, it is better to recruit individuals who are capable of self-reflection and have appropriate personal and/or professional expertise with respect to the material to be conveyed, as well as the teaching skills required to convey it. It is also recommended that teaching tasks be assigned based on their skills, interests, and personal aspirations.

To ensure that people with disabilities are considered by all as partners in the initiative, proponents should: (a) make sure that everyone has a hand in planning, teaching, and assessment; (b) check to what extent people with disabilities wish to participate in the transfer of scientific knowledge and adapt their involvement accordingly; (c) assign tasks, set the number of sessions, and explore the possibility of future collaboration in advance; (d) agree on a vision of the initiative and its objectives and clearly conveyed to learners; (e) insist on the complementary nature of professional and experiential expertise to learners throughout the initiative (Bollard et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Maestri-Banks, 2013; Martin & Hoy, 2013; Sadao & Robinson, 2002). Issues of confidentiality as well as copyright and subsequent use of written documents or videos must be negotiated before the initiative begins (Terry, 2012).

Regardless of the level of involvement of people with disabilities, it is important to make sure that they are suitably prepared for their assigned tasks. Initiative proponents must therefore: (a) offer training in line with individual needs (organization’s policies, discursive norms in the classroom, assessment, scientific knowledge, or use of online platforms and software applications); (b) provide the required material resources (e.g., ICT equipment, software); (c) make sure that the place where the initiative is carried out is accessible to people with disabilities; (d) plan and implement appropriate support mechanisms when sensitive or stressful issues are raised (Doucet et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Martin & Hoy, 2013). Several authors stressed the importance of tangibly recognizing the contributions people with disabilities make to the training initiative (e.g., financial compensation) (Doucet et al., 2012; Martin & Hoy, 2013; Towle et al., 2014). A means of ongoing communication should be established to inform them of how the initiative is progressing and of new opportunities for getting involved (TSPRCBC, 2011). It was suggested that opportunities for interacting with learners be put in place once an initiative is over so that participants could strengthen the ties they have forged and discuss the outcomes of the initiative if they wished to (TSPRCBC, 2011).

5.2 Reference frameworks and teaching/ learning strategies

The authors champion the involvement of people with disabilities in undergraduate education and professional training initiatives. Some suggest promoting interprofessional teaching and learning (Sadao & Robinson, 2002; Smith et al., 2006; TSPRCBC, 2011), integrating a community service component (Muwana & Gaffney, 2010; Novak et al., 2009), focusing on experiential learning (Zirkle et al., 2008), or using forum theatre (McClimens & Scott, 2007) or the arts in general (TSPRCBC, 2011). All these aspects aim to apply theory to practice. Regardless of the reference framework chosen, all training initiatives should use teaching and learning strategies that are consistent with professional practice (Bollard et al, 2012).

During team activities, initiative proponents should play a secondary role or act as mediators with learners, or between experiential experts and learners, in order to raise awareness of the etiquette of communicating with people with disabilities, facilitate communication, support learning, and intervene as needed (Muwana & Gaffney, 2010; Siebens et al., 2004; Towle et al., 2014). They also must clearly understand and use various ways to help learners and other participants feel comfortable interacting (Terry, 2012).

Discussion

As all the initiatives of this literature revue highlight, active involvement of people with disabilities in education gives rise to the creation of mutual dynamic relationships uniting people receiving care and learners from various fields of study. In doing so, students learn **from** and **with** these people, instead of just learning **about** them from a teacher who has a theoretical comprehension of their reality (Bleakley & Bligh, 2008). Towle and Godolphin (2011, p. 500) believe that “patient-led education sends an important message to students about the value of patients’ expertise […] in which professionals and patients are ‘co-producers of health’”. Experiential experts can share what they consider to be important that future professionals learn, paving the path towards true person-centered care and services. Moreover, putting the person at the center of an educational intervention creates quite a different learning environment and inevitably brings with it a shift in power, role and meaning from the relationship between current or future professionals and people receiving services, in a way that maintains their authentic and autonomous voice (Bleakley & Bligh, 2008).

However, in order for this shift in power, role and meaning to truly occur, all kinds of people with all types of disabilities and from various ethnic and cultural backgrounds should be perceived as potential equal partners (with the help of their carers or family members if needed). For example, while it is understandable that initiative developers aspire to recruit guest lecturers or trainers who are experienced and/ or gifted in articulate public speaking and teaching, there is a risk of reinforcing a socially constructed dichotomy between people who have so-called acceptable or relatable disabilities versus people whose disabilities are seen as overly disruptive of social interaction norms and communication protocols. Because people with disabilities are people first and foremost with an array of distinct characteristics, practitioners must be made aware of the subtleties experienced by those whose identities are subject to the forces of oppression inhabiting intersections of gender, sexual orientation, class, ethnicity, and so on (Yuval-Davis, 2006). It is rather encouraged to work with a wide range of people with disabilities, with respect to their potential, in order to avoid perpetuating negative social perceptions, ignorance-based discomfort and inequalities.

With the notion of equal partnership comes that of equitable involvement and compensation. If we are to include people with disabilities in the education of students and professionals, we must create the conditions and opportunities within which they may contribute further to all aspects of said education: consultation, planning, marketing and publicity, student admissions, hiring of staff, teaching and evaluation. However, this literature review has pointed out that of all active involvement strategies, giving personal accounts of real life situation and teaching remain the most popular. Likewise, recruiting, selecting and soliciting people's expertise in training should always be accompanied by offering them appropriate compensation. Payment for involvement, for example, is sometimes associated with increased formal recognition and status. While certain people prefer other forms of compensation (ex. co-writing an article and being published, presenting at a conference, etc.) (Towle & Godolphin, 2013) they should still be given a choice in the matter.

Finally, it is recommended in most of the initiatives in this study that public and institutional educational policies be reviewed in order to support the active involvement of people with disabilities in large-scale training initiatives. While small-scale initiatives can be beneficial to learners, national and institutional championing of large-scale initiatives would increase the visibility, credibility, and legitimacy of educational patient/community-professional partnerships, impacting on their ability to boost their resources), ensuring their growth and enhancing their capacity to reach an exponentially greater number of students.

Although our comprehension of the issues discussed in this article stems from a highly rigorous process, we should not overlook the limits of our literature review. Unfortunately, only twenty initiatives fit our selection criteria, which demonstrates the novelty of these initiatives, but limits the scope of our review. This could also be attributed to the diversity of terms used within the literature when speaking of educational initiatives involving people with disabilities. While our research was thorough, we may have missed certain initiatives as a result of this abundance of terminology. Furthermore, certain articles contained scarce information, which made it difficult for us to gain insight on who was involved, how they were involved and how their involvement influenced the learners implicated.

Conclusion

The initiatives studied in this review show that to improve professional practice and the quality of services given to people with disabilities, it is important to seek their active participation in educational initiatives targeting learners from a range of disciplines and using a diversity of teaching strategies. In light of our analysis of these initiatives, however, we believe that more effort should be invested in ensuring that people with disabilities contribute to the entire process of creating educational initiatives, from content selection to learner assessment.

Although we focused on initiatives that actively involved people with disabilities, we recommend a similar review of initiatives involving informal caregivers and family members. We would also like to point out that not all outcomes of the referenced initiatives have been thoroughly evaluated. And for the initiatives that were the subject of research projects, only short-term outcomes were studied. Further research should include longitudinal studies in order to better assess the long-term benefits of such initiatives (Spencer et al., 2011).

Finally, the more we know about what is being done, how it is being done as well as if, how and to what extent it is or isn't beneficial for all those involved, the better equipped we will be as researchers, professors, practitioners and members of an inclusive society to work and evolve side by side with people who have disabilities.

References

Bleakley, A., & Bligh, J. (2008). Students learning from patients: Let's get real in medical education. *Advances in Health Sciences Education*, *13*(1), 89-107. doi: 10.1007/s10459-006-9028-0

Bollard, M., Lahiff, J., & Parkes, N. (2012). Involving people with learning disabilities in Nurse Education: Towards an inclusive approach. *Nurse Education Today, 32*(2), 173-177. doi: 10.1016/j.nedt.2011.10.002

Doucet, S., Andrews, C., Godden-Webster, A. L., Lauckner, H., & Nasser, S. (2012). The Dalhousie Health Mentors Program: Introducing students to collaborative patient/client-centered practice. *Journal of Interprofessional Care, 26*(4), 336-338. doi: 10.3109/13561820.2012.680631

Heneage, C., Morris, D., & Dhanjal, K. (2010). Nothing about us without us: Combining professional knowledge with service user experience in training about mental health and learning disabilities. *Mental Health and Learning Disabilities Research and Practice, 7*(2), 119-129.

Iezzoni, L. I., & Long-Bellil, L. M. (2012). Training physicians about caring for persons with disabilities: "Nothing about us without us!". *Disability and Health Journal, 5*(3), 136-139. doi: 10.1016/j.dhjo.2012.03.003

Jha, V., Quinton, N. D., Bekker, H. L., & Roberts, T. E. (2009). Strategies and interventions for the involvement of real patients in medical education: A systematic review. *Medical Education, 43*(1),10-20. doi: 10.1111/j.1365-2923.2008.03244.x

Jorgensen, C. M., Bates, K., Frechette, A. H., Sonnenmeier, R. M., & Curtin, J. (2011). "Nothing about Us without Us:" Including people with disabilities as teaching partners in university courses. *International Journal of Whole Schooling, 7*(2), 109-126.

Kroll, T., Groah, S., Gilmore, B., & Neri, M. (2008). Consumer-directed teaching of health care professionals involved in the care of people with spinal cord injury: The Consumer-Professional Partnership Program. *Journal of Continuing Education in Nursing, 39*(5), 228-234. doi: 10.3928/00220124-20080501-05

Maestri-Banks, A. (2013). Learning disability, education and empowerment: Learning from individuals who live with a learning disability. *Health and Social Care Education, 2*(1), 21-24. doi: 10.11120/hsce.2013.00022

Martin, D., & Hoy, L. (2013). Service user and carer participation in an endoscopy nursing programme. *British Journal of Nursing, 22*(18), 1051-1055.

Mathieson, A. (2002). The real deal: Involving Scots with learning disabilities in the creation of a national framework for nurse education was a masterstroke. *Learning Disability Practice, 8*(8), 6-7.

McClimens, A., & Scott, R. (2007). Lights, camera, education! The potentials of forum theatre in a learning disability nursing program. *Nurse Education Today, 27*(3), 203-209. doi: 10.1016/j.nedt.2006.04.009

Morgan, A., & Jones, D. (2009). Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: A literature review. *Medical Teacher, 31*(2), 82-95. doi: doi:10.1080/01421590802526946

Muwana, F. C., & Gaffney, J. S. (2010). Service-learning experiences of college freshmen, community partners, and consumers with disabilities. *Teacher Education and Special Education: The Journal of the Teacher Education Division of the Council for Exceptional Children, 34*(1), 21-36. doi: 10.1177/0888406410371354

Novak, J., Murray, M., Scheuermann, A., & Curran, E. (2009). Enhancing the preparation of special educators through service learning: Evidence from two preservice courses. *International Journal of Special Education, 24*(1), 32-44.

Repper, J., & Breeze, J. (2007). User and carer involvement in the training and education of health professionals: A review of the literature. *International Journal of Nursing Studies, 44*(3), 511-519. doi: 10.1016/j.ijnurstu.2006.05.013

Sadao, K., & Robinson, N. B. (2002). Teaching the culture of collaboration: The validity of a case-based, interactive teaching methodology in higher education. Retrieved from http://eric.ed.gov/?id=ED466447

Siebens, H., Cairns, K., Schalick, W. O., Fondulis, D., Corcoran, P., & Bartels, E. (2004). PoWER Program: People with disabilities educating residents. *American Journal of Physical Medicine & Rehabilitation, 83*(3), 203-209. doi: 10.1097/01.phm.0000113407.47657.46

Smith, R., Anderson, L., & Thorpe, L. (2006). SWAP report: Interprofessional Education. Southampton, UK.: Higher Education Academy. Subject Centre for Social Policy and Social Work.

Spencer, J., Blackmore, D., Heard, S., McCrorie, P., McHaffie, D., Scherpbier, A., . . . Southgate, L. (2000). Patient-oriented learning: A review of the role of the patient in the education of medical students. *Medical Education, 34*(10), 851-857. doi: 10.1046/j.1365-2923.2000.00779.x

Spencer, J., Godolphin, W., Karpenko, N., & Towle, A. (2011). *Can patients be teachers? Involving patients and service users in healthcare professionals' education*. Newcastle, UK: The Health Foundation.

Terry, L. M. (2012). Service user involvement in nurse education: a report on using online discussions with a service user to augment his digital story. *Nurse Education Today, 32*(2), 161-166. doi: 10.1016/j.nedt.2011.06.006

The Social Planning and Research Council of BC (TSPRCBC) (2011). An external review of patient and community voices in health professional education: Final report. Retrieved from http://meetingofexperts.org/files/2011/10/PCV-External-Review-Final-report.pdf

Towle, A., Bainbridge, L., Godolphin, W., Katz, A., Kline, C., Lown, B., Madularu, I., Solomon, P., & Thistlethwaite, J. (2010). Active patient involvement in the education of health professionals. *Medical Education, 44*(1), 64-74. doi: 10.1111/j.1365-2923.2009.03530.x

TOWLE, A., & GODOLPHIN, W. (2011). A meeting of experts: The emerging roles of non-professionals in the education of health professionals. *Teaching in Higher Education, 16*(5), 495-504. doi: 10.1080/13562517.2011.570442

TOWLE, A., & GODOLPHIN, W. (2013). Patient involvement in medical education In K. Walsh (Ed.), *The Oxford Textbook of Medical Education* (pp. 311-322). Oxford, UK.: Oxford University Press.

TOWLE, A., BROWN, H., HOFLEY, C., KERSTON, R. P., LYONS, H., & WALSH, C. (2014). The expert patient as teacher: An interprofessional health mentors programme. *The Clinical Teacher, 11*(4), 301-306. doi: 10.1111/tct.12222

TRACY, J., & IACONO, T. (2008). People with developmental disabilities teaching medical students : Does it make a difference? *Journal of Intellectual and Developmental Disability, 33*(4), 345-348. doi: 10.1080/13668250802478633

WORLD HEALTH ORGANIZATION (WHO) (2011). World report on Disability. Retrieved on http://www.who.int/disabilities/world_report/2011/en/

WYKURZ, G., & KELLY, D. (2002). Developing the role of patients as teachers: Literature review. *British Medical Journal, 325*(7368), 818-821. doi: 10.1136/bmj.325.7368.818

YUVAL-DAVIS, N. (2006). Intersectionality and feminist politics. *European Journal of Women's Studies, 13*(3), 193-209. doi: 10.1177/1350506806065752

ZIRKLE, D., WILLIAMS, K., HERZOG, K., SIDELINGER, D., CONNELLY, C., & REZNIK, V. (2008). Incorporating the experiences of youth with traumatic injury into the training of health professionals. *American Journal of Preventive Medicine, 34*(3 Suppl), S62-66. doi: 10.1016/j.amepre.2007.12.012

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Toward a More Balanced Representation of Disability? A Content Analysis of Disability Coverage in the Flemish Print Media

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Abstract: Although the relations between media coverage and the public are complex, the media has a powerful influence on the way 'disability' as a phenomenon is perceived and on the process of attitude formation. Hence, it is important to document the depiction of people with disabilities and the myths and stereotypes perpetuated by media portrayals of persons with disabilities. This paper reports on a quantitative examination of the extent and nature of the coverage of people with disabilities in the print media in Flanders, the Dutch speaking part of Belgium. Seven newspapers and 16 magazines between January 2003 and December 2012 were content-analysed. Key findings include a sorely limited coverage, or even total lack of representation, in certain media sources. The study also discovered interesting correlations between gender, age and type of magazine on the one hand, and the type of disability on the other. Analysis also revealed that print media focuses on certain disabilities. In addition, the results showed that, looking over the ten-year time span, some events have more influence than others on the evolution of the quantity of coverage. The paper concludes with a discussion of these findings and their implications, from the perspective of disability studies and with reference to Cooley's concept of the looking glass self. It is argued that media representation of disability reflects certain broader ideologies and socio-political processes shaped by basic exclusionary social frames. Yet, the media do more than hold up a mirror to basic mindsets and frames. As the media functions as mechanisms for strengthening and entrenching the social order, they transmit hegemonic conceptions and play a significant role in the on-going construction of disability discourses.

Keywords: disability, representation, media, intersections, content-analysis

Résumé : Même si les relations entre la couverture médiatique et le public sont complexes, la presse a une forte influence non seulement sur la façon dont « le handicap » est perçu en tant que tel, mais également sur le processus de développement des comportements. Par conséquent, il importe de documenter la façon dont sont décrites les personnes en situation de handicap ainsi que les mythes et stéréotypes les concernant et comment ceux-ci sont perpétrés par les médias. Cet article présente une analyse quantitative de l'étendue et du caractère de la couverture médiatique concernant les personnes en situation de handicap dans la presse écrite en Flandres, la partie néerlandophone de la Belgique. Les articles de sept quotidiens et de seize magazines datant de janvier 2003 à décembre 2012 ont été soumis à une analyse de leurs contenus. Les résultats principaux soulignent une couverture particulièrement limitée ou même inexistante dans certains médias. L'étude montre une corrélation intéressante entre le genre, l'âge et le type de magazine d'un côté et le type de handicap de l'autre. L'analyse indique également que la presse écrite se concentre sur certains types de handicap. De plus, les résultats montrent que - sur une période de dix ans - certains événements ont davantage d'influence que d'autres sur l'évolution du nombre de sujets couverts. En conclusion, l'article discute ces résultats ainsi que leurs répercussions sur la base de la perspective des études sur le handicap et en se référant au concept de Cooley du « looking glass self ». On y fait valoir que la représentation médiatique du handicap reflète une gamme plus large d'idéologies et de processus socio-politiques façonnés par des discours d'exclusion de base. Pourtant, les médias ne présentent pas seulement un miroir des mentalités et des façons de penser de base. Vu que les médias fonctionnent comme des mécanismes renforçant et ancrant l'ordre social, ils transmettent des conceptions hégémoniques et jouent un rôle significatif dans la discussion sur le handicap en construction permanente.

Mots-clés : handicap, représentation, média, intersections, analyse de contenu

Introduction

The mass media is a useful source of information about current and historical norms and values, public opinions and attitudes on disability. The content itself especially reflects dominant discourses about disability. This is not to say that media content is a mirror image of the realities of disability identities in the social world. The world we inhabit is a world of representation, and constructions of disability have no essential, fixed or true meaning against which coverage and distortion can be measured (Hall, 1997). In line with the intersectional framework, we believe that disability constitutes as sites of fluid construction and creativity rather than determination. Opposed to the great binary aggregate abled/disabled, reality is far more complex and the social world cannot be neatly divided into binary categories (Jacob, Köbsell, & Wollrad, 2010; Raab, 2007). Hence, the media do not just represent the reality that exists *out there*, nor do they simply reproduce or distribute knowledge: they are active producers of knowledge and construct and constitute the very core of our social existence (Kunz & Fleras, 1998) and dominant discourses on disability.

The mass media play a major role not only in reflecting generally held public attitudes and perceptions on disability, but also in shaping them (Auslander & Gold, 1999; Mutz & Soss, 1997). There are, of course, a number of factors other than press coverage that can influence public opinion on a subject such as disability, ranging from personal experience to historical and political views. Media studies suggest a complex relationship between coverage and the public, but there are evident correlations between increased coverage and growing public priorities (McCombs & Shaw, 1972; McLeod, Becker, & Byrnes, 1974). The media not only provide information but also help to create or reinforce ideas about disability and what it means to be human. As Auslander and Gold (1999) state, the media have an influential role in 'news gatekeeping'. Besides, "the amount of media coverage an issue receives is related to the importance placed on that issue by individuals in society, regardless of any measure of the issue's objective importance" (p. 421). Moreover, Siperstein (2003) points out that the public's perception of capabilities of people with a disability have a major influence on their ideas on education and work for people with a disability, and more generally, on the public's perceptions on inclusion and participation in society. Consequently, a correct media representation contributes to the ways in which people think about inclusion.

Taking into account this nuanced and complex view on disability, media and the public, and in line with the United Nations (UN) Convention on the Rights of Persons with Disabilities, which gives explicit attention to the correct representation of people with a disability in the media, we want to introduce this first baseline measure study, as the first of a two part study. The second study will examine the portrayals of people with disabilities by means of a framing analysis.

This first media study is conducted to establish a baseline of disability portrayals in Flemish print media through a quantitative content analysis of magazines and newspapers. During ten years (2003-2012), the portrayals of people with disabilities by seven Flemish newspapers and 16 Flemish magazines were systematically analysed, examining how the media represented people with disabilities. In the work presented here, this study seeks to obtain a baseline measure of disability, gender and age distribution across the different sources of current print media. Because media character portrayals and demographics of people with a disability may influence the publics' perceptions of social reality (Gerbner, Gross, Morgan, & Signorielli, 1994; Shrum, 1999), establishing sound baseline measures of media character demographics is a necessary step in conducting research on representation and perceived social reality. As we do not believe in the existence of a single representation, different print media were analysed, ranging from popular to quality press and from targeted to specific audiences to oriented on specific themes.

Despite the ratification of the UNCRPD in Belgium and the fact that 15% of the population are classified as having a disability (World Report on Disability, 2011), the inclusion and participation of people with a disability in Flanders is among the lowest in Europe (FRA, 2010; Vlaams Ministerie van Onderwijs en Vorming, 2014). As mentioned, a series of factors are assumed to play part in the process of inclusion, however, there is a lack of research into how people with a disability are culturally represented in the Flemish media. The existing content analytical work done on Flemish media has focussed on the representation of social minority groups other than people with disabilities, or solely on the depiction of people with a disability in the television news (Vissers & Hooghe, 2010). A clear underrepresentation and an emphasis on people with physical disabilities were two of the main findings of this last study. Although these studies are important steps in examining media content, there is still much left to discover, including a more basic study of representation. This study here represented was designed to fill this gap and seeks to examine a baseline measure of disability, gender and age distribution in the depiction of persons with disabilities in the print media.

Methodology

This study examined articles on disabilities and people with disabilities published in seven newspapers and sixteen magazines in Flanders, Belgium, over a ten-year time span between 2003 and 2012. All of the issues for this period were surveyed, including each section and article. Data from the newpapers were gathered through Gopress, an electronic news archive that contains all the articles of Flemish newspapers. Because the other media chosen was not included in this online archive, we conducted a manual search in the magazines, collected from the Belgian legal deposit. Although there is a legal requirement that copies of publications need to be submitted to this repository, a small number of copies were missing.

Articles were accepted into the study sample if they included a reference to disability in general, or to a specific disability or chronic illness which incurs disabilities. The selected articles could relate to a broad range of disabilities and conditions which lead to disability, from any cause and at all levels of severity. That reference could appear anywhere in the article: in the headline, text or accompanying image.

Articles were then examined as to the extent of coverage and by the way they related to the year of publication, the demographics and the type of medium (popular newspapers, lifestyle magazines, celebrity and gossip magazines, news and opinion magazines, age-oriented magazines, quality newspapers, other). The coded demographics included gender (men, women, mixed), age (child, adolescent, adult and mixed) and type of disability (non-categorical, acquired -, multiple -, auditory -, intellectual -, physical -, visual impairment, chronic health conditions, autism, behavioural problems, learning problems). Two coders were trained to code the data independently and compare and discuss discrepancies.

Since some periodicals were published daily, some weekly and some monthly or as a quarterly, all study results are weighted in such a way that the data are defined on the same scale. Instead of each article contributing equally to the final result, articles from weekly and monthly magazines contribute more than articles from daily newspapers.

Results

The reading of the seven newspapers and 16 magazines of the period 2003-2012 yielded 14,529 articles containing some mention of disability. The overall amount of articles in these ten years was not countable within this study.

With regard to the evolution of media coverage across time, Table 1 shows that a relatively continual stock of messages including disability can be distinguished in this ten-year time span. The years 2004, 2005, 2006 and 2011 illustrate this constant undercurrent, with a percentage of about 9.5%. This does not mean that disability is fairly represented in the media; this number only shows the percentage of found articles in those years over the total amount of articles containing mentions of disability in the period 2003-2012. The years 2007 (12.68%) and 2003 (12%) are characterised by the largest number of representations of disability, with a 3% increase compared to the undercurrent. This can be explained by the attention on the European Year of People with Disabilities in 2003, the adoption of the Convention on the Rights of Persons with Disabilities by the United Nations at the end of the year 2006 and the European Year of Equal Opportunities for All in 2007. These augmentations fade out relatively quickly. The amount of articles in the years 2009 (10.91%) and 2010 (10.27%) also slightly increased, possibly influenced by the Belgian ratification of the Convention on the Rights of Persons with Disabilities on July 2, 2009. Again, this can be considered as a short-term effect because we see a decrease in representation over the last years of the ten-year time span. In 2012, the representation declines strongly below the undercurrent (7.61%). Despite the influence of events on a political level, other events such as the Special Olympics or Paralympics do not seem to affect the amount of messages in a year.

TABLE 1. THE WEIGHTED DISTRIBUTION OF ARTICLES BY THE YEAR

Year	Percent (%)
2003	12.00
2004	9.52
2005	9.58
2006	9.75
2007	12.68
2008	8.34
2009	10.91
2010	10.27
2011	9.35
2012	7.61
Total	100.00

As shown in Table 2, far more articles about disability are published in the popular press, with popular newspapers (35.01%) the highest, followed by lifestyle magazines (27.27%), and celebrity and gossip magazines (15.95%). The popular press covers a much larger amount of articles about disability (78.23%) than all the other media types combined. Strikingly, only 4.87% of the articles on disability came from quality newspapers. Even the celebrity and gossip magazines score higher (15.95%) than the quality newspapers and news and opinion magazines combined (12.66%).

TABLE 2. THE WEIGHTED DISTRIBUTION OF ARTICLES BY THE TYPE OF MEDIUM FOR THE PERIOD 2003-2012

Type of medium	Percent (%)
Popular newspapers	35.01
Lifestyle magazines	27.27
Celebrity and gossip magazines	15.95
News and opinion magazines	7.79
Age-oriented magazines	6.78
Quality newspapers	4.87
Other	2.32

In line with expectations, the majority of the articles focussed on adults with a disability (70.6%), more than twice the proportion of articles that focussed on children, adolescents or a mix of ages (Table 3). Only in the teen celebrity magazine ('Joepie'), do we see more adolescents than adults with a disability, which seems logical as this magazine mostly targets teenage customers. Remarkably, in some cases children and/or adolescents with a disability remain out of sight, even in children and youth magazines. Also, in news and opinion magazines, children are strongly underrepresented. When we found articles on children with a disability, most of the time they were published in newspapers instead of (weekly or monthly) magazines. The articles on children referred mostly to general disabilities and on individuals with intellectual disabilities, autism, behavioural problems and learning problems, which concerns the created connection between children on the one hand, and learning and education on the other hand. Considering all these facts, the overall focus on adults with a disability in the print media is extremely manifest.

Concerning gender, Table 3 shows us a slight emphasis on male representation (47.94%) compared to the amount of women with a disability in the print media (42.89%). Noteworthy is that articles about physical impairments involve more men, while news about chronic health conditions includes more women. In some newspapers and magazines, there is a strong and unbalanced focus on men with disabilities (like in 'De Tijd', 'P-Magazine', Glam*It, 'Flair'). In two of the cases, this was expected because this media focuses on a male audience or is economically oriented. In other – mostly female orientated – media we found slightly more women with disabilities than men (like in 'Joepie', 'Story', 'Goed Gevoel', 'Libelle', 'Dag Allemaal', 'Klap').

TABLE 3. THE WEIGHTED DISTRIBUTION OF ARTICLES BY AGE AND GENDER FOR THE PERIOD 2003-2012

Variable	Percent (%)
Age:	
Child	16.11
Adolescent	8.29
Adult	70.60
Mixed	5.01
Gender:	
Men	47.94
Women	42.89
Mixed	9.18

In most cases, articles are non-categorical, focussing on general disabilities and not on specific identified groups or individuals with disabilities. As expected, these general announcements are peculiar in newspapers, as newspapers intend to bring general information to the public and keep people well-informed on important events. When concerning the most frequently depicted disability, most prevalent, by far, were articles that dealt with physical impairments (28.8%). The popular male magazine 'P-magazine' leads this physical oriented tendency. The second most frequent depicted disabilities were intellectual disabilities (22.4%) and chronic health conditions (19.3%). Remarkable is that articles focussing on people with intellectual disabilities appear almost only in newspapers. Auditory impairments, autism, visual impairments, behavioural and learning problems are clearly underrepresented in our sample (under 9%). Articles on behavioural problems are more common in lifestyle magazines, while articles on visual impairments can be found mostly in the only religious magazine ('Kerk en Leven') we analysed. Across time, no meaningful trends concerning types of disability in the media can be observed.

Discussion

- Lack of representation

A first striking finding from this study is the **sorely limited coverage, or even total lack of representation**, of certain persons with disabilities in some Flemish print media sources. For example, children and/or adolescents with a disability remain out of sight in certain children and youth magazines. For the young readership of these magazines, children and/or adolescents with a disability are virtually nonexistent. Even though the Flemish government has pointed to the importance of the correct representation of people with a disability in the media and despite the substantial difference with the number of children and/or adolescents with a disability in the real world population, this group remains close to being invisible.

This finding mirrors the reality that **children with and without disabilities share few or even no collective activities**, notwithstanding Belgium agreed to develop a more inclusive system with the ratification of the UN Convention on the Rights of Persons with a Disability (2006). Flanders in Belgium still has an extensive network of segregated services and special schools for children with a disability (Vlaams Ministerie van Onderwijs en Vorming, 2014). In this dual educational system, there are very few opportunities and support for children with special needs in the mainstream educational system and society. With the highest percentage of students in segregated special schools in the European Union, Flanders has opted more than other countries for segregated settings in education: 5.2% of the total student population attends special education (NESSE, 2012). This tradition of exclusion in education is also visible in our manner of representing children with disabilities in the media.

These findings on the lack of coverage of people with a disability in the media endorse previous international works (Donaldson, 1981; Henderson & Heinz-Knowles, 2003; Saito & Ishiyama, 2005) and reflect that people with disabilities continue to be strongly underrepresented in the media, which adds to the notion that people with disabilities are not fully part of society. This clear underrepresentation falsely implies that people without disabilities are the standard and impedes the struggle of people with a disability for position in social space.

- *Evolution of coverage*

When examining what influences the quantity of disability coverage in the print media, it can be stated that, looking over the long-term span from 2003-2012, **political events might have a clear influence, based on the bigger amount of articles and the date of publication**. In particular, this concerns the adopting and ratification of the UN Convention on the Rights of Persons with Disabilities and the European Year of People with Disabilities. Unfortunately, these effects are short-term as the amount of articles on disability recede the year following the event, despite the persistent number of human rights abuses and discrimination towards people with a disability in Flanders (Belgian Disability Forum, 2014; Hardonk et al., 2013). Looking at other big events that could possibly have an influence on the quantity of coverage of disability in the print media, such as the Paralympics or Special Olympics, no clear connection can be observed. This finding can be connected to earlier research claiming that the coverage of the Paralympics and Paralympians is minimal (Tynedal & Wolbring, 2013; Schantz & Gilbert, 2001) and reflects the invisibility of people with a disability more generally in our media.

- *Disability coverage*

What strongly determines the representation of certain groups of persons with disabilities is the degree of **visibility**. Print media rarely depict people with certain disabilities, focussing instead on people with **physical, intellectual and chronic health conditions**. This might be a result of the inherent nature of print media as the medium requires visual images. For example, auditory impairments, autism, visual impairments, behavioural and learning problems are regarded as relatively difficult to portray. In contrast, people with physical, intellectual or chronic health conditions are much easier to depict and dramatise (cf. Haller & Ralph, 2001; Saito & Ishiyama, 2010). The emphasis on people with physical impairments confirms earlier studies (Auslander & Gold, 1999; Haller & Ralph, 2001; Saito & Ishiyama, 2005), which is not surprising in light of the importance of images in print journalism. Besides, since no clear evolution can be observed in the quantity of articles of certain groups of persons with disabilities over time, it can be presumed that categorical **lobby groups** have no clear influence on the amount of articles in the print media concerning the group of people they represent.

- *Looking Glass Self*

In line with other important findings of this research, such as the higher prevalence of found articles in the popular press, the interesting correlations between gender, age and type of magazine on the one hand, and the type of disability on the other, we can interpret the media as a **Looking Glass Self.** This concept was coined by Cooley in 1902, pointing out how our self-image is shaped by society. The Looking Glass Self has been the dominant metaphor in sociology for the development of self-conception. Cooley argued that our self-concepts are formed as reflections of the responses and evaluations of others in our environment. Interpreting our findings, we can argue that media can also be compared to a Looking Glass, shaped by assumptions in society and reflecting underlying societal opinions and traditional power relations. Nevertheless, a right balance must be found between the idea of the media using intentional media strategies and the idea of the media mirroring societal assumptions. Without wanting a unilateral focus on media as a reflection of society, but as well as being an influence on it, and without forgetting the impact of social and citizen media, the concept of the Looking Glass gives us the possibility to interpret some findings on a more abstract theoretical level.

- Type of medium

First, an important and remarkable finding of this study is that far more articles about people with disabilities come from the **popular press**. In quality newspapers and news and opinion magazines, a great lack of coverage of people with a disability and disability related themes is detected.

The higher prevalence of messages about people with disabilities in the popular media indicates in a painful way that **people with disabilities are positioned more in the lower educated target audience of these media**, which reflects powerful underlying societal relations and distributions. In particular, the finding reveals the poignant looking glass of the educational barriers that persons with a disability have and their limited connection with the social world of higher educated people. These limited educational opportunities and disparities in education for people with a disability have been ongoing for generations (Vlaams Ministerie van Onderwijs en Vorming, 2014; World Health Organization, 2011).

Moreover, this result is striking as quality media attempts to be diverse and politically correct, reporting on social exclusion and diversity, whilst concerning disability, they fail to cover an adequate representation of it.

The higher amount of articles about people with disabilities in the popular media can be explained by the fact that popular media, in particular, cover more local and personal information and news. People's lived stories and individual accounts of experience are mainly provisioned in popular journalism, as these media emphasise the particular and personal experiences of individuals at the expense of relating those particularities to more general institutional and structural processes (Sparks & Tulloch, 2000). Although today some shifts in thinking about disability can be tracked, **disability remains peripheral** to the larger political agenda. This can be illustrated by the sidelined and unclear position of disability in the Flemish Government's policy documents (Gatz, 2014; Homans, 2014). Disability is often seen as a matter of a singular personal experience, not relevant to the social and political debate. Recently, disability is increasingly being addressed within a broader human rights context, also in the media, for example by the reporting on the waiting lists for support for people with disabilities. However, disability is situated more within the local agenda than within a larger discourse in respect of human rights. Hence, disability is mainly covered in local popular media, as it is unfortunately not yet embedded in a broadened political discourse on disability in terms of rights and inclusion. The media misses the bigger picture on disability, which is in line with reporting on more general social issues in quality press.

In addition, disability coverage in popular press can be explained by the general prevailing **melodramatic framework** of this media, because of its emphasis on human drama, emotions, scandal and personalities. Their concern is to bring news and reach the public by using and evoking emotions, and people with disabilities can be qualified as perfectly fitting this frame. This eliciting of emotions in portraying characters with a disability in the media is in line with findings in qualitative research (Haller, 2010; Ellis & Goggin, 2015) where the following dominant stereotypes are detected: the supercrip, the victim, the maladjusted burden, and the evil threat (Nelson, 1996), which add up to a spectacle of otherness, and evoke emotions of pity or admiration (cf. Hayes & Black, 2003).

- Gender

Second, another surprising result is that **media about physical impairments involve more men, while reports about chronic health conditions include more women**. These findings can be associated with underlying gender ideologies of men and women regarding dual breadwinner roles, prescribing earning for men and homemaking for women. This gendered approach leads to the notion that men belong to the public and woman to the private sphere. Femininity is often perceived as belonging to the private realm, so women's disabilities are represented more as internal and individual and less visible. Meanwhile, according to this breadwinner model and private/public dichotomy, men act more within the public realm and move freely between the public and the private realm. The association between masculinity and the public is demonstrated in the exteriorisation, where the bodily difference is not a private but a public and visible matter. These norms about gender are reproduced regularly throughout the media. Pompper (2010), for example, found that masculine portrayals often emphasise health and fitness. Hence, reporting by the media on people with disabilities, even if sympathetic, seems to be shaped by the fundamental exclusionary social frames that build on the dichotomous understanding of masculine/external/public/political versus feminine/internal/private/ apolitical.

- Matter-antimatter

Third, noticeable is the finding that articles on people with **physical impairments** are most common in magazines where **physical beauty** is the main emphasis, while articles about **behavioural problems** are most present in **lifestyle magazines** where behaviour and lifestyle predominate. The first emphasises sexuality and the importance of physical attractiveness, setting unrealistic ideals for the body and making direct statements about beauty. The latter contains articles about health, fashion, decorating, food, and well-being, covering ways to improve and get more out of your life.

The distribution of articles on physical impairments and behavioural problems has a visible connection with the core topics of the magazines they are represented in. The scientific metaphor of matter-antimatter can be used to clarify this distribution. This concept suggests that for every particle of matter created, an 'antiparticle' exists with opposite charge. They are defined as polar opposites and serve as mirror images of the particles that make up everything in our everyday world. Where images of the body present idealised versions of beauty, representations of individuals with physical differences are more present. Where discourses surrounding 'the good life/the good mother/the good partner' are framed and discussed in magazines as if they are monoliths shared by the whole community, more articles about behavioural problems are depicted. The media continuously demarcate between the norm and the deviant, between the 'acceptable' matter and the 'unacceptable' antimatter, the *dis* and the *able*, as opposites, and as the antithesis of one another. By establishing clear boundaries between the able-bodied and those who deviate from the norm, the image of the ideal able-bodied person becomes illuminated and reinforced. This distribution mirrors traditional disembodied experiences and dominant constructions of norms that "necessarily hierarchizes and ranks the two polarized terms so that one becomes the privileged term and the other is suppressed subordinates, negative counterpart" (Grosz, 1994, p. 3). By over-presenting normative selves as the only way to live and by creating a visible distance between the (dis)abled, the status of what it means to be a human is constantly defined. Since we live in a culture that constantly defines this dominant image normalcy, the presence of disability urges us to think about conceptions of the human (Kittay & Carlson, 2010). At the same time the status of human is frequently denied in the lives of people with disabilities. As Goodley and Runswick-Cole (2014) argue, becoming dis/human is a response to the ambivalent state we find ourselves in relation to the human: disability recognises the norm whilst simultaneously troubles, reshapes and re-fashions ideas about the human that we might have taken for granted. Dis/ability's disruptive potential urges us to think again about normativity and the condition of the human.

Beside the matter-antimatter metaphor, the eroticisation of the disabled body (Garland-Thomson, 1997) can also be a possible reason for the depiction of people with a physical disability in beauty-oriented magazines.

Beside this distribution of articles on physical impairments and behavioural problems, articles on **visual impairments** are found mostly in the only **religious** magazine included in this research. This cannot be connected by the matter-antimatter metaphor, but can serve a more practical interpretation as most of the Flemish organisations for people with visual disabilities are situated in the Catholic pillar and Catholicism has had a tight grip for a long time on supporting people with visual disabilities. Visual impairment also has a rich Christian iconographic connotation: from a historical point of view, the blind beggar and the blind prophet or seer – famous for his clairvoyance – are major archetypes for people with a disability. Eventually, a more pragmatic editorial reason may also be the case (e.g. a journalist with a disability or family member with a disability, etc.), although the editorial office objects this argument.

- Children with disabilities

Finally, as opposed to adults, the articles on **children** with disabilities mostly refer to general disabilities, **intellectual disabilities, autism, behavioural problems and learning problems**. Children with disabilities get a peculiar status in the media and are related to other types of disabilities than adults. First, it can be claimed that there is a link between children on the one hand, and on learning and education on the other. This result reveals the dominant looking glass on educational beliefs, where children's academic performance is emphasised (Marcon, 1993). A distinguishing characteristic of education today is the emphasis on outcomes and qualification (Biesta, 2011). It is believed that the extent to which children achieve their educational goals determines the achievement in other domains and is mirror of the success of their future life. The increasing amount of pressure that parents, teachers and society are putting on young children as little emperors to succeed academically is very influential on our educational mindset and is visible in the media.

Second, the specific types of disabilities related to children in the media, in particular intellectual disabilities, behavioural problems and learning problems, are consistent with the classification of special education in Flanders. These three types of disabilities correspond to the largest groups in the Flemish special education system (Vlaams Ministerie van Onderwijs en Vorming, 2014). In Flanders, diversity is approached by teaching students with disabilities in segregated settings and homogeneous groups. Normalisation and the attainment of the educational standards is emphasised, especially for students with learning problems, intellectual disabilities and behavioural problems. This categorical thinking poses a vivid debate and can be observed in the media.

Third, connections can be made with qualitative research on the experiences of parents of children with disabilities. Although further research is needed, it could be argued that the stories on children with disabilities in the media are examples of experiences of the moral force of social order parents have when going out in public with their children, where 'unusual behaviour' can embarrass or disorientate "normal" members of society and subvert the social norms of acceptable behaviour (Ryan, 2005).

Lastly, concerning the higher representation of children with autism in the media, Stevenson, Harp, and Gernsbacher (2011) argue that when envisioning the disability of autism, a child is more likely portrayed, rather than an adult. According to the authors, autism is predominantly considered a childhood disability. Children with autism have continually been seen as having a condition that is characterised by a broken self, uncontrollability and exceptional talents, that is so non-normative (Sarrett, 2011) it is attractive for media portrayals. Moreover, the infantilising discourse of autism is characterised by dual stereotypes: either uncontrollable, aggressive, or violent children who cause great stress to their families and carers, or unhappy and often unloved and poorly treated children that evoke pity (Jones & Harwood, 2009).

Conclusion

Since the press has, among other factors, an important role in reflecting and shaping public attitudes towards people with disabilities, and since the Flemish print media serves as an important source of information for the public about the society, an underrepresentation or an incorrect representation of people with a disability in the media has major impact on public perceptions and attitudes towards people with disabilities in our society. In Flanders, many people rely on the media as a crucial source of information, beliefs and values. Because of the marginalisation of social minority groups from mainstream society, many people rely almost entirely on the media for their information about people with disabilities. The relationship between the public and these groups is largely filtered through the values, assumptions and perceptions covered in the media.

The UN Convention on the Rights of Persons with Disabilities emphasises the importance of a correct representation and encourages all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the Convention. Moreover, in 2014, the UN Committee noted with concern “that persons with disabilities in Belgium are portrayed in the media mainly as persons with a disability rather than as citizens who participate fully in society” (CRPD, 2014, p. 3 – no further sources available), and ordered the Belgian media to “take account of diversity in their code of ethical conduct and provide them, and all relevant professionals, with appropriate training and awareness-raising to ensure better representation of persons with disabilities in the media” (p. 3).

Starting from the insight that media coverage is a key element in the process of attitude formation, and from the clear instructions for Belgium based on the UNCRPD framework, the findings of this study indicate biases and stereotypes in the press that have characterised its coverage till now.

Although this study found a relatively continual stock of messages including disability over the years, which indicates a permanent minimal attention to the issue in the media, a lot of socio cultural-driven biases are discovered in the media reporting on people with disabilities. Remarkably, this study found a number of significant differences between the types of media studied; sometimes a total lack of representation, but generally, the media content reflected underlying dominant societal ideologies that can be problematic as they promote the status quo, reinforce stereotypical attitudes and obstruct change for people with disabilities. When people with a disability are represented in the media, the messages do not have the potential to play a role in facilitating social change and altering public perceptions consistent with the framework of the UNCRPD. The disability-as-deficit notion (Gabel, 2005) has a central place, which is in line with the Flemish policy of approaching, orienting and classifying people on the basis of their labels. Besides, the studied articles are constituted on ideas of normalcy and perfection, together with binary and hegemonic perceptions on disability and gender. The representations of people with disabilities are often placed opposite to the idealized norm and seem to be shaped by fundamental exclusionary social frames.

This study provided important discoveries about representation in the media and underlying perceptions in relation to disability and intersections with other social categories. Due to the numerous sources analysed and the integral and systematic way in which they were analysed, we could precisely measure the quantity of media coverage. However, the approach does not provide insight in how people with disabilities are represented. A second study will be conducted on the same sample in order to investigate the quality of media representations by means of a framing analysis.

References

AUSLANDER, G. K., & GOLD, N. (1999). Media reports on disability: a binational comparison of types and causes of disability as reported in major newspapers. *Disability and Rehabilitation, 21*(9), 420-431. doi:10.1080/096382899297404

BELGIAN DISABILITY FORUM (2014). Alternatief verslag verdrag inzake de rechten van de personen met een handicap. Belgium, 20 February 2014. Retrieved on 17 of December 2014 from http://bdf.belgium.be/nl/themes/human_rights/uncrpd/belgian_ratification/rapport_alternatif_bdf.html

BIESTA, G. (2011). Disciplines and theory in the academic study of education: A Comparative Analysis of the Anglo-American and Continental Construction of the Field. Pedagogy. *Culture and Society, 19*(2), 175-192. doi:10.1080/14681366.2011.582255

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD). (2014). *Concluding observations of the Committee on the Rights of Persons with Disabilities: Belgium, 28 October 2014, CRPD/C/BEL/CO/1.* Retrieved on 7 of December 2014 from http://www.ohchr.org/EN/countries/ENACARegion/Pages/BEIndex.aspx

COOLEY, C. H. (1902). *Human nature and the social order.* New York: Charles Scribner's Sons.

DONALDSON, J. (1981). The visibility and image of handicapped people on television. *Exceptional Children,* 47(6), 413-416.

ELLIS, K., & GOGGIN, G. (2015). *Disability and the Media*. London: Palgrave Macmillan.

EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS (FRA) (2010). *The right to political participation of persons with mental health problems and persons with intellectual disabilities.* Vienna: European Union Agency for Fundamental Rights.

GABEL, S. (2005). *Disability studies in education: Readings in theory and method.* New York: Peter Lang.

GARLAND-THOMSON, R. (1997). Feminist Theory, the Body, and the Disabled Figure. In J.L.Davis (Ed.), *The Disability Studies Reader* (pp. 279). New York: Routledge.

GATZ, S. (2014). *Beleidsnota Media 2014-2019*. Brussel: Vlaams Minister van Cultuur, Media Jeugd, en Brussel.

GERBNER, G., GROSS, L., MORGAN, M., & SIGNORIELLI, N. (1994). Growing Up with Television: The Cultivation Perspective. In J. Bryant and D. Zillman (Eds.) *Media Effects: Advances in Theory and Research* (pp. 17-41). Hillsdale, NJ: Lawrence Erlbaum Associates.

GOLD N., & AUSLANDER G. (1999). Newspaper coverage of people with disabilities in Canada and Israel: an international comparison. *Disability & Society, 14*, 709-731. doi: 10.1080/09687599925858

GOODLEY, D., & RUNSWICK COLE, K. (2014). *Becoming dishuman: Thinking about the human through disability.* Discourse: Studies in the Cultural Politics of Education.

GROSZ, E. (1994). *Volatile Bodies: Toward a Corporeal Feminism.* Sydney: Allen & Unwin.

HALL, S. (1997). *Representation: cultural representations and signifying practices.* Sage: London.

HALLER, B. (2010). *Representing disability in an ableist world: essays on mass media*. Louisville: The Advocado Press.

HALLER, B., & RALPH, S. (2001). Profitability, diversity, and disability in advertising in the UK and United States. *Disability Studies Quarterly, 21*(2).

HARDONK, S., DEVLIEGER, P., DETRAUX, J. J., VRIELINK, J., MORTELMANS, D., VAN HOVE, G., DE BECO, G., DE COSTER, M., LINCHET, S., REYNAERT, J. F., HUYSE, A. (2013). *Eindrapport omtrent de situatie van personen met een handicap in België met betrekking tot hun mensenrechten en fundamentele vrijheden zoals gewaarborgd door het VN-Verdrag inzake de rechten van personen met een handicap.* Interfederaal Gelijkekansencentrum, België.

HAYES, M. T., & BLACK, R. S. (2003). Troubling signs: Disability, Hollywood movies and the construction of a discourse of pity. *Disability Studies Quarterly, 23*(2), 114-132.

HENDERSON, J. J., & HEINZ-KNOWLES, K. E. (2003). The trend toward hyper-marginalization: images of disability on prime time television, paper presented at the *Association for Education in Journalism and Mass Communication Annual Meeting,* Kansas City, MO, 30 July 2 August.

HOMANS, L. (2014). *Beleidsnota Gelijke Kansen 2014-2019*. Brussel: Vlaams Minister van Binnenlands Bestuur, Inburgering, Wonen, Gelijke Kansen en Armoedebestrijding.

JACOB, J., KÖBSELL, S., & WOLLRAD, E. (2010). *Gendering Disability. Intersektionale Aspekte von Behinderung und Geschlecht*. Bielefeld: Transcript.

JONES, S. C., & HARWOOD, V. (2009). Representations of autism in Australian print media. *Disability & Society, 24*(1), 5-18. doi:10.1080/09687590802535345

KITTAY, E. F., & CARLSON, L. (2010). Introduction: Rethinking philosophical presumptions in the light of cognitive disabled person send notes from the battlefield. *Metaphilosophy, 40,* 606-627.

KUNZ, J. L., & FLERAS, A. (1998). Women of Colour in Mainstream Advertising: Distorted Mirror or Looking Glass? *Atlantis, 22*(2), 27-38.

MARCON, R. (1993). Socioemotional versus academic emphasis: Impact on kindergartners' development and achievement. *Early Child Development and Care, 96*, 81-91. doi:10.1080/0300443930960108

MCCOMBS, M. E., & SHAW, D. L. (1972). The agenda-setting function of mass media. *The Public Opinion Quarterly,* 36(2), 176-187. doi:10.1086/267990

McLeod, J. M., Becker, L. B., & Byrnes, J. E. (1974). Another look at the agenda setting function of the mass media. *Communication Research, 1*, 131-166. doi:10.1177/009365027400100201

Mutz, D. C., & Soss, J. (1997). Reading public opinion: The influence of news coverage on perceptions of public sentiment. *The Public Opinion Quarterly, 61*(3), 431-451.

Nelson, J. A. (1996). The invisible cultural group: images of disability. In P. Lester (Ed.), *Images that injure: pictorial stereotypes in the media* (pp. 119–125). Westport, CO: Praeger.

NESSE (2012). *Education and disability / special needs policies and practices in education, training and employment for students with disabilities and special educational needs in the European Union.* Retrieved on 17 of December 2014 from http://europa.eu/rapid/press-release_IP-12-761_en.htm

Pompper, D. (2010). Masculinities, the Metrosexual, and Media Images: Across Dimensions of Age and Ethnicity, *Sex Roles, 63*, 682-696. doi:10.1007/s11199-010-9870-7

Raab, H., (2007). Intersektionalität in den Disability Studies. Zur Interdependenz von Behinderung, Heteronormativität und Geschlecht. In A. Waldschmidt & W. Schneider, *Disability Studies, Kultursoziologie und Soziologie der Behinderung. Erkundigen in einem neuen Forschungsfeld*. Bielefeld: Transcript.

Ryan, S. (2005). 'Busy Behaviour' in the 'Land of the Golden M': Mothers and children with learning disabilities in public places. *Journal of Applied Research in Intellectual Disabilities, 18*(1), 65-74. doi:10.1111/j.1468-3148.2004.00225.x

Saito, S., & Ishiyama, R. (2005). The invisible minority: under-representation of people with disabilities in prime-time TV dramas in Japan. *Disability and Society, 20*(4), 437-451. doi: 10.1080/09687590500086591

Sarret, J. C. (2011). Trapped Children: Popular Images of Children with Autism in the 1960s and 2000s. *Journal of Medical Humanities, 32(2*), 141-153. doi:10.1007/s10912-010-9135-z

Schantz, O. J., & Gilbert, K. (2001). An ideal misconstrued: newspaper coverage of the Atlanta Paralympic Games in France and Germany. *Sociology of Sport Journal***,** *18,* 69-94.

Shrum, L. J. (1999). Television and Persuasion: Effects of the Programs between the Ads. *Psychology and Marketing, 16*(2), 1119-40.

Siperstein, G. B. (2003). *Multinational study of attitudes toward individuals with intellectual disabilities.* Washington, DC: Special Olympics Inc.

Sparks, C., & Tulloch, J. (2000). *Tabloid Tales. Global Debates over Media Standards.* Oxford: Rowman and Littlefield.

Stevenson, J. L., Harp, K., & Gernsbacher, M. A. (2011). Infantilizing autism. *Disability Studies Quarterly, 31*(3).

Tynedal, J., & Wolbring, G. (2013). Paralympics and Its Athletes Through the Lens of the New York Times. *Sports*, *1*(1), 13-36. doi:10.3390/sports1010013

Vissers, S., Hooghe, M. (2010). *Onzichtbare burgers. Personen met een handicap in het televisienieuws bij VRT en VTM, 2007-2009*. Leuven/Antwerpen: ENA (Elektronisch Nieuwsarchief).

Vlaams Ministerie van Onderwijs en Vorming (2014). *Statistisch jaarboek van het Vlaams onderwijs - schooljaar 2013-2014.* Retrieved on 17 of December 2014 from http://www.ond.vlaanderen.be

World Health Organization (WHO) & the World Bank. (2011). *World report on disability 2011.* Geneva, Switzerland: WHO Press.

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Friday Night Disability: The Portrayal of Parent-Child Interactions on Television's *Friday Night Lights*

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Abstract

Studies of television portrayals of parent/child relationships where the child has a disability are rare. Using the social relational theory perspective, this study examines interactions between parents and a young man with a disability as portrayed in the acclaimed contemporary television series, *Friday Night Lights*. We found a nuanced relationship between the portrayed teen and his parents and a powerful influence of the community on the parent-child relations and family life.

Keywords: parent-youth relations, disability, social relational theory, film and television, *Friday Night Lights*

Résumé

Des études portant sur les représentations de relations parent-enfant à la télévision où l'enfant a des incapacités sont rares. À l'aide de la théorie des relations sociales, cette étude observe les interactions entre un jeune homme ayant des incapacités et ses parents dans la télésérie contemporaine *Friday Night Lights.* Nous avons trouvé une relation nuancée entre le jeune homme et ses parents, ainsi qu'une influence importante de la communauté sur les relations parent-enfant et la vie de famille.

Mots-clés : relations parent-enfant, incapacité, théorie relations sociales, film et télévision, *Friday Night Lights*

Introduction

Scholars have been examining the representation of people with disabilities (PWDs) in the media for more than three decades (Black & Barnes, 2015; Elliott & Byrd, 1983; Harris, 2009; McManus et al., 2012; Owen, 2012; Pirkis et al., 2006; Safran, 1998; von Sikorski & Schierl, 2013). The portrayals have varied across disabilities and ranged from positive to negative in tenor, with specific disabilities having unique stereotypes attached to them and characters with disabilities themselves being constructed both favorably and less so, depending on the types of disabilities that they might have (Berger, 2015; Hartnett, 2000).

Analogously, researchers from across academic domains including psychology (Baker, Baker, & Crnic, 2014), nursing (Kearney & Griffin, 2001) and mental health (Kubicek et al., 2013) have also studied family relationships as they are portrayed off-screen (Lightsey & Sweeney, 2008; Little, 2001; Rieger & McGrail, 2013; 2015), including families with children with disabilities. Because the parent-child dyad is so crucial to the development of children, it tends to be a strong predictor of the absorption of values, morals and general behavioral norms in them, in conjunction with children's interactions with those with whom they are closest — primarily their parents and guardians (Kuczynski & Hildebrandt, 1997; Kuczynski & Parkin, 2007). However, little research is available that combines the examination of parent-child relationships within the larger body of work on mass media portrayals of PWDs, particularly in the ubiquitous medium of television. This study is intended to partly fill that gap by examining interactions between parents and a youth with a disability as portrayed in the contemporary television series, *Friday Night Lights* (Berg, 2007).

- Current Literature

Scholars agree that overall, people with disabilities are both underrepresented and misrepresented in film and television (Agosto, 2014; Armstrong, 2004; Crow, 2013; Devlieger et al., 2008; Wahl et al., 2007; Warzak et al., 1998). Scherman (2008) analyzed full-length Disney Films produced between 1930 and 2010 to determine the frequency of main characters with physical disabilities. She found that 13, or 7%, of the 178 analyzed films featured characters with physical disabilities. Based on the preliminary body of research examined for the current study, physical disabilities and mental illness are the two types of disabilities most commonly portrayed. Most recently, portrayals of autism, a neurological disorder, are a rising focus of research in movies and television programs (Hannam, 2014; Marinan, 2014).

Black and Pretes (2007) defined six media stereotypes of characters with disabilities. They are: "pitiable and pathetic; supercrip; sinister, evil and criminal; better — off dead; maladjusted, his or her own worst enemy; a burden, and unable to live a successful life" (p. 67). These stereotypes are based somewhat on the early work of Biklen and Bogdan (1977) and Nelson (1994). Black and Pretes (2007) found that among the 18 films that they analyzed, the most commonly portrayed stereotype was one in which the disabled person was unable to live a successful life. Hartnett (2000) argues that one important reason that persons with disabilities have been othered and marginalized is that they are not seen in popular media as part of the structure of intimate society, that is, as members of families and of networks of friends. However, none of the themes and/or stereotypes Black and Pretes (2007) explored focused specifically on the relationship between the main character who was a PWD and his or her family. This is despite the fact that young people with a disability usually require the investment of larger inventories of time from their parents or guardians than is otherwise typical of children of commensurate age (Rieger & McGrail, 2013).

An additional research focus within the existing body of literature examines how negative portrayals of PWDs impact viewers with and without disabilities (England, 2008; Hannam, 2014; Holton, Farrel, & Fudge, 2014; Kama, 2004; Rider, 1994; von Sikorski & Schierl, 2014). Zhang and Haller (2013) surveyed more than 300 PWDs to determine their viewpoints regarding the portrayal of people with disabilities in the media. Zhang and Haller's (2013) research suggests that "people with disabilities are more likely to develop positive and confident self-identity when exposed to media stories about the accomplishments of individuals with disabilities" (p. 330).

Schwartz et al., (2010) used the medium of documentaries to examine the reaction of graduate students, faculty and staff, and community members to depictions of PWDs during an annual college-sponsored film festival. Their results indicate that viewing realistic portrayals can influence public perception about people living with disabilities.

Although none of these or many other studies focus on the families of PWDs, one researcher (Holton, 2013) does examine parent/child relationships in the NBC television program *Parenthood* (Katims, 2010). In the depicted family the youngest son, Max, is diagnosed with autism. Holton argues that common stereotypes are reenforced by the show's treatment of Max as a detached loner oblivious to the experiences of those around him. Holton also argues that the show gives no voice to Max, as the parents' perspective dominates the storyline. More recently, Hasson (2016) emphasized the challenges that the parents in this series face in dealing with school administrators and outside support services, although giving less attention to the parent-child relationships and interaction in their analysis.

We find, therefore, that there has been significant scholarly interest in media depictions of PWDs, somewhat less interest in how the media portray familial relations (Berry, 1998; Ferguson, 2010; Skill & Wallace, 1990), but quite scant interest in the two areas taken together.

While the number of programs on television that focus on PWDs has been small, a few high profile programs have provided portrayals. Fink (2013) examined the portrayal of people with disabilities on the long-running series, *The Simpsons* (Groening, 1989). Their analysis revealed a "carnivalesque" portrayal of people with disabilities, much like the off-screen practice of travelling freak shows documented by Bogdan (1993, 1988). This may have been made easier by the fact that *The Simpsons* is a cartoon, in which realism is not generally a goal (Mittell, 2001). Investigations of the live-action program that we treat, *Friday Night Lights*, as a text are plentiful, and a few treat the issue of disability (e.g. Cherney & Lindemann, 2014; Ellis, 2012) but they generally do not concern the familial relations of a PWD, even though such relations are important to the plot of the first two seasons of this program.

Skill and Wallace (1990) provided the only study that we could find that focused primarily on the power dynamics between parents and children on prime-time television, the genre to which our program of interest belongs. They studied the composition of television families, as well as the type and frequency of parent/child interactions displayed. They found that members of "in-tact" families were less likely to assert power than those of "non in-tact and mixed families" (p. 259).

Research on the off-screen, real-life relationships between parents and children with disabilities was also pertinent to the current study. Volumes have been written on this subject from the standpoint of educators (Burke & Hodapp, 2014), medical professionals (Kaplan, 2014), social scientists (McStay et al., 2014; Meirsschaut, Roeyers, & Warreyn, 2011), and advocates for the advancement of PWDs (Chadwick et al., 2013; Farrell & Krahn, 2014).

For the purposes of comparing media portrayals with real life, we located a representative sample of articles published within the last ten years that centered on the relationships between children and/or adolescents with disabilities and their family members. The common thread throughout the research surveyed was that parents of children with disabilities generally report higher levels of stress overall than parents of typically developing children (Darling, Senatore, & Strachan, 2011; Hayes & Watson, 2012; Weitlauf, Vehorn, Tylor, & Warren, 2014).

Huang, Ososkie, and Hsu (2011) found that "negative feelings of parental favoritism, negligence and jealousy were commonly experienced by younger siblings of children with disabilities" (p. 223). Baker, Baker, and Crnic (2014) found that mothers of children age 5 and 6 with disabilities showed more "negative controlling" behaviors than that of the mothers with same age, typically developing children (p. 332). Vacca (2013) reported that in his study the most common concerns reported by fathers with autism was around "impaired social interactions" (p. 90).

Whether it is art imitating life or life imitating art, this focus on the family impact of having a child with disabilities appears to validate Holton's (2013) assessment that to date most of the emphasis is put on the other actor(s) and not enough on the individuals with disabilities – both on and off the screen. The studies also tend to foreground the parent, sibling, or caregiver perspective rather than that of the child. Nor do these studies seem to discuss in depth the ways in which the parent *and* the child with disability exercise agency or negotiate power dynamics around the issues of disability.

The current study is therefore designed to extend the existing body of work by asking specific questions that remain relatively unexplored:

- What forms of child-parent interaction and socialization are being portrayed in the popular series, *Friday Night Lights*?
- What forms of child-parent agency occur in these portrayals?
- What assumptions do these portrayals make about parent/child with disability relations today?

- *Theoretical Framework(s)*

To study the portrayals of parent-child interactions, we employed and modified as required Kuczynski's (2003) select constructs from his bilateral conceptual framework, social relational theory which was developed to study "dynamics in parent-child relations" (p. 4).

Lollis and Kuczynski (1997) argued that "research on parent-child interactions tends to have a microanalytic perspective that considers bidirectional influence within social interactions but neglects bidirectional influences between social interactions and the encompassing long-term relationship" (p. 441). According to social relational theory, reciprocity in attitudes, behaviors, and responses between children and parents in the parent-child relationship is a form of socialization (Newton, Laible, Carlo, Steele, & McGinley, 2014). Importantly, socialization within this theoretical perspective is framed as a bidirectional process, rather than a unidirectional activity. That is, unlike "the traditional depiction of the parent-child relationship exclusively as a vertical power arrangement" (Kuczynski & Hildebrandt, 1997, p. 236), interactions between parents and children within the family structure are based on a bilateral model: each actor in the dyad influences the other, and each affects the efficacy of the overall socialization of the other. To this end, social and cultural gains made by both the parent and child are thought to be mutual rather than independent of one another.

Accepting that parents modify their own behavior and expectations to some degree based on the interactions with their children yields a viewpoint of dialectic causality.

> Dialectic causality emphasizes the inherent contradictions that exist within individuals and their various contexts as well as the generative qualitative transformations that result as these elements actively interact with each other… Through this process novel forms emerge constantly during development and also in the course of short-term problem solving, such as during social interaction. (Kuczynski, 2003, p. 7)

Within this relational process, human agency is brought to the forefront and is assigned a dialectical function (Kuczynski, 2003; Kuczynski & Parkin, 2009). Kuczynski and Parkin (2007) argued that parents and children act as "agents in socialization" when they interact with one another (p. 260). That is, they both have the capacity to influence the other and to exert power in response to agency exercised by the other. This study seeks to understand the forms of socialization in interactions between a youth with a disability and his parents, as portrayed in the high-profile network television series, *Friday Night Lights* (Berg, 2007). Examining the direction (unilateral or bilateral), the nature of influence (power and agency arrangements), and the resources employed in interaction with each other, and the type of socialization from the relational perspective are the factors that this study sought to uncover.

Of course, the parent/child dyad with and within disability is different from that in which disability is not a feature. Setting aside for a moment the problematic nature of disability as a “tragedy” (Glasscock, 2000; Hayes & Black, 2003; Preston, 2014; Rogers, 2007), parenting a child who has or acquires a disability involves a vastly greater marshalling of emotional, financial and social resources (Darling, Senatore, & Strachan, 2011; Farrell & Krahn, 2014; Hayes & Watson, 2012). Rieger and McGrail (2013; 2015) noted that humor was often an anodyne to these challenges, and was found to be a force for better family functioning and a powerful communicative force when employed between young PWDs and their parents.

More recently, probably because of the effort not to demean PWDs or to otherwise give overt offense, a construction of PWDs as “supercrips” has been noted by several scholars (Fink, 2013; Hartnett, 2000; Holton, 2013; Kama, 2004). “Generally, the supercrip is recognized as a stereotypical representation of disability that appears in contemporary journalism, television, film and fiction” (Schalk, 2016, p. 73). In addition, “[S]upercrip narratives emphasize (over) compensation for the perceived ‘lack’ created by disability” (Schalk, 2016, p. 74).

It was therefore important to us in our selection of a media text to choose one that placed a young PWD in a setting in which popular heroism was very much in the background, as it is in the series, *Friday Night Lights*.

Methodology

- *Data Collection/Choice of Subject Matter - Friday Night Lights*

The data source for this qualitative study (Creswell, 2007) is a selection of scenes portraying parent/child-with-disability interactions in the television NBC series, *Friday Night Lights* (Berg, 2007). Although we examined all five of its aired seasons, seasons 3-5 did not include any instances of interactions between the parent(s) and the teen with a disability and so were not discussed.

This television program was selected for this analysis because it was one of the few recent programs that met the following criteria:

a) it was fictional in nature;
b) it featured a youth with a disability in a key role;
c) it had a parent or caregiver in a supporting or an important role;
d) it was a television program in wide release;
e) it was created in the modern television era (post-1990).

Out of the 76 total episodes of the five seasons aired from 2006-2011, there were 16 instances of high intensity and one instance of low intensity interactions between the parent(s) and Jason Street, the teen with a disability (see Table 1). These interactive scenes occurred over seven episodes of season 1 and three episodes of season 2 for a total of approximately 13 minutes of the approximately 26 hours and 45 minutes. (There were many other scenes that concerned Jason Street and his interactions with others, but these did not feature his parents in any way, and were not treated.)

While a few programs may have more generally fit our criteria, we decided to focus on the NBC series *Friday Night Lights* for several reasons. First, “the show remains one of the few prime-time television series to portray disability in the context of sport” (Cherney & Lindemann, 2014, p. 2). It was also critically acclaimed, having won the Television Critics Association Award in 2007 for Outstanding New Program of

TABLE 1. *FRIDAY NIGHT LIGHTS*: SCENES THAT FIT THE SELECTION CRITERIA

Selected Scene/Season/Episode (Approximate time code)	High Incidence (Major) A few keywords to label and code the scene	Low Incidence (Minor) A few keywords to label and code the scene
Season One		
Disc 1 Season 1/ Episode 1: Pilot		
35:01-36:05; **Length:** 1:04 min	Jason's disabling spine injury on the field	
45:13-45:21: **Length:** 00:08 sec.		Family gathers around Jason's bed after his unsuccessful surgery
Disc 1 Season 1/Episode 2.Eyes Wide Open		
24:01-24:36; **Length**: 00:35 sec	Doctor comments on Jason's irrevocable disabled condition	
Season 1**Disc 1**/Episode 3: Wind Sprints		
40:11-41:16; **Length:** 1:05 min	Jason leaves hospital; parents help with the move to rehab facility	
Season 1**Disc 2**/Episode 3 : Homecoming		
13:23-14:02; **Length:** 00:39 sec.	Jason makes college plans with parents	
28:40-29:44; **Length:** 1:04 min	Jason wheels onto the football field as an honorary captain	
Season 1/**Disc 3**/Episode 10: It's Different for Girls		
2:39-4:20; **Length: 1**:41 min	Jason returns home from rehab	
6:48-7:40; **Length:** 00:52	Jason's first morning at home after his return from rehab	
17:24-18:52; **Length:** 1:29 min	Jason's interview with the lawyer	
Season 1/**Disc 3**/Episode 11: Nevermind		
1:53-2:39; **Length:** 00**:**44 sec.	Jason has an argument with his mother about a lost music CD	
Season 1/**Disc 3**/Episode 12:What to Do While You're Waiting		
7:48-9:16; **Length:** 1:28 min.	Jason disagrees with parents about coach's responsibility for his injury	
Season 1/**Disc 5**/Episode 20: Mud Bowl		
6:32-7:05; **Length:** 00:33 sec.	Parents worried about Jason's future	
Season Two		
Season 2/**Disc 1**/Episode 1: Last Days of Summer		
43:57-43:59; **Length:** 00:02 sec.	Parents watch Jason receive the championship ring	
Season 2/**Disc 3**/Episode 9: The Confession		
6:15-6:38; **Length:** 00:23 sec	Mother brings a snack to Jason's bedroom	
36:20-36: 28; **Length**: 00:08 sec.	Jason comes home late; parents had been worrying all night about his whereabouts	
40:31-40:50; **Length:** 00:19 sec.	Jason moves out to live on his own; parents help with the move	

the Year (tvcritics.org) and having received the award for Outstanding Achievement in Drama by the Television Critics Association in 2011. For its first two seasons, it enjoyed a viewership of roughly 6 million (Gorman, 2010).

Moreover, many of the critics who praised the show spoke of the show's naturalistic settings and dramatic realism, especially concerning themes such as teen sexual discovery, death and murder, dashed athletic hopes, financial privation, educational competition, and many others that resonate in our current cultural *zeitgeist* (Cole, 2011; Heffernan, 2006; Shales, 2006). We therefore thought it instructive to observe whether the show's realism would in some sense carry over to its portrayal of adolescent disability in parent/child relations.

- Data Analysis

A qualitative content analysis (Kohlbacher, 2006; Mayring, 2000) using the social relational theory perspective was employed to examine social interactions between parents and the teenager with a disability, Jason Street, based on the bilateral model of parent-child relations (Kuczynski & Hildebrandt, 1997; Kuczynski, 2003; Kuczynski & Parkin, 2009). Qualitative content analysis was selected because it can be applied to the analysis of text as well as any form of communication, including video data. Both screen script, where available, and audio-visual data (the televisual aspects of the program itself) were the data sources for this study. Our qualitative content analysis also allowed examining the overt and covert meanings in the portrayals of parent-child with disability interactions in our study.

In addition, the qualitative content analysis we performed is a "theory-guided analysis" (Kohlbacher, 2006, para, 4.2.2.2 Basic ideas), with theory playing a critical role in identifying and analyzing units of analysis and categories of codes associated with these units, as relevant to the research question(s). More specifically, the constructs of context "as interaction within relationships" (p. 7), "power as "interdependent asymmetry" (p. 14) and resources as "constituting power," (p. 15), which are borrowed from the bidirectional model by Kuczynski (2003), were employed to define, identify and analyze the units of analysis and categories of codes associated with these units in our television series of interest. We explored the following research interests of importance to this study:

a) the parent/child-with-disability dynamics (unilateral or bilateral) in the portrayed relations;
b) the nature of influence (power and agency arrangements);
c) the resources used by children and parents to negotiate these relations;
d) the assumptions governing these portrayals that are read as social representations of disability today.

To accomplish these goals, three procedures from qualitative content analysis techniques were adapted. "Summary," which aims at reducing the material to a manageable corpus through paraphrase and abstraction of data; "Explication," which involves "explaining, clarifying and annotating the material"; and "Structuring," which consists of "filter[ing] out a particular structure from the material", with a specific theoretical basis. As a result, definitions for each coding category were developed and they were accompanied with examples and rules specific to this category (See Table 2). Category definitions and rules formed "a coding agenda". During the first round of coding, "the data locations" were identified and indexed on a timeline. During the second round of coding, the relevant data selections were "processed and extracted" (Kohlbacher, 2006, para, 4.2.2.3 Method and procedures).

Multiple coders were used, coding the data first independently and then together, via the use of an agreed-upon coding agenda, whilst checking for both intercoder reliability (consistency of coding across coders) and intracoder reliability (consistency of the coding of one coder) (Kohlbacher, 2006). Of our four authors, two served as coders and two served as auditors, making sure that factual statements made were evidenced in the text.

TABLE 2 CODING AGENDA FOR *FRIDAY NIGHT LIGHTS*

Category	Definition	Examples	Coding Rules/Notes
C1: Individual Resources	Resources that a child or parent possesses independent of each other, such as physical strength, control over rewards, expertise, and executive functioning (Kuczynski, 2003, p. 16).	Father installs a ramp for Jason's return home (skill and talent). Jason displays athletic ability; his expertise working with football players.	Only a single individual resource must be identifiable to be included.
C2: Relational Resources	Resources that are dependent on the relationship a parent and child share. These resources result from the interaction between the two and vary in degree from dyad to dyad.	The parents modify the house to suit Jason's needs. The parents install modified controls for the truck Jason uses.	Only applicable when the resource is directly tied to the social interaction between parent and child. Could be mother and child, father and child, or mother and father with child.
C3:Cultural Resources	Constraints, rights, and entitlements conveyed to parents and children by the laws and customs governing the culture within which they are interacting (Kuczynski, 2003, p. 17).	Jason describes that a store clerk he has known for years "won't even look at him" [Message: Going against the Panthers is going against the town.]. Jason is unable on his own to buy beer; a football friend has to help him. Jason and his parents sue the school (and his coach) to get money to pay for his rehabilitation.	The context of the interaction must be considered both on the micro (e.g., family, neighborhood, town) and macro (e.g., ethnicity, geographical region, generational influences).
C4: Relationships	The people directly involved in the interaction whether it be parent and child, parent to parent, child to peer, etc.	The parents are clapping and smiling as Jason (post-injury) ventures onto the football field; he looks for them in the crowd and gives a wave to them.	The interaction must include two or more characters within one scene.
C5: Enculturation	"a largely unconscious process, whereby individuals learn the ideas and practices of a culture by being enfolded in the culture" (Kuczynski, Navara & Boiger, 2011, p. 174).	Father is deferring to mother's decision to sue the coach [Perhaps father is teaching his son the role of a supportive husband.].	This is in contrast to the idea of socialization which is a conscious act between the parent and the child.

Category	Definition	Examples	Coding Rules/Notes
C6: Socialization	The conscious act of teaching morals, traditions, and values to one's children. (Kuczynski, Navara, & Boiger, 2011, p. 174).	The parents exit Jason's bedroom when they bring him home from the rehabilitation center [to give him some space]. The parents wonder why Jason can't get the Nevermind CD online or to download it; Jason wants the hard copy. (message: practicality rather than sentimentality about an object).	Telling or communicating values through words and actions, rather than just actions alone.
C7: Short term compliance	"Short-term compliance is defined as compliance with a request or prohibition in the immediate situation and usually in the parents' presence" (Kuczynski, 1984, p. 1062).	Jason is swayed by his parents to follow through with the lawsuit.	Compliance is in the presence of the parents.
C8: Long-term compliance	"Long-term compliance is compliance that persists beyond the immediate situation, such as in the parent's absence" (Kuczyski, 1984, p. 1062)	The parents collect and display trophies in Jason's new bedroom [to welcome him home and to share their pride of his accomplishments].	Generalized compliance that occurs across contexts wherein the child's or adolescents' parents are not present.
C9: Context	The setting in which a behavior or interaction occurs.	Jason appears on the field once before his injury, and then later on in the season after his injury with the team. He appears also during Homecoming, and also as the team is presented with the state championship rings for the current season, as former player and current assistant coach.	This involves not only the location, but the individuals (parents, peers, siblings, etc.) present in that particular setting.

Limitations

There are a few limitations to this study. First, the data source for this work is a fictional program, not a real life event involving real life participants. This is not to say that the events portrayed *in Friday Night Lights* would not occur or play out in real life as they do on the small screen. Television programming using realism as an aesthetic technique is capable of depicting reality as situations analogous to real life (Monaco, 2009). Indeed, the series was praised for its naturalistic settings and dramatic realism (Cole, 2011; Heffernan, 2006; Shales, 2006).

Second, this study focuses on one television series, and we recognize that the findings are therefore representative of only this program. Further research would be needed to examine other contemporary television series in the United States and abroad, in order to have a broader reach and to better understand the social representation of parent-child relations among those both with and without disabilities on television today, and the benefits as well the consequences that accrue from these representations.

Findings

- *Dynamics between the Parent and Child with Disability*

In terms of the parent/child with a disability dynamic, *Friday Night Lights* portrays a complex relationship. Jason Street, a teen, is arguably the character whose tragedy sets the series in motion; his debilitating football injury, which is permanent quadriplegia, both removes football for him as a career option and makes the way for another player to move into his spot. The injury affects not only Jason and brings emotional dilemmas for him, but it also "disables" his family: they need to come to terms with his injury and the ensuing consequences. His reaction to all of this, and his parents' struggle to secure a future for Jason, result in a tense and multifaceted relationship. Faced with these challenges, both Jason and his parents find themselves being influenced and influencing the other in ways they have not experienced or considered before, in a bidirectional process that we describe next.

Connection and relating to each other

There is evidence of significant emotional connection in the parent-child relations throughout the series. For example, Mitchell and Joanne Street, Jason's parents, and Jason share the same value system concerning the role and importance of sports (i.e., football) in their lives. The parents cheer together with the crowd and encourage their son to win through verbal and non-verbal communication during the weekly games, a cultural event in which they all participate on a regular basis.

Jason and his parents also relate to each other when things don't go well and when they are under a great deal of stress. These latter feelings come to a head when Jason gets hurt and is down on the ground on the field and to an even greater degree when he is found unconscious after the surgery in the hospital.

It is in these moments, whether they reflect good or challenging times, that we witness reciprocity in attitudes, aspirations and behaviors that are characteristic of a bidirectional power relationship (Kuczynski, 2003) between Jason and his parents. That is, we see both Jason and his parents working together, redefining and renegotiating the nature and direction of influence in decision-making as a family unit and within their relationships, as they embrace their difficult situation and search for ways to confront the problems that arise. Conflicts and emotional upheaval are inherent to this dialectic process.

Disconnect and lack of understanding

At other times, Jason and the parents strongly disagree with each other and do not necessarily understand or relate to each other. This is particularly evident in the scenes concerning a proposed lawsuit against the high school where Jason played, and Eric Taylor, Jason's football coach, as a strategy to secure the necessary money to cover medical costs and take care of Jason's needs in the future. Out of loyalty to his coach, Jason strongly opposes this idea.

On a later occasion, Jason and his parents have a charged exchange when he makes the choice to stay out all night without calling them or letting them know. As viewers, we are not privy to whether this was something he had done before the accident or not. However, it is clear that both his mother and father are alarmed and disappointed by his actions. Although his mother is more visibly frustrated and verbal, his father expresses his concern too, but without words. Jason remains calm and agrees that it was irresponsible of him not to check in and that it won't happen again — not because he doesn't plan to stay out all night in the future — but because this has cemented his decision to move out from under his parents' roof.

Empathy (trying to understand and support one another)

There are times in the series when the Street parents and Jason try to reach out to each other and work toward an agreed-upon solution, which in turn reflects a dynamic and mutually responsive (i.e. bidirectional) orientation in their relationships. For example, on one occasion Jason is in his bedroom with a friend perusing a dating web site when his mother enters the room without knocking, offering the two young men cookies and carrots. Jason is embarrassed on multiple levels, but seeing that his mother's intentions are good, he graciously accepts the snack and does not allow his frustrations and/or embarrassment to be known until she exits the scene. This is just one occasion of many in which Jason's conflict between wanting to be independent, and wanting at the same time emotional comfort and support from his mother is evidenced through his facial expressions, words, and actions.

Eventually, Jason's parents come to understand Jason's need to have an independent life and let him move out and live with his friend, Herc, who also uses a wheelchair. Jason, too, begins to understand his parents' position on things, even as to appreciating his parents' efforts to secure money for him in the future and conceding to the lawsuit against his coach. In light of social relational theory (Kuczynski, 2003; Kuczynski & Parkin, 2009), the examples above represent a bidirectional socialization process, in which both Jason and his parents influence one another, and as a result, act as "agents in socialization" with one another (Kuczynski & Parkin, 2007, p. 260). They help each other understand and relate to their individual feelings and ways of coping with Jason's disability and the challenges it has brought to their daily interactions and across their relationships.

- *Resources Used by the Parent and Child with Disability*

Jason and his parents are depicted as using a range of resources as per the bilateral conceptual framework of Kuczynski (2003), including individual, relational and cultural resources, to negotiate their social interaction and influencing of each other.

- *Jason*

Initially, when we are introduced to Jason, he relies heavily on his individual resources (talent, expertise, and physical prowess as quarterback). A radio announcer calls him "the number one football player in America." His individual resources are, however, vastly depleted when during a daring move on the football field, he is seriously injured and cannot just get up and walk away. The announcer summarizes this unfortunate turn of events and foreshadows Jason's descent from his pinnacle as quarterback when he narrates to the crowd that he is being "carted off on a stretcher."

Jason uses his emotional strength as a resource to stand for himself at a lawsuit hearing and to make decisions about his future life. Later, he uses the same determination to help him become a successful wheelchair rugby player, an assistant football coach with the Dillon Panthers, and to move out and have a fulfilling life as individual with a disability with a child to support and his own family, career, and business. Jason's personal courage and strength in adversity is also evident when he demands to know the whole truth about his medical condition, and in finding the way to deal with the loss of his sweetheart to his best friend, Tim Riggins.

In terms of relational power, Jason is shown to be able to assert himself when he challenges his parents' plans to mount a lawsuit against the school and Coach Eric Taylor, when he speaks to the coach in the courthouse despite the instructions to not do that, and by speaking for himself at the lawsuit and making an offer to reach a settlement with the high school lawyers. However, he maintains his role as "a good son" in that even when he disagrees with his parents, he is generally respectful to them.

He also contests exterior stereotypical views of him as he desires to be seen as more than "the town cripple" or "the boy in the wheelchair" and gets a job as a car salesman and as an assistant coach. Taken together, Jason's attitude, beliefs and actions contest the following media stereotypes of individuals with disabilities: "pitiable and pathetic;" "a burden, and "unable to live a successful life" (Black & Pretes, 2007, p. 67).

- Jason's Parents

The parents as a family unit are shown to resort to several scarce resources such as having to use their own financial wherewithal to cover the costs of Jason's hospital treatment and the necessary renovations in the house and the customization of their van to accommodate Jason's needs as an individual with a disability. They also seek legal counsel to mount the lawsuit against the high school and the coach to secure the money to take care of Jason's needs now and in the future.

In addition, they exercise their executive functioning power on numerous occasions. This is evident when they decide to override Jason's request not to sue the coach and when they discipline Jason when he returns home in the morning after having spent the night out without informing them of his whereabouts. They muster the courage to go against the community and to fight for Jason's money from the high school administration and the coach.

In terms of cultural resources, the parents are shown to draw emotional reinforcement from the community in support of Jason's football career. This form of reinforcement is evident when they share with the community moments of joy, triumph and pride when Jason and his team are doing well, especially when they win the state championship, as well as moments of tension, agitation and disappointment when the team is losing.

From the social relational theory standpoint (Kuczynski, 2003; Kuczynski & Parkin, 2007), the parents have assumed and acted upon the social roles typically expected of the parents whose child pursues a football career. This is a result of having been subjected to both the enculturation and socialization processes to which they had all been exposed, owing to living in a small town community whose primary source of entertainment and social activity was football. As part of the enculturation process, the Street parents appear to have been inducted into the Dillon community of football, and they come to embrace the mutual benefits and obligations by their membership in this community.

Town-held rallies, football sponsorship campaigns, and local media reporting and commentary, on the other hand, serve as socialization processes, that is, they are the conscious efforts on the part of the town to instill in Jason's parents, and their quarterback, Jason, "the morals, traditions, and values" (Kuczynski, Navara, & Boiger, 2011, p. 174) that this community associated with the football experience. These were expected to be followed by anyone involved in football in their town. As primary caregivers, the parents passed on these values, traditions and morals to Jason, their son. Through participation in the football games, practice, and other related social events, they were contributing to Jason's enculturation (a subconscious process) into the complex football community relationship.

As for relational means, the parents are depicted as utilizing a variety of resources, albeit often different for each parent. Joanne Street relies heavily on her maternal drive and desire to protect and provide for her only son. We thus hear her say to Jason, "You call me on my cell if you need anything" when she leaves for work and Jason stays home after his return from the rehabilitation center.

Jason's mother is shown to be willing to do whatever it takes to take care of her son. An example of such determination is when she accepts the potential rejection of the community and chooses to go ahead with the lawsuit against the high school and Coach Taylor himself: "I've come to terms with the fact that there are people in this town who aren't gonna understand that."

Religion and faith are other important cultural resources for Jason's mother. They give her and her son hope for a recovery. This is evident in this response she makes after learning about the medical condition of Jason after his spine surgery, “We’ll keep praying.”

She also uses her intellect and logic to convince both her husband and Jason that the school does owe them something. Specifically, following a heated conversation among Jason, his mother and his father about whether or not to seek financial retribution, Jason and his mother continue to talk after her husband leaves for work. By the end of the conversation, Jason is willing to agree with his mother that “maybe somebody should have taught me to tackle,” thus consenting to her decision to pursue legal options.

The series depicts Mitchell Street, the father, employ at various points in time a different set of resources to cope with the disability-related situation than those of his wife. Specifically, he uses less verbal communication than Joanne Street does in his interactions about and with their son. An example of such communication is when Mitchell asks no questions and makes no comments when the doctor is explaining Jason’s medical condition after his spinal surgery. Instead, he uses eye contact and body language to communicate his concern and support for his son when Jason asks the doctor if he will be able to walk again. Mitchell as a father resorts to non-verbal modes of communication when he gives Jason a fist pound to communicate that he is on his side after Jason reassures his mother that he is going to be fine on his own while they are at work.

Jason’s father is shown to draw from the executive functioning resource when the family discusses college plans for Jason in the cafeteria scene. During that scene, the mother argues that it is too soon for Jason to return to high school and make college plans while Mitchell Street openly challenges his wife in front of their son: “The sooner he can get back to the normal routine, the better.”

Mitchell Street is also resourceful in that he is able to increase Jason’s accessibility by converting his home office to Jason’s new bedroom and building a ramp leading up to the front door. He, like Jason, is conflicted between his loyalty to the team and Coach Taylor in particular and Jason’s long-term financial needs. He wants to be seen by his wife as a provider, but he also wants to stay in good graces with the larger community because he knows his business depends on it.

Discussion and implications

- *Child-Parent Interaction and Agency Forms in the Series*

The purpose of this study was to analyze interactions between a teenager, Jason Street, who acquires a disability and his parents, in the television series *Friday Night Lights*, using the bilateral model of parent-child relations (Kuczynski & Hildebrandt, 1997; Kuczynski, 2003; Kuczynski & Parkin, 2009). Overall, the themes that we have presented here reflect many aspects of the bilateral model and social relational theory in general. In the series, we see the interaction patterns and socialization processes depicted between the parents and Jason as representative of a bilateral relationship and power dynamics.

Specifically, we observe both the Street parents and their son Jason involved in various social processes and decision making at the onset of Jason’s injury and after the surgery, when they discover that Jason will not be able to walk again, and again when they are left with the difficult question of how to proceed further. In their responses, both the parents and the child are shown to act as agents in a discussion and decision-making process on the way to solution. Both the son and the parents are shown to draw from a range of resources, including individual, relational and cultural resources to negotiate their individual positions and to influence the other.

Not all theoretical categories from the social relational theory are represented in our data and not all theoretical elements have the same precedence in our findings. For instance, we found that the majority of the resources both the parents and Jason use to exercise their agency fall in the individual and relational resource categories, with cultural resources being utilized the least.

We are privy to almost no accounts of the socialization and enculturation processes between Jason and his parents when Jason was a child, the time period in his life when influencing and relationships forming were most likely the strongest.

Analogously, although we know that both Jason and his parents have been enculturated into football, the relationship between him and his parents is not one of enculturation *per se*. Because they love him presumably for reasons other than football, after his injury, they are compelled to see him in a different light despite the enculturation into football. In other words, his parents' love for him must find a different footing. Post-injury, they can no longer admire him because he is such a successful football player. His athleticism no longer is, nor can it be a reason for their devotion.

Since the series treatment concerning these topics was limited, it made certain aspects of enculturation and socialization described in the bilateral model of parent-child relations (Kuczynski, 2003; Kuczynski & Parkin, 2009) less applicable to some of the data we analyzed and therefore less evident in our analysis and discussion of the findings. Nevertheless, enculturation, socialization and other elements of the bilateral model of parent-child relations were connected to other topics that we discovered in our data and we discuss these theory manifestations in our findings.

- *Assumptions about the Parent-Child with Disability Relations Today*

Gender Role Stereotypes

The representation of the mother's and father's reactions to Jason Street's injury (trauma) is gendered and somewhat stereotypical, with his mother being portrayed as being more externally emotional than his father is. It may also be evidence of gendered ways of dealing with issues when Jason's father leaves the room and lets his mother deal with Jason's response to the newspaper news about the lawsuit. There is evidence also of gendered ways of disciplining the child.

Within the parenting style literature, research supports the presence of differing reactions and expressiveness to disability among mothers and fathers as they attempt to adapt to the disability (Hornby, 1992a; Hornby, 1992b; Little, 2002). In *Friday Night Lights,* the mother and father openly and directly differ in the extent to which they express their emotions. These gendered differences are supported by research, to wit: “In comparison with fathers, mothers reported being significantly more expressive” (Halberstadt et al., 1995, p. 100) and “Other research [Boyd & Beail, 1994; Krugman, 1996] suggests that these types of differences may be due to men valuing other types of coping experiences for themselves and socio-cultural biases that discourage men from acknowledging their emotional pain and seeking help” (Little, 2002, p. 569). Due, then, to cultural biases, men are expected to be cool and keep their emotions under control. Yet it is evident in *Friday Night Lights* series that the father is also experiencing intense reactions to his son's initial diagnosis.

In terms of implications, it may well be that some of the social relational memes about gender roles portrayed in *Friday Night Lights* series have been transmitted to audience members subconsciously. That is, the social relational values that this show purveys about gender and gender roles might have been absorbed in part by the target audience, which research shows is likely. As Lauzen, Dozier, and Horan (2008) note: “When applied to prime-time television programming, this literature suggests that the basic social roles assigned to female and male characters by storytellers are tremendously important contributors to the construction and maintenance of gender stereotypes” (p. 201).

- *Stereotypical Views of Disability*

There is evidence of stereotypical viewing of the person with disability and his/her ability to support him/herself. Jason's mother is concerned about his future and his ability to support himself. For his part, Jason challenges the stereotypical perceptions of individuals with a disability. He also challenges the game that lawyers play: "You know, is that all I am here? Huh? Just some cripple boy that you can wheel out in front a bunch of people to make some money off me?"

This behavior signifies his refusal to be socially conditioned into a dependency within his own community and is contrary to the stereotypical socialization expectations of children to be dependent on their parents in general (Stolz, 2010) and media portrayals of the individuals with disabilities as being unable to support themselves or have a successful life (Black & Pretes, 2007).

Serious injury such as a permanent disability is however perceived by the Streets as the direct threat of being stigmatized or crippled for life. McRuer (2006) calls this threat "compulsory able-bodiedness" (p. 5). Jason's parents represent the ableist tendencies to view disability/illness as stigmatizing (Stolz, 2010) and thus we have Jason's father pushing him to get back to a normal routine to avoid taking any chances on being stuck with the stigma of being seriously injured (disabled). This position reflects however a lack of acknowledgement on the part of the parents that "the problem of disability" is "in society rather than in the individual" (Stolz, 2010, p. 13).

Thus, the media and sport culture and the community in Dillon, Texas, the setting for this show, define the concepts of normalcy, and those with disabilities fulfill those expectations (Stolz, 2010). Instead of his school making adjustments so that Jason can play with his team even though he uses a wheelchair, he is given a one-night honorary captain's send-off by the audience and broadcast media: Announcer: "Ladies and gentlemen, please welcome tonight's honorary captain, number 6, Jason Street." The crowd responds with cheers and chanting and Jason waves back to the crowd and leads the charge through the banner as the team enters the field, representing that, at least for the recent past, he is still seen as a leader by the team, coach, and community.

Lawyers in the series too are portrayed as using certain strategies that depend on the perceptions of disability – many of them stereotypical – to win the case, such as appealing to people's emotions and engendering a sense of pity for the disabled in the courthouse. In the lawsuit story thread, Jason's lawyer says, "I don't care who pays us. But I want you to have a good look at that boy right there. Because when I put him on the stand in his wheelchair and he tells his story, there is not a jury in Carr County that is not gonna give us three times what it is we're asking for." In this sense, the embeddedness of legal, social and cultural norms regarding disability create skewed advantages for different parties. The parents initially consider and embark upon the lawsuit because the laws and regulations about settlements for football players put them at a disadvantage. They are set up to support the school interests but not those of the parents of football players.

In light of social relational theory (Kuczynski, 2003; Kuczynski & Parkin, 2007), the Street family's position however demonstrates their ability to marshal the cultural resources available to them as individuals, despite the apparent lack of such provisions from their community. Parents of a child with a disability are encouraged by this example to exercise their right to draw from the cultural resources, whether they are available to them immediately or not. The communities in which parents of children with a disability live in turn should provide the programs that emphasize such agency and that provide the resources to the parents to act upon it.

- *Socialization and Enculturation within the Community*

As illustrated above, the community has a strong influence on Jason's family life although the community's response to Jason's situation is inconsistent. They provide a great deal of emotional support for Jason when he is a successful player, but after his injury they are not as helpful in providing the necessary financial and educational and counseling support for his family to help them take care of Jason and his needs.

Throughout the series, high expectations – even unrealistic ones – are held by the town community for Jason and his team. Mass media, most potently in the form of television and radio coverage of their games, also amplify the stratospheric expectations of a football-saturated community and their emotional requirement that their beloved Panthers football team always come out on top:

> Announcer: "The Panthers should win this game, there is no question about it. With all the buildup and the hope of this season, and the talent they have on this team… it is that great offensive backfield for Dillon that has everybody's eye, Jason Street, the quarterback…"

This puts a great deal of pressure on Jason, his teammates, Coach Taylor and vicariously on Jason's parents. At the same time, on more than one occasion Jason explicitly states, "You don't go against the Panthers" indicating his understanding of their significance and influence in the community. Importantly, Jason's statement indicates that he and his family have internalized the ideals, values, and expectations of football players within the cultural milieu that exists within the Dillon fictional town community, an action that represents the process of enculturation into that community (Kuczynski, Navara, & Boiger, 2011).

Unfortunately, the long term support that Jason needs from his community is not present, as Jason points out that pancake dinners and town fundraisers will only last for so long and that he and his family need to think long-term.

Neither did we come across any mention of counseling support for Mitchell and Joanne Street as parents of a young man with a disability. These might well have been cultural resources to which they were entitled, legally speaking. As noted earlier, the Dillon community appeared to have failed to provide these means to the Street family. This is ironic, given the fact that Coach Taylor's wife is a guidance counselor at the high school and that we see the school provide counseling support for football players in terms of their academics and social needs.

Jason's parents, like any parent who learns about their child's disability, are fearful, and they need to go through the process of grieving a loss of their dream child and eventually making new dreams in order to successfully cope with a disability (Taub, 2006). "[F]ear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one?" (McGill Smith, 2003, p. 2).Therefore, they need counseling for Jason and for themselves from Jason's school. According to the literature, "Professional school counselors are often the designated (and sometimes lone) advocates for children with special needs and their parents in an intricate and often intimidating educational bureaucracy" (Erford, House, & Martin, 2003, p. 18).

Lack of professional counseling support and the fear of the future do not, however, immobilize Jason's parents. On the contrary, they deal with the adjustments to a disability one day at a time. They remodel the house to welcome and accommodate Jason when he returns home from the rehabilitation center. They seek legal counsel to advocate for Jason and his financial needs. While these actions are indicators of healthy family functioning in times of a crisis (Lightsey & Sweeney, 2008; Olson, 2011) and family adjustment and or adaptation to a disability (Butera-Prinzi, Charles, & Story, 2014), the resources from which they draw to exercise such agency are the individual and relational resources that had either resided in them or that they were able to garner through their personal efforts, mutual responsiveness and shared supportive affect within their relationships (Killen & Smetana, 2014). They are not cultural resources (Kuczynski, 2003; Kuczynski & Parkin, 2007) that arguably should have been conveyed to them by their community. Hence the "takeaway" or message to communities at large and their respective governing bodies might be that they should make appropriate legal and counseling support provisions for their citizens who have children with disabilities and that they should motivate their community members to make such programs and initiatives available to the members who need them the most, the families of children with disabilities.

Conclusion

By depicting both sides (the good and the bad) of the lived experience associated with a teen athlete acquiring a disability, and by deconstructing the intricate network of influences from the community and the diverse power and relational dynamics between Jason Street and his parents, *Friday Night Lights* presents a more than typically realistic social representation of adolescent disability and of child/parent relations in our current cultural zeitgeist.

As parents who are on the cusp of having to let go of their daily authority and oversight of Jason, Joanne and Mitchell Street are seen as struggling mightily with a future for their son that is shadowed in doubt. Jason is not pictured as a supercrip, and his parents are not presented as superheroic. As portrayed, these depictions form a counternarrative to the stereotypical representations of disability in the popular culture and media (Black & Pretes, 2007; Crow, 2014). However, the Streets are also depicted as conservative middle-class Americans of good character who view disability as an end to all good things – especially football – rather than as a challenge to acquire a different, but happy and productive life for their son.

References

Agosto, V. (2014). Scripted curriculum: What movies teach about dis/ability and black males. *Teachers College Record, 116*(4), 1-24.

Armstrong, T. (2004). Dumb and dumber: The concept of "learning disabilities." *Paths of Learning*, 19, 8-14.

Baker, J. K., Baker, B. L., & Crnic, K. A. (2014). Parent-child interaction over time in families of young children with borderline intellectual functioning. *Journal of Family Psychology, 28*(3), 326-335. doi:10.1037/a0036537

Berg, P. (2007). [Director]. *Friday Night Lights* [Television Series]. Universal City, CA: Universal.

Berger, R. J. (2015). Disability and humor in film and television: A content analysis. In R. J. Berger & L. S. Lorenz (Eds). *Disability and qualitative inquiry: Methods for rethinking an ableist world*. London: Routledge.

Bernstein, A., & Blain, N. (2002). Sport and the media: The emergence of a major research field. *Culture, Sport, Society, 5*(3), 1-30.

Berry, G. L. (1998). Black family life on television and the socialization of the African American child: Images of marginality. *Journal of Comparative Family Studies*, *29*(2), 233-242.

Biklen, D., & Bogdan, R. (1977). Media portrayals of disabled people: A study in stereotypes. *Interracial Books of Children Bulletin, 8*(6-7), 4-9.

Black, J., & Barnes, J. (2015). Fiction and social cognition: The effect of viewing award-winning television dramas on theory of mind. *Psychology of Aesthetics, Creativity and the Arts, 9*(4), 423-429.

Black, R. S., & Pretes, L. (2007). Victims and victors: Representation of physical disability on the silver screen. *Research & Practice for Persons with Severe Disabilities*, *32*(1), 66-83.

Bogdan, R. (1988). *Freak show: Presenting human oddities for amusement and profit*. Chicago: University of Chicago Press.

Bogdan, R. (1993). In defense of *freak show*. *Disability, Handicap & Society*, *8*(1), 91-94.

Burke, M. M., & Hodapp, R. M. (2014). Relating stress of mothers of children with developmental disabilities to family-school partnerships. *Intellectual and Developmental Disabilities, 52*(1), 13-23.

Butera-Prinzi, F., Charles, N., & Story, K. (2014). Narrative family therapy and group work for families living with acquired brain injury. *The International Journal of Narrative Therapy and Community Work, (1)*, 51-60.

Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., & ... Harrington, G. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26*(2), 119-132.

Cherney, J. L., & Lindemann, K. (2014). Queering Street: Homosociality, masculinity, and disability in Friday Night Lights. *Western Journal of Communication*, *78*(1), 1-21. doi:10.1080/10570314.2013.792388

Cole, J. (2011, September 18). At Emmy Awards, “Friday Night Lights’ finally punches through to the end zone. The Canadian Press. Retrieved from http://www.winnipegfreepress.com/arts-and-life/entertainment/TV/at-emmy-awards-friday-night-lights-finally-punches-through-to-the-end-zone-130096438.html

Creswell, J. W. (2007). *Research design: Qualitative, quantitative, and mixed methods approaches (3rd Ed*.). Thousand Oaks, CA: Sage.

CROW, L. (2014). Scroungers and Superhumans: Images of disability from the summer of 2012: A Visual Inquiry. *Journal of Visual Culture*, *13*(2), 168-181. doi: 10.1177/1470412914529109

DARLING, C. A., SENATORE, N., & STRACHAN, J. (2012). Fathers of children with disabilities: Stress and life satisfaction. *Stress & Health: Journal of the International Society for the Investigation of Stress*, *28*(4), 269-278. doi: 10.1002/smi.1427

DEVLIEGER, P., GROSVENOR, I., SIMON, F., VAN HOVE, G., & VANOBBERGEN, B. (2008). Visualizing disability in the past. *Paedagogica Historica: International Journal of the History of Education, 44*(6), 747-760. doi: 10.1080/00309230802531757

ELLIOTT, T. R., & BYRD, E. K. (1983). Attitude change toward disability through television portrayal. *Journal of Applied Rehabilitation Counseling, 14.*

ELLIS, K. (2012). Because of rather than in spite of: *Friday Night Lights* important cultural work of intersecting disability and masculinity. *IM8: Interactive Media E-Journal*, 2012 - ISSN 1833-0533. Retrieved from http://imjournal.murdoch.edu.au/

ENGLAND, K. E. (2008). Media representations of attention deficit disorder: Portrayals of cultural skepticism in popular media. *Journal of Popular Culture*, *41*(1), 91-117.

FARRELL, A. F., & KRAHN, G. L. (2014). Family life goes on: Disability in contemporary families. *Family Relations*, *63*(1), 1-6. doi:10.1111/fare.12053

FERGUSON, G. (2010). The family on reality television: Who's shaming whom? *Television & New Media*, *11*(2), 87-104. doi: 10.1177/1527476409357595

FINK, M. (2013). 'People who look like things': Representations of disability in the Simpsons. *Journal of Literary & Cultural Disability Studies, 7*(3), 255-270.

GERBNER, G., GROSS, L., MORGAN, M., & SIGNORIELLI, N. (1986). Living with television: The dynamics of the cultivation process. In Bryant, J., & Zillmann, D. (Eds.). (1986). *Perspectives on media effects* (pp. 17-40). Hillsdale, NJ: Lawrence Erlbaum Associates.

GLASSCOCK, R. (2000). Practice applications of research: A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatric Nursing, 26,* 407-410.

GORMAN, B. (2010). Final 2009-10 Broadcast primetime show average viewership. Retrieved from http://tvbythenumbers.zap2it.com/2010/06/16/final-2009-10-broadcast-primetime-show-average-viewership/54336/

GROENING, M. (CREATOR). (1989). *The Simpsons* [Television Series]. USA: Fox.

GUVEN, U. Z. (2011). Social class and family on screen: Do prime-time television series "create" images of family in Turkey? *Global Media Journal: Turkish Edition*, *2*(3), 69-83.

HALBERSTADT, A. G., CASSIDY, J., STIFTER, C. A., PARKE, R. D., & FOX, N. A. (1995). Self-expressiveness within the family context: Psychometric support for a new measure. *Psychological Assessment*, 7(1), 93-103.

HANNAM, K. (2014). The portrayal of autism in film, post Rainman. *Good Autism Practice, 15*(1), 91-99.

HARRIS, R. (2009). *A cognitive psychology of mass communication* (5th Ed). New York, NY: Routledge.

HARTNETT, A. (2000). Escaping the ‘Evil Avenger’ and the ‘Supercrip’: Images of disability in popular television. *The Irish Communications Review, 8*, 21-29.

HASSON, D. (2016). *Representing youth with disability on television*. New York, NY: Peter Lang.

HAYES, M. T., & BLACK, R. S. (2003). Troubling signs: Disability, Hollywood movies and the construction of a discourse pity. *Disability Studies Quarterly, 23*(2), 114-132.

HAYES, S. A., & WATSON, S. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642.

HEFFERNAN, V. (2006, October 3). Friday Night Lights: On the field and off, losing isn’t an option [Review]. The New York Times. Retrieved from http://www.nytimes.com/2006/10/03/arts/television/03heff.html?_r=0

HOLTON, A. E. (2013). What’s wrong with Max? Parenthood and the portrayal of autism spectrum disorders. *Journal of Communication Inquiry*, *37*(1), 45-63. doi: 10.1177/0196859912472507

HOLTON, A. E., FARRELL, L. C., & FUDGE, J. L. (2014). A threatening space? Stigmatization and the framing of autism in the news. *Communication Studies*, *65*(2), 189-207. doi:10.1080/10510974.2013.855642

HORNBY, G. (1992a). Counseling family members of people with disabilities. In R. Brown & S. Robertson (Eds.), *Rehabilitation counseling*. London: Chapman & Hall.

HORNBY, G. (1992b). A review of fathers’ accounts of their experiences of parenting children with disabilities. *Disability, Handicap, and Society, 7*(4), 363-374.

HUANG, Y. T., OSOSKIE, J., & HSU, T. (2011). Impact on marital and sibling relationship of Taiwanese families who have a child with a disability. *Journal of Comparative Family Studies, 42*(2), 213-232.

JORDAN, A. B. (1995). The portrayal of children on prime-time situation comedies. *Journal of Popular Culture*, *29*(3), 139-147.

KAMA, A. (2004). Supercrips versus the pitiful handicapped: Reception of disabling images by disabled audience members. *Communications: The European Journal of Communication Research*, *29*(4), 447-466.

KATIMS, J. (Creator). (2010). *Parenthood* [Television Series]. United States: Universal Media Studios.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, *34*(5), 582-592. doi:10.1046/j.1365-2648.2001.01787.x

Killen, M., & Smetana, J. E. (Eds.). (2014). *Handbook of moral development* (2nd Ed). New York, NY: Psychology Press.

Kohlbacher, F. (2006). The use of qualitative content analysis in case study research. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 7*(1). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/75/154).

Kubicek, L. F., Riley, K., Coleman, J., Miller, G., & Linder, T. (2013). Assessing the emotional quality of parent-child relationships involving young children with special needs: Applying the constructs of emotional availability and expressed emotion. *Infant Mental Health Journal*, *34*(3), 242-256. doi:10.1002/imhj.21384

Kuczynski, L. (2003). Beyond bidirectionality: Bilateral conceptual frameworks for understanding dynamics in parent-child relations. In L. Kuczynski (Ed.), *Handbook of dynamics in parent-child relations* (pp.3-20). Thousand Oaks, CA: Sage.

Kuczynski, L. (1984). Socialization goals and mother–child interaction: Strategies for long-term and short-term compliance. *Developmental Psychology*, *20*(6), 1061-1073. doi:10.1037/0012-1649.20.6.1061

Kuczynski, L., Navara, G., & Boiger, M. (2011). The social relational perspective on family acculturation. In Chuang S. & Moreno R. (Eds.)*, Immigrant children: Change, adaptation, and cultural transformation* (pp. 171-192). Lanham, MD: Lexington Books.

Kuczynski, L., & Parkin, C. M. (2009). Pursuing a dialectical perspective on transaction: A social relational theory of micro family processes. In A. Sameroff (Ed.), *Transactional processes in development* (pp. 247-268). Washington, DC: APA Books.

Kuczynski, L., & Parkin, C. M. (2007). Agency and bidirectionality in socialization. In J. E. Grusec & P. Hastings (Eds.). *Handbook of socialization: Theory and research* (pp.259-283). New York, NY: Guilford Press.

Kuczynski, L., & Hildebrandt, N. (1997). Models of conformity and resistance in socialization theory. In J. E. Grusec & L. Kuczynski (Eds.), *Parenting and the internalization of values: A handbook of contemporary theory* (pp. 227-256). New York, NY: Wiley.

Lawson, A., & Fouts, G. (2004). Mental illness in Disney animated films. *Canadian Journal of Psychiatry*, *49*(5), 310-314.

Lauzen, M., Dozier, D., & Horan, N. (2008). Constructing gender stereotypes through social roles in prime-time television. *Journal of Broadcasting & Electronic Media, 52*(2), 2008, 200-214.

Lightsey, O. R., & Sweeney, J. (2008). Meaning in life, emotion-oriented coping, generalized self-efficacy, and family cohesion as predictors of family satisfaction among mothers of children with disabilities*. Family Journal: Counseling and Therapy for Couples and Families, 16*(3), 212-221.

Little, L. (2002). Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. *Pediatric Nursing, 28*(6), 565-70.

Lollis, S., & Kuczynski, L. (1997). Beyond one hand clapping: Seeing bidirectionality in parent-child relations. *Journal of Social and Personal Relationships, 14*(4), 441-461.

Marinan, J. J. (2014). More than tattoos: Rhetorical discourse and autism in Girl with the Dragon Tattoo. *PsyArt, 2*(5). Retrieved from http://www.psyartjournal.com/article/show/marinan-more_than_tattoos_rhetorical_discourse_a

Mayring, P. (2000). Qualitative content analysis [28 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 1*(2). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1089/2386

McGill Smith, P. (2003). You are not alone: For Parents when they learn their child has a disability. *News Digest, 20*, 1-16.

McManus, B. M., Mandic, C. G., Carle, A. C., & Robert, S. A. (2012). The effect of parent-child function on physical activity and television viewing among adolescents with and without special healthcare needs*. International Journal of Disability, Development and Education, 59*(3), 305-319.

McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: New York University Press.

McStay, R., Dissanayake, C., Scheeren, A., Koot, H., & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism: The International Journal of Research & Practice, 18*(5), 502-510.

Meirsschaut, M., Roeyers, H., & Warreyn, P. (2011). The social interactive behavior of young children with autism spectrum disorder and their mothers. Is there an effect of familiarity of the interaction partner? *Autism, 15*(1), 43-64.

Mittell, J. (2001). Cartoon realism: genre mixing and the cultural life of *The Simpsons*. *Velvet Light Trap 47*, 15+. *Academic OneFile*, Accessed 12 Jan. 2017.

Moore, M. I. (1992). The family as portrayed on prime-time television, 1947-1990: Structure and characteristics. *Sex Roles*, *26*(1/2), 41-46.

Nelson, J. A. (1994). *The disabled, the media, and the information age*. Westport, CT: Greenwood Press.

Newton, E. K., Laible, D., Carlo, G., Steele, J. S., & McGinley, M. (2014). Do sensitive parents foster kind children, or vice versa? Bidirectional influences between children's prosocial behavior and parental sensitivity.

Developmental Psychology, *50*(6), 1808-1816. doi:10.1037/a0036495

OWEN, P. R. (2012). Portrayals of schizophrenia by entertainment media: A content analysis of contemporary movies. *Psychiatric Services, 63*(7), 655-659.

PEHLKE, T. I., HENNON, C. B., RADINA, M. E., & KUVALANKA, K. A. (2009). Does father still know best? An inductive thematic analysis of popular TV sitcoms. *Fathering*, *7*(2), 114-139. doi:10.3149/fth.0702.114

PENN, A. (DIRECTOR). (1962). *The miracle worker* [Motion Picture]. United States: Playfilm Productions.

PIRKIS, J., BLOOD, R. W., FRANCIS, C., & MCCALLUM, K. (2006). On-screen portrayals of mental illness: Extent, nature, and impacts. *Journal of Health Communication*, *11*(5), 523-541. doi:10.1080/10810730600755889

PRESTON, J. M. (2014). Fantasizing disability: Representation of loss and limitation in popular television and film. Doctoral Dissertation. The University of Western Ontario.

REDMAN, J. H. E. (2003). The American happy family that never was: Ambivalence in the Hollywood family melodrama. *European Journal of American Culture*, *22*(1), 49-69.

RIDER, E. (1994). Media portrayals of people with handicaps: Does accuracy matter? *Studies in Popular Culture, 16(2),* 85-93.

RIEGER, A., & MCGRAIL, J. P. (2015). Relationships between humor styles and family functioning in parents of children with disabilities. *Journal of Special Education*, *49*(3), 188-196. doi:10.1177/0022466914525994

RIEGER, A., & MCGRAIL, J. P. (2013). Coping humor and family functioning in parents of children with disabilities. *Rehabilitation Psychology, 58*(1), 89-97*.*

ROGERS, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education, 34*(3), 136-143.

SAFRAN, S. P. (1998). The first century of disability portrayal in film: An analysis of the literature. *Journal of Special Education*, *31*(4), 467-479.

SCHALK, S. (2016). Re-evaluating the supercrip. *Journal of Literary & Cultural Disability Studies, 10*(1), 71-86.

SCHARRER, E. (2001). From wise to foolish: The portrayal of the sitcom father, 1950s-1990s. *Journal of Broadcasting & Electronic Media*, *45*(1), 23-40. doi:10.1207/s15506878jobem4501_3

SCHERMAN, E. L. (2008). Of use to me: A content analysis of physical disability in Disney films. Paper presented at the annual meeting of the NCA 94th Annual Convention, San Diego, CA. Retrieved from http://citation.allacademic.com/meta/p256210_index.html

SCHWARTZ, D., BLUE, E., MCDONALD, M., GIULIANI, G., WEBER, G., SEIRUP, H., & ... PERKINS, A. (2010). Dispelling stereotypes: Promoting disability equality through film. *Disability & Society*, *25*(7), 841-848. doi:10.1080/09687599.2010.520898

SHALES, T. (2006, October 3). 'Friday Night' Kicks off with a great formation [Review]. The Washington Post. Retrieved from http://www.washingtonpost.com/wp-dyn/content/article/2006/10/02/AR2006100201439.html

SKILL, T., & WALLACE, S. (1990). Family Interactions on primetime television: A descriptive analysis of assertive power interactions. *Journal of Broadcasting & Electronic Media*, *34*(3), 243-262.

STOLZ, S. M. (2010). Disability trajectories: Disabled youths' identity development, negotiation of experience and expectation, and sense of agency during transition [Doctoral Dissertation]. San Diego, University of California (Access No. 3403098). Retrieved from https://escholarship.org/uc/item/7zg9w5ht#page-1

TANNER, L. R., HADDOCK, S. A., ZIMMERMAN, T. S., & LUND, L. K. (2003). Images of couples and families in Disney feature-length animated films. *American Journal of Family Therapy, 31*(5), 355-373. doi:1080/01926180390223987

TAUB, D. J. (2006). Understanding the concerns of parents of students with disabilities : Challenges and roles for school counselors. *Professional School Counseling, 10*(1), 52-57.

VACCA, J. J. (2013). The parenting process from the father's perspective: Analysis of perceptions of fathers about raising their child with autism spectrum disorder. *Best Practice in Mental Health*, *9*(2), 79-93.

VON SIKORSKI, C., & SCHIERL, T. (2014). Attitudes in context: Media effects of salient contextual information on recipients' attitudes toward persons with disabilities. *Journal of Media Psychology: Theories, Methods, and Applications*, *26*(2), 70-80. doi:10.1027/1864-1105/a000113

WAHL, O., HANRAHAN, E., KARL, K., LASHER, E., & SWAYE, J. (2007). The depiction of mental illness in children's television programs. *Journal of Community Psychology, 35*(1), 121-133.

WARZAK, W. J., MAJORS, C. T., HANSELL, A. G., & ALLAN, T. M. (1988). An analysis of televised presentations of disability. *Rehabilitation Psychology, 33*, 105-112.

WEITLAUF, A. S., VEHORN, A. C., TAYLOR, J. L., & WARREN, Z. E. (2012). Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism: International Journal of Research and Practice*, *18*(2), 194-198.

ZHANG, L., & HALLER, B. (2013). Consuming image: How mass media impact the identity of people with disabilities. *Communication Quarterly*, *61*(3), 319-334. doi:10.1080/01463373.2013.776988

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Le handicap brouille-t-il le genre?
La mise en « Portrait » du handicap dans le journal *Libération*

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Article original ● Original Article

Résumé

En partant d'une approche intersectionnelle, cet article propose de mettre en évidence de quelle manière les discours journalistiques construisent une image spécifique des femmes et des hommes en situation de handicap. L'analyse porte sur un corpus de trente portraits parus durant une vingtaine d'années dans le journal français *Libération*. Les résultats montrent que le handicap intervient pour brouiller les frontières classiques du genre, ainsi qu'une forte mise en évidence du caractère extraordinaire des personnes portraitisées qui prennent un rôle de « modèles » pour les lecteurs.

Mots-clés : handicap, média, genre, représentation sociale, journalisme

Abstract

Based on an intersectional approach, this article aims to underline the manner in which mass media can build a particular representation of women and men with disabilities. It analyses thirty portraits published by the French newspaper Libération during twenty years. The results show how disability interferes with the traditional boundaries of gender. They also highlight the exceptional nature of the portrayed people who become “role models” for the others, readers of the newspaper.

Keywords: disability, newspaper, gender, social representation, journalism

Invisibilité et dépréciation résument en partie les conclusions d'études généralistes sur les représentations des femmes dans la presse en France (Bertini, 2007; Coulomb-Gully & Méadel, 2012; GMMP[1], 2010), comme celles de recherches médiatiques plus ciblées sur l'image des femmes en politique ou dans les pratiques professionnelles : « Les conclusions de ces travaux vont dans le sens d'une sous-médiatisation des femmes et d'une stéréotypisation au travers d'un traitement porté sur les tenues vestimentaires, la vie privée, l'explication de leur place par un entourage masculin, etc. » (Damian-Gaillard, Montañola, & Olivesi, 2014, p. 15).

Les femmes sont invisibles, car elles sont objectivement cinq fois moins nombreuses que les hommes (Coulomb-Gully & Méadel, 2012), mais leur invisibilité numérique dans la presse est accentuée par le piètre statut intellectuel et la position subalterne qui leur est octroyée. Ainsi, l'enquête sur la place et l'image de la femme dans les médias réalisée en 2006 par l'Association des Femmes Journalistes[2] (Bertini, 2007) fait apparaître que leur parole est moins retranscrite sur la scène publique que la parole masculine, qu'elles n'occupent pas de position professionnelle prestigieuse ou bien que leur statut professionnel n'est pas mentionné, et qu'elles sont qualifiées en fonction de leur statut matrimonial ou familial, statut qui confère leur légitimité[3]. Les recherches posent le même constat sur les domaines de compétence des femmes. L'Observatoire mondial des médias sur le Genre (GMMP) montre que « la séparation des sexes est […] une séparation des mondes : dans celui des hommes, il y a le sport, la politique, le monde syndical, la création ou l'expertise. Dans celui des femmes, il y a… des hommes, puisqu'elles n'ont pas non plus d'univers qui leur serait exclusivement ou même massivement réservé » (Coulomb-Gully & Méadel, 2012, p. 21).

Les hommes, quant à eux, sont représentés dans les médias de façon moins anonyme que les femmes; ils sont les sujets des reportages, ou occupent des positions d'experts dans les rubriques réputées de politique ou d'économie. Bien insérés dans la vie sociale, leur statut professionnel est largement mentionné et prend une place importante, au détriment de leur statut familial, qui relève alors de la vie privée. Les hommes apparaissent ainsi « en creux » et peut-être mal étudiés, car les études sur le genre dans les médias, nécessairement focalisées sur les femmes dans un premier temps, trouveraient de nouveaux éclairages à ne pas séparer le féminin du masculin : « Le masculin a longtemps été impensé, en grande partie parce que conçu comme étant la norme, donc universel et neutre, ou plus exactement "neutralisé". Il n'en est évidemment rien, et ce que révèlent les travaux sur les hommes qui se développent dans le sillage des recherches sur les femmes, c'est que la construction de la masculinité n'a rien à envier à celle de la féminité » (Coulomb-Gully & Méadel, 2012, p. 19). Quelques contre-stéréotypes - des hommes extériorisent leurs émotions et s'occupent de leurs enfants (Damian-Gaillard, Montañola, & Olivesi, 2014) - n'occultent pas l'injonction forte d'une image masculine puissante et conquérante. Aussi, le poids normatif de masculinité peut apparaître aussi douloureux pour les hommes que le poids normatif de féminité pour les femmes (Coulomb-Gully & Méadel, 2012).

Le portrait de presse

Issu de l'hybridation entre une tradition picturale et une tradition littéraire, « le portrait de presse emprunte à toutes les ressources héritées » (Wrona, 2012, p. 19). Tour à tour dénommé portrait, récit de vie ou encore biographie médiatique, le « portrait de presse »

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[1] « Qui figure dans les nouvelles? » Rapport national 2010 du GMMP - Global media monitoring project (Observatoire mondial des médias sur le Genre). Les titres français de presse analysés sont *Le Figaro, Libération, Le Monde, Ouest France, Le progrès, Le Parisien,* à la date du 10 novembre 2009. http://whomakesthenews.org

[2] L'enquête menée par l'Association des femmes journalistes (AFJ) s'est appuyée sur les articles publiés le 10 mai 2006 dans *Les Dernières Nouvelles d'Alsace, Le Figaro, L'Humanité, Libération, Le Monde, Ouest France, Le Parisien.*

[3] Une citation sur cinq émane d'une femme; une femme sur trois est citée sans sa profession contre un homme sur vingt; 18 % des femmes sont citées avec un lien de parenté contre 4 % des hommes.

s'inscrit dans un genre journalistique qui mêle forme et contenu : « faire le portrait d'un personnage c'est, à la manière d'un peintre, le faire vivre (par des mots) pour les lecteurs, le raconter comme on retrace un événement. Une description, donc, et un récit. » (Agnès, 2008, p. 271).

De la narrativité, l'art du portrait ne prend pas simplement la description de la vie ou d'un pan de la vie d'une personne choisie, vis-à-vis de laquelle un(e) journaliste demeurerait faussement transparent(e) et non impliqué(e). Au contraire, c'est une rencontre que le portrait met en scène, entre un(e) journaliste et une personne contemporaine, qui justifie d'une attention médiatique par son implication dans une action personnelle (Agnès, 2008; Wrona, 2012).

L'action réalisée, motif de l'entrevue, peut varier : publication d'un livre, sortie d'un film, réalisation d'un exploit, fait de société… Mais la raison explicite de la rencontre peut n'être qu'un prétexte pour aborder des aspects plus personnels de la vie de la personne interviewée. En effet, la forme journalistique du portrait permet d'insérer des éléments d'intimité qui sont censés éclairer la personnalité de la personne portraitisée. « Des anecdotes sont souhaitables pour faire pénétrer dans l'intimité de la personne, de son histoire » (Agnès, 2008, p. 273). Faire exister la personne rencontrée dans un contexte familier, avec des détails quotidiens, décrire un moment intime à son domicile ou autour d'un café, transforme une personnalité en personne de proximité, vivant la même vie ordinaire que le lecteur potentiel (Durrer, 2000).

Ce dévoilement de la personnalité, cette immersion dans l'intimité de la personne, donnent au portrait ce ton de proximité qui touche le lecteur (Agnès, 2008; Legavre, 2004), et lui confère une place entre information et peopolisation (Dakhlia, 2010). D'autant que la description de la personnalité s'appuie sur quelques traits habilement choisis, résumés par un qualificatif souvent repris en titre qui va donner l'angle[4] de la narration. « Le trait qui résume la personnalité, qui caractérise le personnage, sera souvent notre "message essentiel" » (Agnès, 2008, p. 273). L'histoire qui est racontée repose sur la finesse du choix des événements biographiques; il s'agit alors pour les journalistes de « bien choisir parmi les faits glanés ceux qui sont le plus significatifs, qui vont le mieux faire comprendre la personne et son évolution » (Agnès, 2008, p. 273).

S'il est recommandé pour un portrait de porter le focus sur un trait emblématique qui va guider la narration, une autre règle est souvent enseignée aux journalistes[5] : « la description physique du sujet est un élément du portrait : son regard, son allure, ses gestes, ses tics, ses habits, ses goûts… » (Agnès, 2008, p. 273). Traits du visage, couleur des yeux, coiffure, stature, habillement, timbre de voix, langage… les détails choisis pour décrire la personne concernée permettent de visualiser ce qui ne peut l'être par la seule interview. Cette description constitue le versant narratif de l'image, l'autre versant étant le visuel photographique qui accompagne systématiquement un portrait.

La rubrique « Portrait » du journal *Libération*

Du point de vue de la mise en page, la rubrique « Portrait » du quotidien *Libération* respecte les contraintes éditoriales du genre et s'insère dans un rubriquage dédié. Celle-ci se décompose en un article principal entouré d'un surtitre, d'un titre et d'un sous-titre. La titraille des portraits - en particulier pour ce journal dont un signe distinctif est le soin accordé à la « bonne formule » du titre - donne d'emblée deux éléments clés au lecteur : le nom et une focale sur un trait essentiel de la personne interviewée permettant souvent d'appuyer l'angle de l'article. Une photo occupant environ un tiers de l'espace est toujours présente. Enfin, un encadré biographique synthétise la vie de la per-

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[4] Choix narratifs qui déterminent le déroulé du portrait.

[5] La notion de « genre journalistique » est mobile et varie selon les manuels. Nous nous en référerons dans cet article au genre journalistique tel qu'il est défini par Yves Agnès (2008).

sonne en cinq ou six dates clés. Dans le quotidien, le portrait est particulièrement mis en valeur, se déployant sur la dernière page du journal, « l'une des pages les plus prisées dans l'univers de la presse » (Legavre, 2004, p. 213), faisant partie du contrat général de lecture (Veron, 1985) que ce journal propose à ses lecteurs. Le journal, à travers ses pratiques et son savoir-faire collectivement construit, a été précurseur pour standardiser la rubrique. Ainsi, l'âge, la description physique ou l'information sur les origines sociales de la personne interviewée sont des éléments exigés, tout comme la révélation d'informations de sa vie privée : « Un peu de rencontre, un peu de description physique, un peu de papa-maman, un peu d'itinéraire, un peu d'étude de caractère », explique un journaliste de la rubrique interrogé par Jean-Baptiste Legavre (2004, p. 228).

Les femmes et les hommes en situation de handicap portraitisés dans *Libération*

L'étude des personnes en situation de handicap, et plus particulièrement l'étude des portraits, nous paraît tout à fait heuristique pour contribuer à mieux comprendre les représentations véhiculées par la presse généraliste quotidienne. En effet, posées d'emblée « hors-norme » dans les représentations sociales, nous analysons dans cet article la façon dont les médias montrent la féminité et la masculinité des personnes en situation de handicap, lorsque les normes habituelles du genre ne peuvent s'appliquer à première vue, et lorsque la situation de handicap peut en brouiller les représentations habituelles.

Cet article interroge l'articulation handicap-genre dans la sphère publique, à partir d'un corpus de portraits constitué d'articles issus de la rubrique éponyme du quotidien français *Libération*. Les articles ont été sélectionnés avec le mot-clé *handicap* dans les archives en ligne du journal[6].

Trois critères ont présidé au choix :

- la référence explicite et constante à la situation de handicap;
- la voix narrative à la personne en situation de handicap et non à une personne de son entourage;
- la prise en compte de l'ensemble de la période de la rubrique « Portrait » en ligne, à savoir 1995-2014[7].

Depuis 1995, trente articles[8] dans la rubrique « Portrait » du journal *Libération* mettent en scène une personne en situation de handicap explicite et prégnant, dix articles représentent une femme[9] et vingt articles concernent un homme. Nous avons adopté une méthode d'analyse thématique de contenu (Paillé & Mucchielli, 2012) pour analyser ce corpus à partir des éléments suivants - le motif de la rencontre, les incapacités, l'apparence physique, la situation familiale ou conjugale, la situation sociale ou professionnelle - en les interrogeant via le prisme du genre.

Analyse : caractéristiques des portraits

- *Le motif de la rencontre*

« Ce ne sont pas, de fait, les valeurs morales, le génie esthétique ou politique des individus qui motivent leur portrait médiatique, mais bien plutôt un événement, qui assure la mise en publicité de leurs qualités individuelles. L'homme du jour surgit sur la scène publique par un coup d'éclat, une publication, un discours ou une initiative qui, littéralement, “font date”».

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[6] www.liberation.fr. La recherche multicritère permet d'accéder aux rubriques.

[7] Si la recherche couvre l'ensemble de la période 1995-2014, il n'existe pas de portrait de personne en situation de handicap en 2014.

[8] Au regard des quelques 250 portraits publiés chaque année par le journal *Libération* (Legavre, 2004), les personnes en situation de handicap bénéficient d'une couverture médiatique extrêmement réduite dans cette rubrique.

[9] Deux articles présentent la même femme à douze années d'intervalle. Un article met en scène une fratrie masculine; deux articles présentent le même homme à trois années d'intervalle.

(Wrona, 2012, p. 228-229). Dans le corpus étudié, les événements qui motivent l'intérêt des journalistes se déclinent en cinq univers :

1) culture (seize articles);
2) politique et milieu associatif (cinq articles);
3) handicap et santé (trois articles);
4) juridique (trois articles);
5) études et emploi (trois articles).

Ce sont donc les motifs culturels, conformes au choix éditorial du journal *Libération* (Legavre, 2004), qui donnent le plus souvent prétexte à la rencontre de personnes en situation de handicap (par comparaison à d'autres univers, politique, économique, juridique ou sportif), le référent culturel étant sans doute un cadre plus adéquat pour la mise en scène de figures « déviantes », « hors-normes », offrant des occasions inédites pour explorer et étendre les possibles narratifs.

Un tiers des portraits reflète la classique dichotomie femme/homme dans le choix des thèmes et la façon de les aborder. Un sujet exclusivement féminin concerne la contraception et plus précisément l'accident survenu à une jeune femme à la suite de la prise de pilule, sujet habituellement « réservé » aux femmes dans les médias (Coulomb-Gully & Méadel, 2012). Les thèmes qui mettent en scène les hommes se rapportent aux exploits sportifs (la parution de livres autobiographiques qui narrent des performances de natation ou de course à pied), aux distinctions (le prix littéraire de l'Académie française à Alexandre Jollien), ou à la politique : « Un corps qui raconte d'âpres batailles. Il est comme ça depuis toujours. Depuis qu'il a l'âge de se reconnaître dans le miroir, qui lui raconta sa polio attrapée à neuf mois dans un baraquement sans eau de Levallois-Perret, et lui promit si peu […]. Malek Boutih, 38 ans, ex-patron de SOS Racisme, a fait cette année son entrée dans les instances dirigeantes du PS » (22). Ils se réfèrent également à des thèmes plus transgressifs, avec un article consacré au cannabis à usage thérapeutique, un autre qui relate une bataille juridique pour rétablir l'autorisation du « lancer de nains », ou un troisième qui témoigne du militantisme risqué de Marc Ona Essangui, lauréat du prix Goldman pour l'environnement, déjà incarcéré pour son activité à la tête d'une organisation non gouvernementale (ONG) : « Cette reconnaissance internationale le protégera-t-elle, désormais, des foudres du pouvoir? Pas sûr. Il y a un an, Marc Ona avait été jeté en prison avec plusieurs activistes gabonais. […] Sous la pression internationale, […] cet homme timide de 47 ans a été relâché, après une dizaine de jours de cachot dans des conditions sanitaires épouvantables » (12).

Des sujets communs aux femmes et aux hommes, tels que le voyage ou la sexualité, ne sont pas traités sous le même angle. Par exemple, si une femme aventurière et aveugle part au Tibet, c'est pour consacrer sa vie à l'éducation des enfants et créer une école pour des élèves aveugles. L'homme voyageur, pour sa part, reviendra avec le récit autobiographique qui témoignera de son épopée. Sur le thème du corps, une femme revendique une pratique naturiste désexualisée, une autre femme, dans l'exposition de photos qui sert de prétexte à l'interview, « apparaît le sein nu sous des ombres, ou les yeux clos et tout en lingerie fine, lascivement couchée un drap blanc sur les fesses, suggérant l'amour » (18). Si la femme suggère, il en est tout autrement pour un homme au corps sévèrement atteint qui, de façon bien plus explicite, réclame de façon frontale un droit à la sexualité, à travers la publication d'un livre autobiographique.

Les femmes comme les hommes sont présents sur les questions de l'euthanasie et du droit de mourir dans la dignité, sur le thème des études supérieures, celui de la promotion d'un spectacle, celui de la survenue violente de la situation de handicap (attentat, tir de flash-ball), ou la publication de récits autobiographiques qui racontent l'irruption du handicap ou de la maladie et de ses conséquences pour leur vie.

- Les incapacités

Pour l'ensemble des protagonistes, ce sont principalement les atteintes du corps qui sont regroupées sous le terme « handicap ». Pourtant, femmes et hommes ne présentent pas les mêmes types d'incapacités. Si les personnes interviewées porteuses d'incapacités motrices sont largement représentées, les hommes présentent davantage de maladies invalidantes et évolutives[10].

Dans ce corpus, sur un axe qui va de l'invisible au visible, l'incapacité uniquement féminine est la surdité (totalement invisible et n'atteignant pas l'intégrité physique de la personne), alors que l'incapacité uniquement masculine est l'amputation (qui peut être particulièrement visible et sévère, car pouvant toucher les quatre membres).

Outre la sévérité du handicap, c'est également sa survenue qui est plus tardive et plus violente pour les hommes. Près de la moitié des articles décrivent la survenue du handicap à l'âge adulte, et parfois de façon dramatique. Ainsi, l'histoire de Philippe Croizon, qui un jour « grimpe sur le toit démonter l'antenne télé. Les 20 000 volts rentrent par ses mains pour ressortir par ses jambes. Trois décharges, coup sur coup. […] Suivent trois mois de semi-coma au centre des grands brûlés de Tours. Il y est amputé des quatre membres, l'un après l'autre. Un bloc de chair et de douleur. » (5).

- L'apparence physique

La description physique fait partie des critères exigés par une rubrique « Portrait », pourtant la description du corps des femmes du corpus étudié concerne seulement la moitié d'entre elles. Pour celles-ci, le critère de beauté physique est valorisé : « Emmanuelle Laborit, 23 ans, est belle. Très belle » (30), jusqu'à insister sur la beauté de la partie lésée du corps de la personne, pour mieux souligner la normalisation de ce corps féminin : « La première chose qui frappe quand on rencontre Sabriye Tenberken, c'est son regard. Vous a-t-on déjà fixé avec autant d'intensité, de manière aussi troublante? Ce regard qui dit tout est celui d'une aveugle » (24). Il arrive que la description du physique de la femme interviewée fasse référence à la femme « d'avant le handicap », comme s'il était encore plus regrettable pour une femme attirante de perdre ces atouts-là : « Avant, elle était une fusée, pour ne pas dire un avion de chasse. 1,75 m, un sourire et des jambes de déglingo. » (3).

Pour les autres femmes, les portraits délivrent peu de descriptions physiques autres que celles des conséquences du handicap sur le corps. Lorsque, dès l'enfance, le corps se transforme en « corps handicapé », passage irréversible vers le monde du handicap : « Mino devient “la petite fille en fer”, troque ses robes à volants pour un harnachement de cuir et de métal qu'elle doit porter pour tenir debout. […] “Mon corps, ce n'est pas moi. J'en suis la prisonnière” » (21), le corps de la femme adulte est évoqué avec discrétion par un physique qui ne correspond pas ou plus aux normes : « Mino a pris 20 kilos et son mari peine à la porter, à la laver et à la coucher » (21).

La condition des hommes correspond davantage aux normes habituellement rencontrées dans la presse, à savoir peu ou pas de descriptions physiques (au profit d'autres critères tels que le statut ou la vie professionnelle). Le physique des hommes peut être balayé en quelques mots : « beau gosse à barbe de quelques jours, regard franc » (8) sans plus y accorder d'importance au cours du portrait.

Lorsque la description s'attarde, elle illustre la situation de handicap de l'homme interviewé : « “Vous me reconnaîtrez sans peine à mon fauteuil roulant, voire à mon chapeau.” À l'heure dite, chapeau et fauteuil sont là, au bout du quai. Sous son bob beige, qu'il s'excuse de ne pas ôter à cause de vieilles fractures au crâne, Philippe Rahmy a, malgré ses 48 ans, quelque chose de mutin, tête d'oisillon et bar-

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[10] Pour les femmes : quatre présentent une incapacité motrice - tétraplégie, hémiplégie, atteinte des membres inférieurs, incapacité motrice cérébrale ou paralysie cérébrale; deux ont une incapacité visuelle; une femme (représentée deux fois) a une incapacité auditive; une femme a développé une maladie invalidante (polyarthrite juvénile); une femme est porteuse de troubles autistiques.

Pour les hommes : six (un homme est représenté deux fois) présentent une incapacité motrice (poliomyélite, incapacité motrice cérébrale, petite taille, amyotrophie spinale, atteinte des membres supérieurs); sept ont développé une maladie invalidante (os de verre, anosmie, mucoviscidose, sclérose en plaques, maladie auto-immune, neuropathie); quatre sont amputés; deux hommes ont une incapacité visuelle.

bichette » (1), où justement le chapeau ne représente pas un vêtement, mais le signe visible des conséquences de la maladie.

- La situation familiale ou conjugale

Une femme entreprenante, séductrice, poursuit une vie sentimentale après (et malgré) un accident, les signes visibles d'incapacités n'empêchant pas de valoriser le corps : « Marion Larat boite d'un pas décidé, les jambes en bataille, mais le buste en avant. Ce jour-là, sur les marches du centre culturel et social, un bel et sombre inconnu lui tape dans l'œil. Elle le suit dans le hall jusqu'à ce que l'homme, coincé, se sente obligé d'engager la conversation. Il est professeur d'arts plastiques et donne ici des cours de photo. Cela peut-il l'intéresser? La matière enseignée, moyen. Le corps enseignant, en revanche… Elle lui confie sa passion pour l'image et s'inscrit à la formation. Marion et Charles sont ensemble depuis un an » (3). Mais la capacité à séduire n'est pas réservée à cette femme, dont on pourrait penser qu'une bonne image d'elle-même construite avant l'accident lui permettrait d'imaginer séduire à nouveau. Par exemple, Delphine Censier, jeune femme tétraplégique depuis la naissance, adopte une attitude décomplexée vis-à-vis de son corps et déterminée vis-à-vis de ses rencontres amoureuses : « Elle a rencontré son copain Olivier, 23 ans, préparateur en pharmacie, dans une soirée chez des amis. “Je lui ai bien fait comprendre qu'il me plaisait... Il n'a pas résisté à mon charme insoutenable, s'amuse-t-elle. Le samedi suivant, il était dans mon lit” » (18). Ainsi, trois portraits de femmes montrent qu'une incapacité sévère est compatible avec une vie conjugale et intime, en mettant cependant l'accent sur l'association catégorielle femme-besoin d'affection.

Les portraits de deux hommes séducteurs mêlent davantage vie sexuelle et vie sentimentale. Ils portent la focale sur leur capacité à séduire, malgré des difficultés avérées, et brossent des portraits d'hommes conquérants, indépendants, et ayant le mérite de se construire seuls, sans appui extérieur, multipliant les conquêtes amoureuses : « Il a aimé souvent, s'est séparé, s'est retrouvé » et préoccupés de rompre leur solitude : « L'Internet a sauvé sa vie sentimentale. Il y a trouvé un médicament miracle […]. Et une compagne » (17).

Pour autant, les autres portraits ne donnent pas de détails sur la vie sentimentale des personnes interviewées. Si leur situation familiale est évoquée, ou le nom de leur compagne ou compagnon cité, cet aspect de leur vie ne fait pas l'objet de longs développements, même quand la rencontre conjugale s'avère être capitale. « 30 ans, c'est aussi l'âge auquel elle rencontre Rémy, “un valide”, employé de la SNCF, qui partage désormais sa vie » (21) : sobre et factuelle, la tonalité de la description contraste avec l'importance de cette rencontre pour Mino Knockaert, qui projetait de mettre fin à ses jours à cet âge.

L'irruption du handicap dans la vie des femmes et des hommes peut conduire à une séparation, subie « sa femme le quitte sept ans après l'accident » (5), ou choisie « elle dit “dégage” à son amoureux d'alors qui lui avouait, pas finaud, rester avec elle “par devoir”» (3), mais, dans ce cas, le célibat sera transitoire avant de nouer une nouvelle relation.

Dans les portraits du journal *Libération*, les rôles dédiés aux femmes et aux hommes dans la sphère privée apparaissent moins conformes lorsque la situation de handicap s'en mêle[11]. Si les femmes peuvent être « épouses de », en revanche, elles ne sont quasiment jamais « mères de ». De leur côté, les hommes en situation de handicap apparaissent plus souvent en couple que les hommes ordinaires; et bien davantage « pères de », même s'ils sont séparés, et même si les enfants sont nés avant la survenue du handicap ou de la maladie.

- La situation sociale ou professionnelle

En grande majorité, les femmes portraitisées dans le journal *Libération* exercent un emploi ou une activité bénévole de militante associa-

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[11] Sept femmes sur neuf citent leur compagnon ou mari et deux femmes sont mères; la moitié des hommes apparaissent aux côtés d'une femme et neuf d'entre eux sont signalés comme père.

tive[12]; un tiers des portraits de femmes ne mentionnent aucune activité professionnelle. Certaines sont aussi entreprenantes dans leur vie professionnelle que dans leur vie sentimentale, même si les femmes investissent des secteurs jugés typiquement féminins, l'éducation, la mode ou la culture, en lien avec les incapacités dont elles sont porteuses. Ainsi, Sabriye Tenberken qui ouvre à Lhassa, avec son compagnon, « la première école pour enfants aveugles du territoire. Une grande maison en chantier perpétuel qui accueille plus d'une vingtaine d'enfants tibétains frappés d'un mal que dans leurs villages on considérait comme une malédiction : la cécité » (24); ou Emmanuelle Laborit qui « ressuscite » l'International Visual Theatre à Paris.

Le même phénomène intervient dans le panel des professions des hommes illustrées dans le corpus. Si la moitié d'entre eux exerce une activité rémunérée, la situation de handicap est au cœur du métier de six hommes (écrivain, conférencier, sportif handisport…). Pourtant, des hommes investissent des domaines sans rapport avec leur situation de handicap, par exemple Marc Ona Essangui exerce dans une ONG pour l'environnement, ou Malek Boutih dans le secteur associatif, puis politique.

Les portraits des étudiants(es) présentent le point commun de décrire l'apport des aides techniques pour compenser les incapacités, mais également le mode de fonctionnement de ces aides techniques : « sur son bureau, il y a son ordinateur qu'il commande à coups de menton » (23), parfois de façon relativement détaillée : « Sans la numérisation, le moindre livre de philosophie niveau terminal s'étend sur 35 volumes au format 24 x 32 » (7), les informations techniques pouvant constituer un gage de sérieux, de réalisme, pour des portraits qui portent un projet de vie professionnelle.

Les études ou la situation professionnelle, avec la valorisation et l'autonomie imaginée par le travail intellectuel, vient parfois compenser un corps défaillant. « Philo, à vrai dire, on ne voyait pas très bien ce que c'était. Mais je me suis dit que, là au moins, il n'aurait pas à employer ses mains et pourrait vivre sa vie » (26) explique la mère d'Alexandre Jollien. La fonction des études n'étant pas uniquement celle de pourvoyeuse d'emploi, mais dans sa vocation de culture générale « pour qu'il ait sinon une vie professionnelle, une vie sociale, une intelligence qui lui permette de communiquer avec les autres » (23), déclare le père d'un étudiant.

Discussion : sublimation et exemplarité

- Des rôles féminins/masculins nuancés

Nous avons adopté dans cet article une approche intersectionnelle[13] (Crenshaw & Bonis, 2005), pour analyser dans quelle mesure le handicap vient interroger les structures « classiques » de la représentation homme/femme (fragilité féminine *versus* combativité, voire agressivité masculine). Autrement dit, pour des personnes dont la situation de handicap peut brouiller les représentations habituelles du genre, notre analyse fait apparaître une perturbation des codes lorsque le handicap intervient.

Le genre attribué aux thèmes, qui dans la presse générale reflète les préférences remarquées dans le traitement médiatique – aux femmes : les sujets « de femmes », aux hommes : les sujets politiques, sportifs, professionnels… (Coulomb-Gully & Méadel, 2012) – apparaît bien moins marqué dans le corpus étudié. En effet, un seul article aborde un sujet considéré comme exclusivement féminin (la contraception), et globalement, les motifs sont moins

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[12] Quatre femmes (une représentée deux fois) exercent une activité rémunérée, une est étudiante, une projette de créer son entreprise, trois sont sans emploi au jour de la rédaction de l'article. Onze hommes (un homme représenté deux fois) exercent une activité professionnelle rémunérée, deux sont étudiants, et six n'exercent pas d'activité professionnelle rémunérée au moment du portrait, même s'ils ont un métier ou se livrent à une activité bénévole.

[13] Les chercheurs mettent ainsi en évidence que pour évoquer l'identité d'une personne, et même l'identité d'un groupe, il ne suffit pas de prendre en compte un seul élément (genre, ethnie, handicap, etc.), mais qu'il faut effectuer une équation qui compose avec ces divers éléments de l'identité.

stricts que ceux attribués aux personnages ordinaires portraitisés dans la presse.

La presse accorde traditionnellement plus d'importance au physique et à l'apparence des femmes qu'à celle des hommes (Bertini, 2007). Ces manières de faire, impliquant des modèles d'écriture, des « routines » de la description, sont instituées dans le travail et la culture de chaque journaliste. Il convient alors de s'interroger sur ce manque de description pour des femmes en situation de handicap, et sur le sens de cette absence. Peut-être le corps différent de ces femmes empêche-t-il les journalistes de les regarder comme les autres femmes. Du point de vue de l'écriture, un corps différent peut laisser les journalistes désemparés. Ils ne disposent pas forcément des « routines » nécessaires pour un objet qui sort de leurs habitudes de travail. Mais la gêne éventuelle autour de la description d'un corps différent, ne correspondant pas aux normes canoniques de séduction, n'interdirait pas de décrire une coiffure, un vêtement, une parure, ce que les journalistes ne font pas. La situation de handicap mettrait ainsi les journalistes devant un grand inconnu, et, dépourvus de leurs instruments traditionnels de description, ils choisiraient *in fine* de rendre invisible un corps non conforme.

Les femmes en situation de handicap sont investies dans la sphère familiale en tant qu'épouses ou compagnes, mais non en tant que mères, alors que la mère est le rôle féminin archétypal par excellence dans la presse (Bertini, 2007). En effet, la représentation de la conjugalité ou de la sexualité est possible pour des protagonistes en situation de handicap, mais celle de la maternité quasiment absente. Deux femmes seulement sont mères alors qu'elles ont des incapacités de naissance. Leur maternité n'est pas mise en avant (quelques mots en conclusion des deux portraits), mais elle est néanmoins affichée médiatiquement. Ces deux femmes, belles (leurs qualités physiques sont mentionnées dans les portraits), actrices, célèbres, occupent peut-être une position qui, dans la représentation, leur permettrait d'accéder à une maternité encore interdite aux femmes inconnues, moins « prestigieuses ». Pour d'autres femmes, la dimension maternelle est exprimée dans des activités de « don de soi », par exemple par le biais d'un investissement militant dans le secteur associatif, qui peut compenser un manque affectif et ouvrir à une reconnaissance sociale.

Ainsi, on peut poser l'hypothèse que les femmes en situation de handicap ne sont pas forcément considérées comme des femmes « à part entière », et donc qu'elles ne sont pas mises en scène au travers de thématiques (séduction, corps, etc.), ni de rôles (maternité), qui leur sont réservés médiatiquement de façon habituelle. Elles se trouvent en revanche davantage au travail ou en activité, ce qui constitue une image moins habituelle pour les femmes ordinaires décrites dans les médias. Ce surinvestissement des femmes en situation de handicap dans la sphère professionnelle peut constituer une sorte de sublimation pour compenser un rôle féminin dont elles seraient exclues, « compensation » tellement intégrée qu'une jeune femme se rebelle et revendique une place pour son corps, en abandonnant ses études avant le bac : « Jusqu'en terminal, les études “étaient mon plaisir”, raconte-t-elle. Elles ont cessé de l'être quand il lui est apparu que son dix-neuf de moyenne était censé la consoler de ne rien pouvoir faire de ses dix doigts. “Et mon corps, alors?” demande-t-elle » (18).

Les hommes en situation de handicap, pour leur part, paraissent plutôt fragilisés sur le plan professionnel, et cette figure d'homme inactif est relativement éloignée de celle des hommes ordinaires dominant la sphère professionnelle qui se rencontre typiquement dans la presse (Coulomb-Gully & Méadel, 2012). Du côté de leur vie personnelle, les hommes en situation de handicap sont mis en scène dans un rôle paternel, ce qui correspond aux nouvelles images des hommes ordinaires. Moins coutumière est la représentation des hommes qui, dans la vie intime, de par leurs limitations physiques, laissent l'initiative à leurs partenaires, ou renoncent à leur passion pour se consacrer à leur famille : « Son plaisir, c'est désormais partager son temps entre son fils et sa femme » (8). Or, dans la culture médiatique, cette abnégation pour la famille est plus traditionnellement attendue des femmes. On peut ainsi poser l'hypothèse que les hommes en situation de handicap seraient « moins hommes » et pourraient accéder à une part plus « féminine » de leur personnalité. Ils seraient en quelque sorte « hors compétition masculine » et seraient performants, non pas dans l'espace public, mais dans la sphère conjugale et paternelle (la naissance des enfants permettant en outre d'afficher visiblement la virilité d'hommes porteurs d'incapacités de naissance et/ou sévères), illustrant ainsi les conséquences d'une « masculinité perdue ».

Les hommes dont l'identité masculine n'est plus en danger peuvent être les protagonistes de récits d'accidents effroyables, dont les épilogues spectaculaires donnent l'image d'individus capables de supporter des douleurs extrêmes. Ces scénarios existant uniquement pour les hommes, nous pouvons émettre l'hypothèse qu'ils se conforment aux idées de force, de courage, d'héroïsme, propres à la représentation masculine. Mais peut-être se conforment-ils également à une idée de « force morale » nécessaire pour basculer d'un corps en pleine santé à un corps amputé. Les hommes pourraient donc, plus que les femmes, faire face à la violence et au changement radical d'intégrité physique.

Ainsi, les personnes en situation de handicap dépeintes dans ces pages journalistiques ne correspondent pas exactement aux codes traditionnels des femmes et des hommes dans les médias. Entravées dans leurs corps, elles doivent inventer et réinventer des modes de sublimation et de façon de vivre. Jouant de façon créative des codes du féminin et du masculin, peut-être sont-elles précurseurs d'une évolution des normes classiques de la féminité et de la masculinité, ces injonctions pouvant être douloureuses tant pour les femmes que les hommes ordinaires (Coulomb-Gully & Méadel, 2012).

Mais l'aboutissement des parcours d'hommes et de femmes en situation de handicap reprend cependant des structures plus classiques, repérées par ailleurs par d'autres analyses sur le genre et les médias. Si au bout des épreuves subies et des batailles engendrées, les hommes deviennent « extraordinaires » (sportif olympique, conférencier international…), les femmes (re)deviennent, de leur côté, plutôt ordinaires. Seule la scène artistique leur permet d'avoir une contribution à l'espace public. En effet, ce qui diffère également dans les choix journalistiques sont les domaines d'activités : pour les hommes, les champs de la politique, du sport ou des réalisations éditoriales; pour les femmes, les domaines de l'art et de la littérature, lieux de l'expression de l'émotion par excellence.

- *Pourquoi mettre en scène des personnes en situation de handicap?*

Les personnages des portraits évoluent entre une vie privée ponctuée par l'intimité du couple et une vie publique marquée par les études ou les activités professionnelles. Ils constituent dans cette optique des membres de plein droit de l'espace public, et y participent en créant des événements (publication, initiative…). Si les journalistes ont porté leurs choix sur des personnes à l'occasion de ces événements, cette approche ne semble pas suffisante pour expliquer l'étendue et la précision des descriptions de la situation de handicap.

- *De l'épreuve à l'engagement militant*

Le trait commun à ces portraits est la construction d'une personnalité qui surmonte les épreuves que la vie lui a soumises, qui se révolte devant ces épreuves ou qui se mobilise pour ses droits sociaux et politiques. Les trames narratives mettent en scène l'évolution et la transformation des personnes présentées qui, malgré leur relatif anonymat, deviennent des figures publiques par la parution de leur portait dans les pages du journal. Car la personne ainsi portraitisée devient emblème : « Au service de l'individu collectif, qui représente plus que lui-même, toute une série de procédés sont mis en œuvre par le portrait de presse. Le principe consiste toujours à doter la figure mise en portrait d'une vertu emblématique » (Wrona, 2012, p. 260). Il s'agit alors de s'interroger sur la « vertu emblématique » portée par la personne en situation de handicap.

Malgré la diversité des personnages, leur relative ressemblance en termes typologiques peut surprendre. Il s'agit d'individus qui bousculent le monde des valeurs, se mobilisent pour des petites ou grandes causes, se révoltent contre la société, leur famille, revendiquent des droits (à la sexualité, à l'accès égal aux études, au choix devant sa mort), arrivent à maîtriser leurs corps « insoumis » aux règles de la normalité. Il s'agit aussi de personnes dont la participation sociale est bien mise en évidence par le discours journalistique. Chez la plupart d'entre elles, l'engagement en faveur d'une cause fait surface. Elles évoluent du faible engagement pour « aider les gens » (15) au militantisme qui redéfinit le sens d'une vie et qui se transforme en moyen de transcender la situation de handicap. Parmi les profils de « militants », les causes sont diverses - lutte contre le racisme, contre une loi, « contre l'obscurantisme de ces gens puritains » (11) - avec un recentrage sur la cause du handicap. Cet engagement peut être à la fois suggéré par l'écriture : « Lui repousse tout ce qui singularise, classe, marque. Il repousse le complexe, le handicap » (22) ou assumé par la personne : « Il est là pour les "petits, les exclus, ceux dont on ne parle pas" » (15).

- Un récit d'exemplarité

Le vocabulaire de la lutte, de la bataille, est presque omniprésent dans les portraits. Si les personnes participent à travers leurs activités à une remise en question des règles préétablies de l'espace public, nous pouvons aussi observer comment le propre corps est un terrain de révolte et de victoire de l'esprit sur la chair. Cette victoire transforme des personnes anonymes en héros du quotidien. Selon A. Wrona (2012, p. 264), « en choisissant "ses" portraits, le journal offre une représentation incarnée à des valeurs partagées avec son lectorat ». Leur caractère exemplaire apparaît sans doute lors de leur lecture, et cette transmission s'effectue à travers les techniques du *storytelling* (Salmon, 1997). C'est finalement le savoir-faire, ou plutôt le savoir-écrire des journalistes qui mettent en place un savoir-être à partager avec leur lectorat.

L'analyse a permis de confirmer une tendance plus large de recentrement sur l'individuel, dans une société à forte dimension narrative (Salmon, 1997). Les vies deviennent exemplaires à travers les choix éditoriaux des journalistes qui sélectionnent les faits marquants dans le parcours de la personne : être « méritant » dans le discours journalistique analysé dans les portraits de *Libération*, c'est faire bouger les limites de son corps et, plus largement, les manières de fonctionner au niveau interindividuel.

Des techniques narratives différentes, selon les parcours de vie des personnes interviewées et en fonction de la chronologie, sans aucun doute, se retrouvent dans le discours journalistique de ces portraits. Le lecteur découvre ainsi des hommes et des femmes rebelles et révoltés (surtout avant 2003-2004). À partir des années 2010[14], les parcours des personnes qui apparaissent dans la rubrique sont beaucoup plus détaillés. Il s'agit de militants du handicap, des êtres qui acceptent leur situation, mais qui ne cachent pas leurs difficultés et leurs douleurs. Malgré leurs souffrances, ils continuent leur lutte pour une vie ou une fin de vie digne.

Au-delà des distinctions individuelles, ce sont bien des parcours « exemplaires » d'autonomie et de dépassement de soi qui sont mis en scène dans les portraits du quotidien *Libération*. Si ces qualités rapprochent indéniablement les personnes portraitisées en situation de handicap des normes souhaitées dans une société individualisée et performante, il convient de s'interroger sur l'impact de ces portraits de héros et héroïnes sur des personnes moins performantes ou moins résilientes.

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[14] Ces évolutions du discours journalistique accompagnent aussi des modifications d'ordre politique, car la France a un gouvernement de droite entre 2002 et 2012. Or *Libération* est un journal de gauche, centre-gauche. En outre, la loi « pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées » est promulguée le 11 février 2005.

Conclusion : se rapprocher de l'altérité, entre recherche d'exemplarité et connaissance de l'autre

L'analyse synchronique d'un corpus d'articles a permis de comprendre comment une forme de spécialisation se met en place. Une complexification des portraits des personnes en situation de handicap a lieu à travers le temps. Cette tendance se manifeste dans le choix des personnes interviewées qui, au début de la période étudiée, ont des incapacités « simples » (sensorielles, motrices), pour laisser place à des personnes ayant des incapacités plus complexes qui demandent une connaissance plus approfondie de la part de l'interlocuteur. De même, la construction de l'image de la personne évolue vers davantage de sentiments, de doutes et de souffrances qui accompagnent souvent l'expérience du handicap. Les premiers portraits sont plus « secs », sans référence à l'intimité de la personne, tandis que dans les portraits plus récents, la mise en scène se complexifie, les personnes livrent davantage leurs émotions, leurs ressentis. C'est ici que le lecteur pourra observer le travail effectué dans le sens d'une reconnaissance publique du handicap ou plus précisément de l'expérience du handicap.

La recherche au niveau des sciences humaines et sociales sur le handicap insiste depuis longtemps sur l'invisibilité sociale du handicap qui laissera place par la suite à une publicisation progressive de cette expérience, à l'instar du champ de recherche des *disability studies* dans l'espace anglo-saxon (Stiker, 2013). Le passage d'un paradigme explicatif médical à un paradigme bio-psycho-social (Gardou, 2006) y occupe une place importante. Par l'analyse de ce corpus, un processus de mise en visibilité du handicap à travers les pages d'un journal peut être observé. Les personnes porteuses d'une (ou de multiples) incapacité(s) y apparaissent. Mais au-delà de la seule visibilité, l'intérêt est de comprendre dans quelle mesure cette visibilité facilite une reconnaissance (Honneth, 2000) de la personne en situation de handicap en tant que membre de pleins droits de la société.

Il nous semble, dans ce contexte, que les portraits analysés constituent une manière de se confronter à l'autre différent et une tentative de le connaître, le sortir de son espace intime, individuel, personnel, pour le rendre visible sur la place publique. Tout cela n'apparaît cependant pas *ex nihilo*. Une construction journalistique se fait à partir des pratiques descriptives, des règles déjà connues. Les journalistes opèrent une sélection dans les faits de vie de la personne en situation de handicap, au risque de la stéréotypisation, vue comme un processus de mise en catégorie parfois critiquée par les personnes elles-mêmes. Mais cette manière presque standardisée de dépeindre le portrait d'une personne ne la déplace pas forcément de sa position d'altérité. C'est plutôt au moment de « l'innovation » journalistique, quand les manières traditionnelles de description du rôle de l'homme ou de la femme dans la société ne fonctionnent pas, que les prémisses d'une possible reconnaissance de la différence de l'autre s'entrevoient. Le handicap n'est plus caché, il devient une composante vue et en partie comprise par tous.

Finalement, le lecteur peut aussi se demander si le genre même du portrait, jouant sur le sentiment de familiarité et de proximité avec le lecteur, rend plus proche la personne en situation de handicap, agissant dans le sens d'un effacement de l'altérité ou plutôt d'une mise en évidence à l'extrême de celle-ci afin de renforcer la normalité. Le travail journalistique a alors le mérite de faire les premiers pas vers cette reconnaissance, en donnant de la visibilité sur la place publique à des personnes qui, à travers leurs parcours, déplacent les frontières de la normalité et de l'humain (Rémy & Winance, 2010).

L'analyse de ces portraits proposés par le journal français *Libération* nous a donc permis de mieux saisir la dynamique de la mise en visibilité des personnes en situation de handicap dans l'espace médiatique, et implicitement dans l'espace public. La présentation des corps handicapés « extraordinaires », des activités spécifiques dans ces écrits journalistiques qui héritent des outils littéraires, nous permet de distinguer la complexité de la production de l’identité de la personne dans les narrations sociales (Thomson, 1997). Une condition ou une identité intersectionnelle semble un terme adéquat pour décrire la réalité des personnes en situation de handicap mises en scène à travers l’espace médiatique par les journalistes. Le handicap demeure à côté du genre, de la classe, de la nationalité, de la sexualité, une catégorie définissant l’expérience du corps vécu (Price, 2011), et de tout rapport à l’expérience d’un environnement divers et inclusif/excluant. Les personnes en situation de handicap représenteraient ainsi « l’ultime sujet intersectionnel, l’image universelle, la modalité importante à travers laquelle nous pouvons comprendre l’exclusion et la résistance » (Goodley, 2010, p. 34, notre traduction).

Des évolutions du traitement discursif du handicap existent sans doute à présent. Une piste ouverte par cet article et intéressante à explorer par la suite serait alors de rencontrer les producteurs des portraits, les journalistes des médias écrits et visuels, afin de mieux saisir les mécanismes à l’œuvre dans la description des portraits et ses déclinaisons au service de la construction d’une identité « diverse » ou « autre ».

TABLEAU RECAPITULATIF DES PORTRAITS ANALYSES (PAR ORDRE CHRONOLOGIQUE DE PUBLICATION)

Personne concernée	Sexe	Handicap	Motif de la rencontre	Situation familiale	Situation professionnelle
Philippe Rahmy	H	maladie des os de verre	publication d’un récit autobiographique (voyage)	conjoint	écrivain
Damien et Nicolas Delmer	H	mucoviscidose	droit à mourir dans la dignité	-	-
Marion Larat	F	hémiplégie et aphasie	contraception	conjointe	future créatrice entreprise
Marcel Nuss	F	amyotrophie spinale	publication d’un récit autobiographique (sexualité)	conjoint et père	écrivain et conférencier
Philippe Croizon	H	amputation	publication d’un récit autobiographique (sport)	conjoint et père	métallurgiste - sportif
Nicolas ?	H	sclérose en plaques	cannabis à usage thérapeutique	conjoint	-
Claire Guillot	F	cécité	entrée à l’École Normale Supérieure	-	étudiante
Aron Ralston	H	amputation	sortie d’un film et d’un récit autobiographique	conjoint et père	sportif, ingénieur - conférencier
Oscar Pistorius	H	amputation	publication d’un récit autobiographique (sport)	-	sportif
Guillaume de Fonclare	H	maladie auto-immune	publication d’un récit autobiographique	conjoint et père	directeur de musée
Miss Ming	F	troubles autistiques	sortie d’un film	conjointe et mère	actrice et doctorante

Personne concernée	Sexe	Handicap	Motif de la rencontre	Situation familiale	Situation professionnelle
Marc Ona Essangui	H	poliomyélite	ONG sur l'environnement	conjoint et père	responsable ONG
Joan Celsis	H	incapacité visuelle	tir de flash-ball	-	étudiant
Sylvie Fasol	F	polyarthrite juvénile	association de naturisme	conjointe	militante associative
Robert Baud	H	neuropathie	candidature à l'élection présidentielle	conjoint et père	livreur, comédien…
Emmanuelle Laborit	F	surdité	création de l'International Visual Theatre	conjointe et mère	directrice de théâtre
Michel Doriez	H	anosmie	publication d'un livre autobiographique	conjoint et père	ingénieur son, scénariste… - accordeur de piano, écrivain
Delphine Censier	F	tétraplégie	exposition de photos de nus	conjointe	-
Guillaume Depardieu	H	amputation	publication d'un livre autobiographique	conjoint et père	comédien
Françoise Rudetzki	F	atteinte membres inférieurs	association SOS Attentats	conjointe et mère	propriétaire magasin – militante associative
Mino Knockaert	F	paralysie cérébrale	droit à mourir dans la dignité	conjointe	-
Malek Boutih	H	poliomyélite	SOS Racisme / parti socialiste	-	politique et médias
Philippe Aubert	H	paralysie cérébrale	études de sociologie	partenaire	étudiant
Sabriye Tenberken	F	cécité	création d'une école pour enfants aveugles au Tibet	conjointe	fondatrice d'une école
Bachir Kerroumi	H	cécité	soutenance de thèse	conjoint et père	consultant, ingénieur de recherche
Alexandre Jollien	H	paralysie cérébrale	Prix littéraire de l'Académie française	conjoint	écrivain et conférencier
Malek Boutih	H	poliomyélite	présidence de SOS racisme	-	présidence association
Jamel Debbouze	H	atteinte membre supérieur	promotion d'un one man show	-	humoriste
Manuel Wackenheim	H	petite taille	revendication du « lancer de nains »	-	-
Emmanuelle Laborit	F	surdité	animation d'une émission télévisée	-	comédienne

Références

AGNES, Y. (2008). *Manuel de journalisme. Écrire pour le journal.* Paris : La Découverte.

AMOSSY, R. (1991). *Les idées reçues. Sémiologie du stéréotype.* Paris : Nathan.

BERTINI, M.-J. (2007). Langage et pouvoir : la femme dans les médias (1995-2002). *Communication et langages, 152,* 3-22.

COULOMB-GULLY, M., & MEADEL, C. (2012). Plombières et jardinières. Résultats d'enquêtes et considérations méthodologiques sur la représentation du Genre dans les médias, in *Médias : la fabrique du Genre. Sciences de la société, 83,* 14-35.

CRENSHAW, K. W., & BONIS, O. (2005). Cartographies des marges : intersectionnalité, politiques de l'identité et violences contre les femmes de couleur. *Cahiers du genre, 39*, 51-82.

DAMIAN-GAILLARD B., MONTAÑOLA S., & OLIVESI A. (2014). Introduction. Assignation de genre dans les médias. Attentes, perturbations, reconfigurations, in Damian-Gaillard, B., Montañola, S. & Olivesi, A. (Eds). *L'assignation de genre dans les médias* (11-19). Rennes : PUR.

DAKHLIA, J. (2010). *Mythologie de la peopolisation.* Paris : Le Cavalier Bleu.

DURRER, S. (2000). La gestion de l'impudeur dans l'interview-portrait de presse écrite, in Wauthion, M., Simon, A.-C. (Eds.) *Politesse et idéologie. Rencontres de pragmatique et de rhétorique conversationnelles* (247-261). Louvain : Peeters, BCILL.

GARDOU, C. (2006). Handicap, corps blessé et cultures. *Recherches en psychanalyse*, 2/6, 29-40.

GOODLEY, D. (2010). *Disability Studies: An Interdisciplinary Introduction.* London: Sage.

Honneth, A. (2000). *La Lutte pour la reconnaissance.* Paris : Ed. du Cerf.

LEGAVRE, J.-B. (2004). Un genre métis : le portrait de presse. Une comparaison Le Monde/Libération, in Legavre, J-B. (Ed.), *La presse écrite : objets délaissés* (211-246). Paris : L'Harmattan.

PAILLE, P., & MUCCHIELLI, A. (2012). *L'analyse qualitative en sciences humaines et sociales* (3ème éd.). Paris : Armand Colin.

PRICE, M. (2011). *Mad at School: Rhetorics of Mental Disability and Academic Life.* Ann Arbor: University of Michigan Press.

REMY, C., & WINANCE, M. (2010). Pour une sociologie des « frontières d'humanité ». *Politix*, 2/90, 7-19.

SALMON, C. (2007). Storytelling. *La machine à fabriquer des histoires et à formater les esprits*. Paris : La Découverte.

STIKER, H.-J. (2013). *Corps infirmes et sociétés. Essais d'anthropologie historique.* Paris : Dunod (1ère édition 1982).

THOMSON, R.-G. (1997). *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.

VERON, E. (1985). L'analyse du « contrat de lecture » : une nouvelle méthode de positionnement des supports de presse, in *Les médias. Expériences, recherches actuelles, applications*. Paris : IREP.

WRONA, A. (2012). *Face au portrait. De Sainte-Beuve à Facebook.* Paris : Hermann.

WRONA, A. (2008). L'ordinaire en portrait : une forme impossible? Biographies au travail dans les séries d'été des Échos. *Communication & langages, 158,* 3-12.

Articles parus dans la rubrique « Portraits » du quotidien *Libération*

(1) « Philippe Rahmy ». 30 août 2013. *En verre et contre tout* (Elisabeth Franck-Dumas).

(2) « Damien et Nicolas Delmer ». 28 juillet 2013. *Dignes de mourir* (Gilbert Laval).

(3) « Marion Larat ». 29 janvier 2013. *Comprimée* (Chloé Aeberhardt).

(4) « Marcel Nuss ». 04 janvier 2013. *Touchable* (Quentin Girard).

(5) « Philippe Croizon ». 12 avril 2012. *Intouchable à palmes* (Cordelia Bonal).

(6) « Nicolas ». 13 octobre 2011. *La fumette, c'est la santé* (Michel Henry).

(7) « Claire Guillot ». 19 septembre 2011. *10 sur 10* (Mourad Guichard).

(8) « Aron Ralston ». 10 février 2011. *Roc star* (Fabrice Droucy).

(9) « Oscar Pistorius ». 08 juin 2010. *Il prend son pied* (Dino Di Meo).

(10) « Guillaume de Fonclare ». 20 mai 2010. *Une vie de batailles* (Christophe Forcari).

(11) « Miss Ming ». 20 avril 2010. *Un beau grain de fille* (Marie Piquemal).

(12) « Marc Ona Essangui ». 16 février 2010. *L'arbre et la forêt* (Thomas Hofnung).

(13) « Joan Celsis ». 03 septembre 2009. *L'arme à l'œil* (Julia Pascual).

(14) « Sylvie Fasol ». 11 novembre 2008. *Mise à nu* (Hubert Prolongeau).

(15) « Robert Baud ». 6 mars 2007. *Candide candidat* (Didier Arnaud).

(16) « Emmanuelle Laborit ». 12 janvier 2007. *Elle dépasse l’entendement* (Caroline de Bodinat).

(17) « Michel Doriez ». 02 mai 2005. *Mort-nez* (Pascale Nivelle).

(18) « Delphine Censier ». 17 novembre 2004. *En roue libre* (Gilbert Laval).

(19) « Guillaume Depardieu ». 11 février 2004. *Empapaouté* (Luc Le vaillant).

(20) « Françoise Rudetzki ». 28 janvier 2004. *Coups et blessures* (Michel Becquembois).

(21) « Mino Knockaert ». 08 janvier 2004. *Ma mort est à moi* (Sonya Faure).

(22) « Malek Boutih ». 12 août 2003. *Pote à modeler* (Judith Perrignon).

(23) « Philippe Aubert ». 07 février 2003. *La tête la première* (Judith Perrignon).

(24) « Sabriye Tenberken ». 02 novembre 2001. *Hauteur de vue* (Pierre Haski).

(25) « Bachir Kerroumi ». 25 avril 2001. *Inutile d’assister* (Nathalie Pessel).

(26) « Alexandre Jollien ». 30 novembre 2000. *Moteur cérébral* (Florence Aubenas).

(27) « Malek Boutih ». 19 février 2000. *SOS image* (Luc Le vaillant).

(28) « Jamel Debbouze ». 12 avril 1999. *Bon qu'à tchatche* (Michel Holtz).

(29) « Manuel Wackenheim ». 04 décembre 1996. *Interdit de vol* (Sylvie Caster).

(30) « Emmanuelle Laborit ». 26 janvier 1995. *La militante des signes* (Sylvie Briet).

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The Formidable Double D: Analysis of Desire and Disability

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Abstract

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

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

Résumé

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

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

> A state judge Thursday cast doubt on the centerpiece of [University] professor [name omitted]'s defense of allegations she repeatedly sexually assaulted a 33-year-old man doctors say has the mental capacity of an 18-month-old.
>
> [The professor]'s lawyer, James Patton, claims the man, known as [name omitted], may be physically impaired but has the mental capacity to understand questions and give his consent.
>
> But during a hearing Thursday in Superior Court in Newark, Judge Siobhan Teare told Patton two decades' worth of psychological testing have concluded [name omitted] is severely mentally disabled and, thus, incapable of giving consent.
>
> "Even if you found [name omitted], has the ability to communicate, you can't overturn 20 years of his being determined to be incompetent," Teare said during the hearing to gauge [name omitted]'s ability to communicate. "He does not have the ability to give consent. (Zambito, 2014)

In the excerpt above, the voices that are heard and therefore the voices that direct the unfolding of a story and the course of this particular piece of history are those of a judge, a journalist, and the implied claims of a defendant (a professor). The words, the story itself, rests silently but heavily on the body of a man at the center of the case. What is not said, who is not given the opportunity to be heard defines a society as much as that which is stated. This makes missing perspectives as vital, if not more so, to the meaning at the heart of a story as those that are included. Marginalization and neglect of voices by those in power comes as no surprise to social justice advocates and much effort and energy has gone toward advocacy and interrogation of once accepted exclusionary practices. Today, while many marginalized groups have made some strides toward equity, majority of the people who are oppressed by the label of intellectually disabled exist in a space of social invisibility and fear. People oppressed by the label of intellectual disabilities[1] are perhaps the most stigmatized group of society (Thomas, 2000). This stigmatization and moral exclusion is evident in how people are represented in media while simultaneously are prevented from representing themselves.

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

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

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

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

Abuse or Desire: Background on the Story

In an east coast US newspaper, a complicated story unfolds, one that is drastically different depending on the perspective. In these articles we learn about two people who might be prevented from engaging in a loving and supportive relationship or we are reading about one person who is abused and taken advantage of by another (Flaherty). These two possibilities exist within all of the articles in which a prominent professor of philosophy and disability rights advocate was introduced to a man. The man's brother (the professor's student) had connected the two of them with the hopes that the professor could teach him a communication method called *facilitated communication*. The man, whose level of disability is one of the contested issues in the case, lives with cerebral palsy. Within a year, the man and the professor find themselves working closely on a regular basis as the man was reportedly expressing himself successfully through this controversial communication method (I will briefly address facilitated communication below but the reader is referred to Biklen & Cardinal, 1997 for more on this method). Together the professor and the man wrote articles and presented at conferences. This intimate collaboration blossomed into a relationship. Two and a half years after being introduced, the couple met with the man's family to share their intention to spend their lives together. Through facilitated communication, the man communicated this desire, while the professor communicated her love with her voice.

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

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

A note on facilitated communication

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

In the current case, the method was considered inadmissible in court rendering the man without a way to share his story. People in the margins of power, such as those placed low on the hierarchy of class, race, and ability, are often silenced by those with power. This includes the legal system and the press. Denying the opportunity to include the perspectives of individuals on the margins reifies society's oppressive structures. In order to no longer silence the man in question and to invite him to take this "border crossing" journey with me in this analysis, the provocative issue of facilitated communication would have to be addressed and deemed legally acceptable so that his story can be reflected in the documents that are produced for publication (Biklen & Cardinal, 1997; Giroux, 1992). Without the ability to make way for his perspective to be represented, he is defined strictly through professional and familial reflections. Many individuals who are defined by assessments, such as the man in this case, have social circles that are limited to family and professional caretakers and doctors. These members of their communities are given full power including the power to define him. Judgments of his likes, desires, thoughts, and life are deferred to his family and the doctors. A practice implicitly encouraged by the discipline of psychology.

My positionality: Background on my Story

Before entering into an exploration of psychology's complicated lineage, I would like to share a bit of mine. In a hermeneutic fashion, I would like to acknowledge the texture of my positionality and how this influences my location on the horizon of possibilities (Gadamer, 2008). Positionality reflects on where the researcher stands within a discourse and how the perspective on the topic at hand may be influenced by this position (Dobbins, 2007). My history as a collaborator at a social justice project seeking to disrupt institutions from within and to offer an alternative to the segregated sheltered workshop model of "vocational" support for people oppressed by the label of intellectual disability provides a meaningful backdrop to my value system from which I understand these issues from. Through this experience I was exposed to the institutions, both housing and vocational, that claim to support individuals society categorizes as intellectually disabled. In these settings from within the institutions, I came to understand the pervasive oppression, injustices, and abuse experienced by those who are inflicted with the violent label of intellectual disability. I was a witness to systemic torture as people I worked with, victims of sexual abuse, were forced to take part in outdated and dehumanizing aversion therapies to stifle any feelings of desire. I was a witness to erasure as all significant decisions related to lives were made by staff, whether about the grocery list or about someone's ability to engage in friendship with others. I was a witness to pervasive, deep dehumanization. In short, I was a witness to the mechanics of moral exclusion (Opotow, 1990). According to Susan Opotow (1990), when groups are morally excluded, they are positioned outside of the scope of justice, making mistreatment, dehumanization, and erasure possible. Due to my experiences within institutions, I perceive the label and the structures that claim to protect the individuals affixed with this label as violent, deeply unjust and complicit in moral exclusion.

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

An unfairly brief but vital history

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

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

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

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

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

Scientific social representations of desire and intellectual disability today

Goddard, Galton, Binet, and other men of science of the 19th and early 20th century, imprisoned people with intellectual disabilities within the labels of *idiot, feebleminded,* and *moron.* Sexuality was mentioned as a point of vulnerability whereby people would be abused or as an aspect of danger to the good society. At the historic intersection of desire and disability, the involuntary sterilization of often involuntarily institutionalized individuals flourished.

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

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

Select search type: All Fields

Search for: sexuality intellectually disabled

Select library: All CUNY Libraries

Browse List: Subjects

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

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

Beneath the fragile surface of the intersection of desire and intellectual disability in psychological literature lurks the unfounded and ancient fear of this label harboring ignorant sexual deviants. Studies claim that there is an increase in incidents of sexual crimes among populations with intellectual disabilities (Lindsay, 2002). Some authors have claimed as much as a doubling of incidents between the years of 1973 and 1983 (Lund, 1990). In light of deinstitutionalization, whereby these individuals are incorporated into the larger community, the question of the prevalence of proper assessment and treatments of sexual deviance in intellectual disabilities has led to an increase in research on these topics in psychology (Lindsay, 2002). Among a slew of characteristics of offenders with intellectual disabilities found within research, including neglect and parental separation, sexual naiveté stands out (Day, 1993). According to the article, the inability to understand sexual relationships and poor impulse control, explains not only why people with intellectual disabilities are more likely to be perpetrators of sexual crimes but also more likely to be victims. Compounding the threat of people with intellectual disabilities as sexual deviants, researchers claim that they are more likely to offend against younger children (Blanchard et al., 1999) and more likely to reoffend (Lindsay et al., 2001). A great amount of the little research occupying this hardly treaded space at the intersection intellectual disabilities and sexuality seeks to understand the behavior of individuals who have committed sexual offenses. Veiled as scientific inquiry, this work has reinvigorated historically rooted stigma.

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

Admittedly, this all too brief survey of academic representations of intellectual disability in psychology and is in no way intended to fully describe the field. It does, however, help shed light on the darker influences that shape the media and popular representations of the intersection of intellectual disability and desire. I would like to make explicit the relationship between the meanings created within academic documents and the social representations circulating in everyday life utilizing Thomas Teo's concept of epistemological violence. Teo (2010) writes of interpretations in psychological papers as a form of action. These interpretations produce meaning, choosing specific ones from a multitude of various alternative meanings. If these actions have negative consequences – ranging from misrepresentations to the neglect of the voices of those it claims to study – Teo considers them to a be a form of violence. Under the authority of social science and knowledge, violence and damage has been inflicted upon individuals oppressed by the label of intellectually disabled. The violence descends from the academic pages and is enacted in the vulnerable underbelly of everyday life.

Social representations of intellectual disability through the lens of one case

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

This issue is deeply complicated and multiple identities and factors intersect in numerous places. Admittedly, elevating representations of only the man in question from the rest of the details robs the conversation from its true richness and complexity. This case is about far more than the accusation of sexual assault, a misunderstood relationship or the validity of the type of communication used by the man. To unravel this court case fully, this discussion should be about far more than the social representations of desire and disability; it is about history, about the meaning of care, about race, class, privilege, and power, among other considerably influential issues. This full characterization will not be possible for some time as the case is currently in progress at the time of analysis. My interest here is to focus in on the way the man (often referred to as the victim by the sources) is described by journalists and readers of the news who have a superficial understanding of the situation. By artificially separating the social representation of intellectual disability and sexuality from other identity markers, I am interested in identifying the kinds of socially shared explanations people evoke to make sense of this particular and disputed topic.

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

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

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

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

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

Only a patient, never a friend

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

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

Infantilizing

The man, who is in fact 33 years old, is constantly referred to as an *infant*, *young man*, *poor kid*, *boy*, and *toddler*. Bloggers, self-identified disability rights advocates, commentators, and professional journalists alike access these labels. The man, unable to communicate verbally and requiring physical supports is denoted to the status of an *infant* and at best *a young man*; all of his possibilities appear filtered through this infantilizing framework. This patronizing phenomenon is well documented in social sciences (Biklen & Burke, 2006).

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

Inconceivability of consent

As a consequence the judgments of doctors and other professionals, the question of consent is not something that is sought to be answered through investigation relating to this relationship, but is assumed to be inconceivable by those who engaged with the story. Referring to the infantilizing characterization of the man as a *toddler*, *infant*, *18th month old*, and *boy*, the response to the idea of a sexual relationship is in outrage. The inconceivability of consent due to his characteristics as someone who does not communicate verbally re-frames all possible sexual experiences as rape. Asexualized through infantilization, the possibility of a sexual relationship is met with anger, outrage, pity, and the call for protection.

Vegetable and guinea pig

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

Conclusion

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

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

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

Desire Denied

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

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

References

ALCORN D. E. (1974). Parental views on sexual development and education of the trainable mentally retarded. *Journal of Special Education*, *8,* 119-130.

BELLUCK, P. (2015, April 13). Sex, Dementia and a Husband on Trial at Age 78. Retrieved April 15, 2015, from http://www.nytimes.com/2015/04/14/health/sex-dementia-and-a-husband-henry-rayhons-on-trial-at-age-78.html?emc=eta1

BIKLEN, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review*, 60, 291-314.

BIKLEN, D., & BURKE, J. (2006). Presuming competence. *Equity & Excellence in Education*, *39*(2), 166-175.

BIKLEN, D. E., & CARDINAL, D. N. (1997). Contested words, contested science: Unraveling the facilitated communication controversy*. Teachers College Press*.

BLANCHARD, R., WATSON, M. S., CHOY, A., DICKEY, R., KLASSEN, P., KUBAN, M., & FERREN, D. J. (1999). Pedophiles: Mental retardation, maternal age, and sexual orientation. *Archives of Sexual Behavior*, *28*(2), 111-127.

BRANTLINGER, E. A. (1985). Mildly mentally retarded secondary students' information about sexual and attitudes toward sexuality and sexuality education. *Education and Training of the Mentally Retarded,* 20, 99-108.

CAREY, A. C. (2009). *On the margins of citizenship: Intellectual disability and civil rights in twentieth-century America*. Philadelphia, PA: Temple University Press.

DANZIGER, K. (1997). The historical formation of selves. *Self and identity: Fundamental issues*, 137-159.

DAY, K. (1993). Crime and mental retardation: a review. In *Clinical Approaches to the Mentally Disordered Offender* (eds K. Howells & C. Hollin), pp. 111-43. John Wiley & Sons, Chichester.

DOBBINS, J. F. (2007). Connections of Care: Relationships and Family Caregiver Narratives. In *The meaning of others: Narrative studies of relationships.* American Psychological Association.

DYER, T. G. (1992). *Theodore Roosevelt and the idea of race*. LSU Press.

FERGUSON, P. (2013). The Development of Systems of Supports: Intellectual Disability in Middle Modern Times (1800 CE to 1899 CE). In *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Brookes Publishing.

FLAHERTY, C. (2014, April 23). *Question of consent*. Retrieved October 26, 2014.

GADAMER, H. G. (2008). *Philosophical hermeneutics*. University of California Press.

FRITSCH, K. (2009, January 1). Resisting easy answers: An interview with Eli Clare. Retrieved March 3, 2015.

GIROUX, H. A. (1992). *Border crossings: Cultural workers and the politics of education*. Psychology Press.

JOSSELSON, R. (2004). The hermeneutics of faith and the hermeneutics of suspicion. *Narrative inquiry*, *14*(1), 1-28.

JOVCHELOVITCH, S. (2007). *Knowledge in context: Representations, community and culture*. Hove, UK: Routledge.

KULICK, D., & RYDSTRÖM, J. (2015). *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. Duke University Press.

LINDSAY, W. R. (2002). Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, *46*(s1), 74-85.

LUND J. (1990). Mentally retarded offenders in Denmark. *British Journal of Psychiatry, 156,* 726-731.

MCCLELLAND, S. I., & FINE, M. (2008). Writing on cellophane: Studying teen women's sexual desires, inventing methodological release points. *The methodological dilemma: Creative, critical and collaborative approaches to qualitative research*, 232-260.

MCRUER, R., & MOLLOW, A. (EDS.). (2012). *Sex and disability*. Duke University Press.

MOSCOVICI, S. (1988). Notes towards a description of social representations. *European journal of social psychology*, *18*(3), 211-250.

MOSCOVICI, S., & MARKOVÁ, I. (1998). Presenting social representations: A conversation. *Culture & psychology*, *4*(3), 371-410.

MOSTERT, M. P. (2001). Facilitated communication since 1995: a review of published studies. *Journal of Autism and Developmental Disorders*, *31*(3), 287-313.

OPOTOW, S. (1990). Moral exclusion and injustice: An introduction. *Journal of social issues*, *46*(1), 1-20.

SMITH, B. V. (2006). Rethinking prison sex: Self-expression and safety. *Colum. J. Gender & L.*, *15*, 185.

SMITH, J. D. (2006). Speaking of Mild Mental Retardation: It's No Box of Chocolates, or Is It? *Exceptionality*, *14*(4), 191-204.

SMITH, J. D., & WEHMEYER, M. L. (2012). Who Was Deborah Kallikak? *Intellectual and developmental disabilities*, *50*(2), 169-178.

SMITH, J. D., WEHMEYER, M.,& NOLL, S. (2013). In search of Science: Intellectual Disability in Late Modern Times (1900 CE to 1930 CE). In *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Brookes Publishing.

SOBSEY, D., & DOE, T. (1991). Patterns of sexual abuse and assault. *Sexuality and Disability*, *9*(3), 243-259.

TEO, T. (2010). What is epistemological violence in the empirical social sciences? *Social and Personality Psychology Compass*, *4*(5), 295-303.

THOMAS, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, *86*(3c), 1155-1156.

TOOMEY, J. F. (1993). Final report of the Bawnmore Personal Development Programme: staff attitudes and sexuality programme development in an Irish service organisation for people with mental handicap. *Research in developmental disabilities*, *14*(2), 129-144.

TRUDEL, G., & DESJARDINS, G. (1992). Staff reactions toward the sexual behaviors of people living in institutional settings. *Sexuality and disability*, *10*(3), 173-188.

VIRGINIA GOVERNOR APOLOGIZES FOR EUGENICS LAW. (2002, May 2). Retrieved December 5, 2014, from http://usatoday30.usatoday.com/news/nation/2002/05/02/virginia-eugenics.htm

WEHMEYER, M., NOLL, S., & SMITH, J. D. (2013). Isolation, Englargement, and Economization: Intellectual disability in late modern times (1930 CE to 1950 CE). In *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Brookes Publishing.

WEST, C. (1993). *Race matters*. Vintage.

WINGES-YANEZ, N. (2014). Why All the Talk About Sex? An Authoethnography Identifying the Troubling Discourse of Sexuality and Intellectual Disability.*Sexuality and Disability*, *32*(1), 107-116.

WOLFE P. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability, 15,* 69-90.

ZAMBITO, T. (2014, April 25). Judge questions consent defense in case of Rutgers-Newark professor accused of sex assault. NJ Advance Media. Retrieved October 26, 2014.