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Jessica Breau, Canada
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Being Deaf in Bengkala : the *Koloks*' Social Representations of Deafness, Hearing and *Kata kolok*

National tutor:
Prof. Lilian Negura, *Canada*   University of Ottawa

uOttawa

Co-tutors:

Prof. Giovanna Leone, *Italy*   Sapienza University of Rome

Prof. Susana Seidmann, *Argentina*   University of Belgrano

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Abstract

There has been a long-standing debate in Western societies when it comes to deafness on whether it should be represented as being a *disability* or if it should be represented as being a *difference* (Davis, 1995 ; Lane, 1995 ; Brueggemann, 1999). These opposing representations have been dominating Western discourse for decades claiming that the d/Deaf body should be considered in its biological state rather than in its cultural state or vice versa. Hence, the Deaf space in the public sphere has been largely decided by the hearing society which has opted to either allow the deaf to integrate the dominant society through medical intervention leading to the acquisition of varying levels of speech and hearing, or allow the Deaf to organize themselves in the fringes of society through the creation of Deaf communities where they can communicate with each other using sign language. That said, there are a few rare exceptions of isolated villages where a high incidence of multi-generational genetic deafness has initiated a community-based approach to deafness which developed independently from the dominating Western ideas. Bengkala, a small farming village located in the mountainous region of northern Bali, Indonesia, is one of these exceptional villages.

In Bengkala, the deaf residents, known locally as *koloks*, have been present in the village for over 200 years. Since then, there have been many community-based adaptations, notably the widespread use of the shared sign language, *Kata kolok,* as a way to include the *koloks* in all village activities. The shared use of *Kata kolok* by the *koloks* as well as more than half of the hearing, or *normal* villagers as they are identified in the village, has been praised internationally in academic and media publications for being indicative of the inclusion of the *koloks* in the larger community. However, in order to have a more in-depth understanding of just how well integrated the *koloks* are in their native community, this ethnographic research

applied both participant observation and one on one interviews in order to document the *koloks'* social representation of deafness, the hearing and the local sign language.

Social representations (SR) are frames of reference to which individuals are continuously referring themselves to in order to identify objects, to determine the best actions to take in any given situation and to understand the world around them. And so, by studying the *koloks* SRs, the objective of this thesis is to explore the existence of a possible alternative path to the two opposing dominant social representations of deafness in Western societies. As a result, the first article studies the *koloks'* SR of deafness through their dual identity. By maintaining simultaneous membership to the *kolok ingroup* as well as the *village ingroup* as a way to represent themselves as fully integrated members of the community, the *koloks* attest to the compatibility of the two groups. The second article examines the *koloks'* representation of the *normals*, which highlights the parity between the two groups while also acknowledging the hearings' unwavering support throughout the years. And the third article focuses on the *koloks'* SR of *Kata kolok* as being one of many linguistic variations in the area which unifies and distinguishes them from the *normals* simultaneously. Thus, this research highlights the positive outcomes of having an unadulterated perception of deafness through community-based adaptations as opposed to prescriptive beliefs of the Deaf persons social identity and social inclusion from the hearing society.

Keywords: Social Representations, Social Identity, Deafness and Deaf Community

Introduction

Nestled in the mountainous region of northern Bali, Indonesia, Bengkala is a small farming village known for its unusually high number of Deaf residents, the *koloks*, and their local sign language, *Kata kolok*. With a growing population, the village of Bengkala is home to just over 3,000 people, with 44 of whom are deaf. In order to put these numbers into perspective, this introduction begins with a general portrait of deafness around the world. This will be followed by a brief summary of the dominant Western social representations of deafness which have impacted the lives of d\Deaf[1] people around the world for centuries. And finally, a review of the literature stating the unique reality of the village of Bengkala and its shared sign language will be presented as a way to provide background to the general topic area of this thesis.

A Global Picture of Deafness Around the World

Deafness occurs in all corners of the world. Whether it be genetic, the result of an illness or an accident, or the product of getting older, deafness affects approximately 360 million people worldwide (WHO, 2015). This figure indicates that between five and eight per cent of the world's population has moderate, severe or profound hearing loss (WHO, 2015; FFSB, 2004). However, when narrowing down this statistic to only cover the number of children who

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[1] The tern d/Deaf is used to encompass both the deaf who adhere to the medical approach to deafness and the Deaf who adhere to the cultural approach.

are born deaf, the numbers become significantly lesser. In fact, only one in one thousand children are believed to be born deaf (Morton, 1991). This means that only 0.1% of the general population is severely or profoundly deaf from birth and the rest of the deaf population has acquired hearing loss later in life. This distinction is important to make, because the moment of appearance of deafness is not without impact (Barnett & al., 2011 ; Mayberry, 2007). People who become deaf as a result of an accident or illness, or even the elderly who gradually lose their hearing over time, do not face the same communication and socialization challenges as people who are born deaf or who become deaf before they have mastered a certain level of language.

In addition, research has been conducted by geneticists to identify which genes could be responsible for the mutations that affect a newborn child's hearing with Sundstrom & al. (1999) stating that half of children born with profound or severe deafness have genetic hearing loss. However, 90% of deaf children are born to hearing parents (Lane & al. 1996). Despite the fact that genetics can provide answers to about half of the parents with a deaf child, they are generally unaware that they carry one of these genetic mutations before the birth of their deaf child. Therefore, these parents have no knowledge or affinity with the Deaf world and all that comes from it. For this reason, they enlist the help of professionals to aid them in finding the best course of action for their child.

This is when the deaf child and their family begin to get introduced to the multitude of different groups in which they could identify. Whether it be parent support groups, Deaf associations, speech therapy groups, Deaf schools, etc., the family is quickly immersed into the world of deafness and they must choose one of two dominant approaches to guide them through the process. Either the parents will decide to go towards the medical or oralist approach

to deafness which promotes the integration of the deaf child into the hearing society through therapy and technological supports. Or they will decide to go towards the cultural or gestural approach to deafness and search for a Deaf community where they will learn to communicate with their child through sign language. Some families will try to merge these two approaches by aiming for bimodal bilingualism, meaning that the child will follow the medical path of having hearing aids or cochlear implants as well as speech therapy, but they will also learn sign language (Metzger, 2000).

However, trying to manage both approaches to deafness becomes very taxing on the family as it demands too much of their time and they find themselves juggling opposing social representations of deafness. And so, these families will often perceive the spoken language as a "survival language" and signed language as a "cultural language" (Mitchiner, 2015). That said, d/Deaf persons themselves navigate in and out of these group at different points in their lifetime questioning where they belong and searching for their social identity. Thus, many studies have shown that once deaf individuals who have been trying to find their identity in the hearing society find the Deaf community, even if it comes later in life, they are able to develop their Deaf identity and it often becomes their primary social identity (Lane, 1995).

This reality of d\Deaf people being torn between two dominant SRs of deafness is felt around the world. Although Bengkala has been able to withstand the pressures of the Western approaches, it is surrounded by special Deaf schools which were created before World War II and are the product of the Dutch reign in the area (Branson & Miller, 2004). These special Deaf schools are known to adopt the "total communication" approach which emphasizes lip reading of the national language *Bahasa Indonesia* in hopes of integrating these children into the hearing society. This method has been criticized as it does not serve any purpose for the Deaf

individuals who want to return to their village after school as *Bahasa Indonesia* is only spoken during state-led events (Branson & Miller, 2004). This means that the Deaf children cannot lipread the local dialects used by their family members, friends and neighbors once they are out of school. That said, there is no telling how long Bengkala will maintain its own SR of deafness and its shared sign language as outside influences are making their way inside the village boundaries. But for the time being, the *koloks* are still very much included in all levels of community activities and *Kata kolok* is still being used daily by both deaf and hearing villagers.

A Brief Look Into Deafness in Bengkala

The first team of researchers interested in studying the population of Bengkala went to the village in the early 1990s. This group of researchers consisted of mostly geneticists from American, Indian and Indonesian universities working together to establish a pedigree of the deaf population of Bengkala (Winata & al., 1995). With the help of genetic testing, they were able to identify a mutation of the DFNB3 gene which is attached to the 17th chromosome and is considered one of 25 genes responsible for "nonsyndromal hearing loss (ARNSHL)" (Sundstrom & al., 1999). Interestingly, the DFNB3 has also been known to cause nonsyndromic deafness in other parts of the world, notably in two unrelated families in India (Wang & al., 1998), as well as individuals in Pakistan, Turkey, Tunisia and Brazil (Duman & Tekin, 2012). This gene is thus known to be a relatively common cause of genetic deafness in several parts of the world. But combined with traditional marriage customs and the remoteness of Bengkala, this genetic mutation has been passed down through many generations making the village known for its deaf population both locally and internationally.

At the time, it was determined that 2,2% of the population was profoundly deaf due to this genetic mutation[2] (Winata & al., 1995). It was also determined that 17.6% of the hearing villagers were carriers of the gene but did not have any symptoms of hearing loss (Winata & al., 1995). Although this genetic data might not be at the center of this research, it provides interesting contextual information as the high incidence of genetic deafness is what marked Bengkala as being a "Deaf village". Also, since most of the deafness in the village is genetic, and has been present for many generations, the element of surprise when a child is born deaf is quasi-non-existing in Bengkala (Hinnant, 2000). The parents of these *kolok* children are often deaf themselves, or they have some deaf family members. And so, the child's deafness does not come as a shock. Whereas with only 10% of deaf children being born to deaf parents around the world, the hearing parents first contact with deafness is often associated with their infant failing a screening test in the hospital. On the contrary, there are no hearing tests for newborns in Bengkala. The parents will perform their own home tests in order to determine whether or not their child responds to sound in the months, and even years, following their child's birth.

Not only does Bengkala differ from Western societies around the world, but it also distinguishes itself from other areas in Indonesia as well. Indonesia is a country comprised of

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[2] Though the DFNB3 gene mutation accounts for the vast majority of the deafness in Bengkala, there are a few rare exceptions of children who were born hearing, but who have become deaf after being ill, or after having an accident. Also, there are deaf adults from other villages who married Bengkala residents, both deaf or hearing, and who now live and have had their own family in Bengkala.

over seventeen thousand islands with many different customs, religions and dialects. Being the fourth most populous country in the world with a population of over 273 million, Indonesia is home to more than 2.5 million Deaf people (People Groups, 2020). With that said, there are two national signing varieties taught in Deaf schools all over the country, the Indonesian Signal System (SIBI) and the Indonesian Sign Language (BISINDO). However, Palfreyman (2011) states that given the archipelagic nature of Indonesia, regular interactions between Deaf people from different areas was not possible until quite recently. Therefore, he stipulates that it is more than likely that there are both lexical and morphosyntactic variations in the sign language varieties used in different regions of Indonesia (Palfreyman, 2011). This is the case with *Kata kolok*, the local sign language used in the village of Bengkala, as it shows no relation with neither of the national sign languages.

Kata kolok was developed by the *koloks* more than five generations ago and has since then evolved into a fully functional, complete and complex language shared by both the *koloks* and the hearing villagers known as *normals* (de Vos, 2012). In fact, the majority of the people who comprise the signing community are hearing as it is estimated that over 1,800 hearing villagers can sign with varying degrees of fluency (de Vos, 2012 ; Marsaja, 2008), while only 44 of the signers are in fact Deaf. As a result of its shared nature, *Kata kolok* is believed to belong not only to the *koloks*, but to all villagers who use it (de Vos & Palfreyman, 2012). Thus, making Bengkala known for being a "Deaf village" (Vice, 2015) where "most speaks sign language" (BBC, 2019).

All things considered, the *koloks* have a very unique deaf experience when compared with the experiences of Deaf people from other villages on the island. Although Indonesia, and more specifically Bali, are dotted with Deaf communities, Deaf organizations and Deaf schools

in most of its major cities, the *koloks* tend to stay within their own village as they are able to communicate freely with the other villagers, regardless of if they are deaf or hearing. In doing so, the *koloks* are able to participate in all of the community activities as opposed to being organized in the margins of the hearing society like is the case for Deaf communities around the world. This is mostly due to the remote area in which Bengkala is located and all the efforts that were put forth by the locals to include the *koloks* into all levels of community activities. Thus, creating their very own inclusive Deaf community and eliminating the need for the *koloks* to search out Deaf communities in order to create their Deaf identity.

The koloks' social representations of deafness, the normals and Kata kolok

Based on the fact that the *koloks* are believed to be integrated in all levels of community activities in Bengkala, this thesis adopts the Social Representations Theory (SRT) to explore the *koloks*' social representations in order to better understand their existing situation. Social representations are made up of opinions, knowledge and beliefs specific to a culture, category or social group (Rateau and Lo Monaco, 2013) and are constantly referred to by individuals in order to identify objects, to determine the best actions to take in any given situation and to understand the world around them. And so, by studying the *koloks* SRs, the objective of this thesis is to explore the existence of a possible alternative path to the two opposing dominant social representations of deafness in Western societies and offer new perspectives on the inclusion of deaf people in a hearing society as well as their social identity. Thus, by adopting an ethnographic approach to the SRT, this thesis will answer the research question : how does the *koloks*' social representation of deafness, hearing and *Kata kolok* influence their inclusion in Bali's deaf village of Bengkala.

In the first article, a review of the social representation of deafness around the world will be presented as a way to establish the frame of reference used by most Deaf people when developing their social identity. Deaf identity is found in members of Deaf communities who adhere to the cultural SR of deafness. On the contrary, the medical SR of deafness represents deafness as being a disability as opposed to a difference. However, in Bengkala, neither of these dominant SRs of deafness have much of a bearing on the *koloks'* social identity. And so, the data collected shows that the *koloks* adhere to both a *kolok* ingroup and a *village* ingroup in which they share their local culture with the hearing villagers. By doing so, the *koloks* are able to share a common identity with Deaf people from all over the world who come to Bengkala to visit the utopian Deaf village while also being included in the local culture and participating equally in all community events.

In the second article, the *koloks'* social representation of the *normals* is explored with the aim of providing more context into the way in which the community is organized. As most Deaf people in Western societies are organized in the margins of the hearing society, there has been a long-standing debate on whether or not Bengkala should even be considered a Deaf community since it differs greatly in the way the Deaf participate in the public sphere. However, after collecting the data on the *koloks'* SR of their hearing family members, friends and neighbors with whom they share this community, the concept of inclusive Deaf community is brought forth. In Bengkala, the *koloks* represent the *normals* as being the "same" as them, yet they also rely on them as supportive members of the community who help them cross communication barriers when needed. That said, to serve justice to the inclusivity in the village while still acknowledging the fact that it shares many similarities with Deaf communities around the world, it is important to consider Bengkala as being an inclusive Deaf community

where there is acceptance of deafness, the adaptation of community events to ensure the *koloks*

inclusion and the allegiance between the *koloks* and the *normals*.

In the third article, the *koloks*' social representation of the shared sign language, *Kata kolok* will be studied in the context of the small isolated village of Bengkala where both dominant Western approaches to deafness have not had much impact on the community. Although Bengkala is surrounded by Deaf communities which organize themselves through the use of the Indonesian sign language (BISINDO) or the Indonesian Signal System (SIBI), as well as their presence in special Deaf schools on the island, the *koloks* have been able to maintain their local sign language as part of their local culture for many generations. Therefore, the relationships between the *koloks* and the *normals* have been able to flourish through their common language allowing the *koloks* to access all levels of community activities independently. This is a testament to the unifying quality that *Kata kolok* has in the community.

In conclusion, the data collected in all three of the articles shows that there is a great divide between the *koloks*' SRs of deafness and all that it entails, and the two dominant SRs of deafness in the rest of the world. This was made possible in large part by the isolated nature of the village and the vast linguistic make-up of the area. Thus, it would be difficult to recreate such a favourable environment for Deaf people in Western societies to be included in the dominantly hearing society. However, the analysis of the data collected highlights the fact that community-based adaptations can withstand the influence of outside sources if and when the social representations in said communities are kept by its members.

*** Design and Methodology

First article

Being Deaf in Bengkala : Identifying as *Kolok* within a *Deaf Village*

Abstract

Bengkala is a small farming village in northern Bali with a long history of having a high incidence of deafness which has prompted community-wide adaptations in all levels of community activities. In most Western societies, deafness is represented as being either a medical matter that requires professional intervention in the way of hearing aids and speech therapy, or deafness is represented as being a cultural matter that emphasizes a common Deaf culture and Deaf identity. Both of these approaches offer contradicting solutions to counter the communication issues which are always associated with deafness. However, in Bengkala, the social representation of deafness has not been imposed by proponents of either of these approaches. Instead, it is the result of multi-generational interactions between the deaf, known locally as the *koloks*, and the hearing, known locally as the *normals*, which were facilitated by the village sign language. When put into the context of Bengkala, the idea of the *koloks* having a traditional concept of a Deaf identity, constructed through Tajfels and Turners' (1979) social categorization, social identification and social comparison, and suggesting that they are in constant competition with the *normals* who represent the *outgroup*, negates all of the efforts put forth by the community to integrate the *koloks* in all levels of activities. By studying how the *koloks* represent deafness, this article will provide insight into their own understanding of their social identity within the village of Bengkala. Thus, discussing the *koloks*' membership to both the *kolok ingroup* and the *village ingroup*, which they share with the local hearing villagers, will explore the possibility of a mutual existing of the Deaf and the hearing.

Keywords : Social Representations, Deafness, Social Identity, Deaf Identity

Introduction

From the moment you arrive in Bengkala, a small farming village in northern Bali, there is a sense that something is different. As an outsider stepping into what seems to be one of many traditional villages around the island, it somehow feels as though the villagers have been expecting your arrival. Although they are not organized around tourism, as many areas on the island are, the locals have become accustomed to the coming and going of vacationers from all around the world. However, there are no souvenir shops, no restaurants, no resorts or anything of the sort. The only attraction seems to be the people of Bengkala themselves. More specifically the *koloks* who have become known both locally and internationally as they represent one of very few remaining groups with a high-incidence of multi-generational deafness in the world.

The word "*kolok*" is used liberally throughout the village to describe anything and everything that relates to deafness. Some of the most common uses of the word are 1) put as a suffix to a deaf person's name in order to identify them 2) used to describe the local indigenous sign language, *Kata kolok,* which translates as "deaf talk", 3) used to refer to the *janger kolok,* the local deaf dance group or 4) used as a substitute for "Bengkala" itself by referring to it as *Desa Kolok*, meaning "deaf village". Although the term "*kolok*" is specific to the deaf population of Bengkala[3], the impact of the word transcends the village boundaries and has been

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[3] The term "*kolok*" is only used to refer to deaf people within Bengkala. The Indonesian translation of deaf is *tuli*.

used in several local and international media coverage as well as academia papers that showcase the uniqueness of the village.

In Western societies, Deaf people establish themselves in the margins of the dominantly hearing society as a way to counter the popular medical approach which aims to rehabilitate deaf people in order to integrate them into society. By offering an alternative to the countless hours of therapy, hearing aids and possible surgeries, Deaf communities take it upon themselves to advocate for their members' unifying culture and unique language. However, in Bengkala, the deaf and the hearing villagers have been living together for many generations without medical nor cultural distinctiveness. Therefore, by studying the *koloks*' social representation of deafness, within the context of the village of Bengkala, this article aims to explore the existence of a possible alternative path to the two opposing dominant social representations of deafness in Western societies which stem from the medical and cultural approaches to deafness.

Research Context

Both the medical and the cultural approached to deafness carry a long history of claiming dominance in the matter of d\Deaf people's inclusion in the public sphere. By proposing opposing strategies to counteract the communication issues associated with being d/Deaf, these two groups convey fundamentally different social representations of deafness. In order to weigh in on the debate, the following section will provide a brief overview of the social representation of deafness around the world. This will be followed by the presentation of the concept of Deaf identity within traditional Deaf communities in hopes of providing some contextual background data to the general topic of this article.

The Social Representation of Deafness

From the 1960s to the 1980s, there was a surge in research on attitudes towards deafness. Studies in the field, like most other forms of impairment, had gained popularity due to the increase in social participation and the political presence of marginalized groups. Although these studies may be dated, it is interesting to reflect on their findings as there was a common train of thought throughout most publications. Researchers found that attitudes towards deafness were perceived more negatively in the Deaf population itself than it was in the hearing population (Furham and Lane, 1984 ; Schroedel and Schiff, 1972 ; Thayer and Schiff, 1974). More so, when deaf subjects were asked how they believed hearing subjects viewed the Deaf population, the results were much more negative than the hearing had actually invoked (Furham and Lane, 1984 ; Schroedel and Schiff, 1972). A plausible explanation for these discrepancies in the Deaf and hearing's attitudes could be the lack of interactions between the two groups (Furham and Lane, 1984). If so, it is believed that the hearing participants who have not had many, if any, interactions with the Deaf population may have responded with overly positive answers in an attempt to please the researchers (Furham and Lane, 1984, Thayer and Schiff, 1974). Whereas for the Deaf participants, their answers would be more representative of the reality as were more than likely based on actual interactions with the hearing.

In more recent years, studies on the social representation of disabilities have been *à la mode* with researchers interested specifically in the social representation of deafness (Golos & Moses, 2011; Marschark & Clark, 2014; Maxwell-McCaw, Leigh & Marcus, 2000; Dagron, 2006; McQuarrie & Parrila, 2009 ; Lavigne, 2010 and Bath, 2012). In his work, Dagron (2006) identifies two distinct representations of deafness : 1) the medical representation of deafness

and 2) the cultural representation of deafness. From a medical perspective, deafness is represented as being a *disability* (Lavigne, 2010). Such, there is no emphasis on sign language or the Deaf community. All the attention is focused on the rehabilitation of the deaf persons and the use of spoken language. This means hearing aids and cochlear implants are presented as solutions that allow deaf people to access the hearing world, and thus integrate society. From the cultural perspective, deafness is represented as being a *difference* (Lavigne, 2010). A lot of attention is put towards the recognition of sign language as well as Deaf culture. In this case, the acceptance of deafness surpasses the desire to rehabilitate and integrate the Deaf into the hearing society. On the contrary, the belief is that if society would be more accepting of sign language, the Deaf people could co-exist with the hearing as a linguistic minority. Hearing aids and cochlear implants are therefore perceived as attacks on the physical and mental integrity of Deaf people (Dagron, 2006).

These two dominant social representations of Deafness have been present in Western societies for centuries and thus are deeply rooted in the common discourse. As a result, when a deaf child is born, these frames of references are called upon as parents and close friends begin to familiarize themselves with this new reality. In modern society, key players in both the medical field, such as ENT physicians, audiologists and speech therapists, and the cultural domain, such as members of the Deaf community, sign language instructors and Deaf advocates, may intervene to offer some guidance in the process of accepting deafness. In doing so, deaf people are led into either of the dominant paths, where they will adopt a certain, contextual appropriate, perspective on deafness from a very young age. In saying so, this allegiance to either group and their social representation of deafness will greatly influence the individuals' social identity.

Social Identity and Deafness

In his thesis on the representation of Deaf Identity in the Deaf Community, Bath (2012) collected his data from newspaper articles published between 2005 and 2010. Throughout his research, Bath (2012) also identifies two theoretical paradigms that act as pillars of difference in the perspectives of Deaf Identity formation : 1) the pathological paradigm and 2) the socio-constructivist paradigm. These paradigms are very similar to the medical and cultural representations found throughout the deaf studies (Dagron, 2006 ; Lavigne, 2010). Interested in the concept of identity, Bath (2012) identifies the problematic reality of minority groups' identity as being controlled by the discourse of the dominant group. In this case, the author is referring to hearing people shaping deaf people's identity by advocating for rehabilitation and integration into the majority hearing society.

To this point, De Clerck (2016) states that the social representation of deafness shared in the hearing society is often negative, pejorative, and centered around communication issues and disability. Furthermore, these dominant ideologies negatively impact the deaf individuals' social identity as they are constantly bombarded with these degrading viewpoints from the majority hearing group. However, the first contact with the Deaf community can offer a new, more positive, perspective for the Deaf. Anmad & al. (2002) also present the effects of the oppressive attitudes of hearing people towards deafness and sign languages by stating that deaf people who are immersed in an oppressive environment tend to internalize this discourse which is why Deaf identity rarely develops within the family. Rather, Deaf identity is developed through interactions with the Deaf community.

In his writings, Holcomb (1997) adopts Epstein's theory of the self (1973) to develop seven possible identities for Deaf people. These categories differ from each other in the degree

of interaction that Deaf people have with one another as well as with the hearing population. Also, the moment of involvement of the deaf person in each of these cultures, Deaf and hearing, has a great influence on the person's ability to integrate and create their self-image. In the case of deaf children born to hearing parents who make no effort to integrate Deaf culture into their child's life, or even the example of an adult who suddenly loses his hearing, these individuals will have difficulty identifying as "bicultural", which seems to be the most desirable of identities.

To sum up the literature on the subject of the social representation of deafness and the Deaf identity, the struggle between the medical and the cultural approaches is widely propagated and felt to a certain extent by most Deaf people around the world. However, Bengkala is an example of one of the few isolated villages in the world where this debate has not yet reached. In Bengkala, the *koloks* and the *normals*, have adapted, over many generations, to the point where not only do they share a local sign language, but they also participate in all the same community activities. And so, by showing interest in the *koloks*' social representation of deafness, and studying their social identity, this article aims to understand a community with a more neutral alternative to the two opposing social representations of deafness (medical and cultural) that have been dominating the interest of scientific research and social interactions for decades.

Theoretical Framework

The Social Representation Theory

Social representations (SR) are a system of cognitive elements, values, ideas and practices shared within a social group and allowing individuals to position themselves *vis-à-vis* a social object or situation with which they are faced (Palmonari & Emiliani, 2017 ; Jodelet,

1994). The founder of the social representation theory, Moscovici (2013), states that social representations have a twofold function. Firstly, they aim to establish an order for individuals to orient themselves in their material and social worlds. Secondly, they aim to enable communication to take place among community members. Thus, SRs are referred to by individuals throughout their day to day activities as they act as reference grids that help them navigate their social environment (Jodelet, 2002).

In Jodelet's sociogenic approach to the social representations theory (SRT), emphasis is placed on the context in which SRs emerge as the result of encounters with unknown objects. These encounters are what initiate the process of formation of new SRs as the unknown objects must be transformed into common knowledge within their context. This transformation is done through the processes of objectification and anchoring and ultimately result in the creation of a new SR (Palmonari and Emiliani, 2017). Focusing on the genesis of SRs, Jodelet (2003) explains that social scientists who choose the SRT as a theoretical framework have a vested interested in exploring the complexity of the data collected within the studied population. The sociogenetic approach looks at both objectification and anchoring and focuses on social objects as complex phenomena in their environment (Rateau and Lo Monaco, 2013). Using this theoretical framework to study the *koloks*' SR of deafness will provide insight into the *koloks*' social identity as they are members of a unique and inclusive community.

The Social Identity Theory

Tajfel (1974) describes social identity (SI) as "the part of an individual's self-concept which derives from his knowledge of his membership of a social group (or groups) together with the emotional significance attached to that membership". In saying so, group membership is always at the core of the individual's social identity. In fact, the central hypothesis of social

identity theory (SIT) is that members of an *ingroup* (us) will seek to find negative aspects of an *outgroup* (them), in the belief that it will enhance their self-image (McLeod, 2008). With that in mind, individuals belong to many different groups. Thus, social identity is comprised of multiple identity claims, such as ethnicity, gender, age, religion and ability status. In addition, an individuals' social identity is dynamic, flexible and situational, meaning that it adapts to changing social relationships between groups and it is an incomplete and emergent process that always involves ambivalence and signification in narrative (Tajfel, 1974 ; Hall, 1991).

In Deaf communities around the world, the concept of Deaf identity is referred to by members of the community as a way to describe the feeling of having been reborn, or having found their place in this world (Gaucher, 2009). Though it might come later in life since most Deaf people are born to hearing parents, once a Deaf person finds their Deaf identity it has the tendency of becoming their primary identity (Lane, 1995). Emphasizing the shared oppression of Deaf people by the hearing society and a unity in terms of language and values, Deaf communities create a welcoming environment for the Deaf (Gaucher, 2009 ; Ahmad & al., 2002). And so, by favouring their membership to the Deaf community over their membership within the majority hearing society, the Deaf began to internalize the groups' SRs creating a divide between the *us* (Deaf, signers) and the *them* (hearing, speakers). Thus, the more integrated the Deaf person becomes into a Deaf network, the lesser the chances for them to become isolated and begin to internalize the negative attitudes towards the Deaf shared by the hearing society. This addresses the need for young Deaf people to have access to a Deaf community from an early age for them to develop "a solid identity as Deaf persons during this crucial period" (Holcomb, 1997). It is through these networks, which provide encouragement

and positive Deaf role models, that newcomers to the Deaf community will garter greater self-esteem.

The concepts of social representation and social identity have contributed to important developments in social psychology and social sciences (Breakwell, 1993 ; Duveen, 2001 ; Howarth, 2011). When put into the context of Bengkala, the idea of the *koloks* having a traditional concept of a Deaf identity, constructed through Tajfels and Turners' (1979) social categorization, social identification and social comparison, and suggesting that they are in constant competition with the *normals* who represent the *outgroup*, negates all of the efforts put forth by the community to integrate the *koloks* in all levels of activities. By studying how the *koloks* represent deafness, this article will provide insight into their own understanding of their social identity within the village of Bengkala. Thus answering the question : how have the *koloks* managed to construct their social identity independently from the two opposing approaches described in scientific research and which have shaped social interactions between deaf and hearing people in most societies?

Methodology

This ethnographical research was conducted over the span of two field studies, for a total of six months, spread over two years (2017-2019). During this time, participant observation was chosen as the data collection method. A field journal was kept in order to document my observations by keeping notes and anecdotes, as well pictures and videos. These observations were documented in both written and electronic journal entries using objective running descriptions, first impressions, feelings, questions and hypotheses. The intention was to create what Geertz (1973) referred to as a "thick description" of the *koloks*' involvement in the community. Thus, with the intention of documenting as much of the *koloks*' interactions,

whether it be with each other, with their local culture and environment or with the outsiders who visit Bengkala, I participated in many cultural events, such as religious ceremonies, rituals, dances and sacrifices, as well as administrative and political duties, such as a national presidential vote, community meetings and tourism management. Following Dodier and Baszangers' (1997) concept of "totalization", I gathered as much knowledge into the processes and conditions that influence the *koloks'* day-to-day interactions as possible.

In addition to participant observation, 30 one-on-one semi-structured interviews were conducted towards the end of the second field study. This research sample includes all the *koloks* who were capable of doing an interview, keeping in mind their age and linguistic abilities. Verges' evocation method (1992) was chosen as a way to loosely format the semi-structured interviews. In its complete version, this technique results in the participants giving the first five words that come to mind when given a stimulus word, in this case "*kolok*", and then ranking them in order of importance. In doing so, the participants prioritize their results rather than leaving them in their order of appearance, which is thought to be more indicative of the actual structure of the social representation. But in the case of the *koloks*, none of the answers were ranked as the concept of importance does not exist in *Kata kolok*. Since there is no sign to attest to such a task, the shorter, non-hierarchical, form, where the data is collected in order of appearance only, was chosen for the interview. In addition, the *koloks* were encouraged to elaborate on their answers which felt much more natural as it resembled our typical day-to-day conversations. In return, the data collected resembled a mix between Verges' non-hierarchical evocation method and a typical semi-structured interview, resulting in a list comprised of representational elements complete with a rich body of discursive data.

Considering the combination of descriptive data collected through participant observation and the more structured elements of representation gathered during the semi-structured evocational interviews, the iterative analysis process was done in two stages. Firstly, the data analysis began as soon as the participant observation started through familiarizing with the data and the identification of recurring themes, attitudes and contradictions. By reading through the corpus of data often and generating concepts which make sense of it, the ethnographical analysis revealed categories for organizing the data which emerged from the context (Hammersley and Atkinson, 2007). Secondly, I proceeded with the content analysis of the semi-structured qualitative evocational data which complemented the data collected through participant observation by giving the *koloks* the opportunity to share their own narrative on the situation. That said, it is important to acknowledge that although the *koloks* identify as being *kolok*, they identify as such within their larger *village identity*.

Thus, considering that in Bengkala, deafness is a characteristic that describes an individual, but it does not necessarily differentiate them from the other villagers in Bengkala, the Western influenced social representation of deafness acted as a limit to this research project. The dichotomy associated with the Deaf and the hearing fails to attest to the *koloks' village* identity as much as their *kolok* identity as they do not represent either of the opposing approaches to deafness. And so, with this research attempting to identify how the *koloks* managed to construct their social identity independently from the two opposing approaches described above, I not only assumed that the Western approaches would apply in the context of Bengkala, but even more so, I neglected to consider the fact that with all of the international researchers and tourists who have visited the village, the *koloks* are aware of the medical and cultural approaches to deafness which in return influences the participants' answers to my

questions. In order to work around these preconceived answers to my questions, many open-ended contextual questions were used throughout the field work. These allowed me to access a better understanding of the *koloks*' daily reality and their navigation of both *kolok* and *village* identity which have not yet been transformed much by Western social representations of deafness.

Results

The *koloks* have been fostering their relationships with each other as well as with the *normals* without the intervention of outside sources for many generations. Although there have been more and more outsiders entering the village and sharing about the Western Deaf world in recent years, their impact is only but starting to be felt in the village. To this day, there is still no trace of hearing aids or implants used by any of the *koloks*, nor are there any speech therapy or sign language classes, all of which are common practice in most other areas of the world. That said, during the one on one interviews, the *koloks* made it clear that they have been juggling two social identities. One which they share with the *koloks* and the other which they share with the local villagers of Bengkala. Thus, two of the *koloks*' social identities are indicative of their membership to the *kolok ingroup* and the *village ingroup*, both of which define appropriate and inappropriate behaviors by reference to the norms of the group as well as influence their level of self-esteem.

Kolok Identity

The *koloks* have been part of the local population in Bengkala for longer than anyone in the village can remember. And although traditional marriage practices which had been intensifying the transmission of the genetic deafness are decreasing in popularity, the number of *koloks* has stayed relatively the same due to the influx of deaf people from other villages on

the island. The following paragraphs will provide some insight into the context in which the

kolok ingroup was created by highlighting the types of relationships that have been fostered

between the *koloks* for many generations. First, the *koloks*' social interactions with each other

will be described as they are the most common of the *koloks* interactions in the village. Then,

the *koloks*' participation in community subgroups will be explored as they attest to the *koloks*

inclusion in local traditional practices. And finally, the *koloks* interactions with Deaf people

from around the island, as well as international tourists who have come to the village, will offer

some insight into the reach of the *kolok* identity.

Deafness in Bengkala is the result of a genetic mutation that has caused multi-

generational hearing loss in the village for centuries. This means that most of the *koloks* are

related to one another and thus have family ties that bind them together from birth. However,

the tendency for the *koloks* to gather together goes beyond the family as the participants

associated the word "*kolok*" with a sense of "togetherness" with not only their *kolok* "family",

but also their *kolok* "friends" in the village. Whether it be at home, in the village, at work or at

school, the *koloks* count on each other for support. They value their friendships and they count

on each other for company as they visit each other regularly in order to make sure that none of

the *koloks*, especially the older generation or the ones born in *normal* families, feel lonely or

sad.

In addition to the informal relationships that have been fostered between the *koloks* in

the village, they form smaller, more structured, subgroups as well. This is typical of traditional

Balinese villages all over the island where village groups are formed to fill specific criteria in

keeping the village functional. In Bengkala, the *koloks* form two groups which fill specific

roles: the *kolok* dance groups and the *kolok* cemetery workers. The participants refer to both of

these groups as being important as they represent the *koloks*' participation in the local culture. On the one hand, dancing plays an important role in all of Balinese culture. And so, the *koloks* share their story by dancing in front of large groups of tourists who visit the village as well as journalists who want to film the performance for their montage. Dressed in colorful costumes, with beautiful hair and makeup, the *koloks* perform to the beat of a drum and the sound of their own voices. On the other hand, the grave-digging group, consisting of six deaf men, is responsible for digging all of the graves and taking care of the village cemetery. This tradition has been in the village for generations and is based on the ancient belief that the *koloks* are stronger and braver than the *normals*. By assuming this social representation as part of their social identity, the *koloks* favor their strength and braveness and take pride in having the responsibility of such an important and spiritual task. Thus, these group activities give the *koloks* a sense of purpose as well as a boost in their self-esteem from the praises they receive from their actions within these groups.

As well as sharing the *kolok* identity with the native deaf population, the participants discussed that deaf people from around the island now come to Bengkala because they have found the village to be more welcoming and accepting of their deafness than their native villages. And so, these *new koloks*, who often marry the local *koloks*, are finding themselves more than ever surrounded by other deaf people with whom they can interact freely and easily. Deaf visitors also come from all around the world looking for the utopian "Deaf village" that has been promoted in media and literature. And while many tourists cycle in and out of the village very quickly, others stay for extended periods of time. In doing so, a few Deaf tourists have created relationships with the *koloks* and have been referred to by name during the interviews as being important friends and members of the *kolok ingroup*.

Village Identity

In addition to identifying with the *kolok ingroup*, the *koloks* gave numerous answers implying they also identify with a *village ingroup* which they share with the *normal* villagers. In Bengkala, the *koloks* and the *normals* have been living together for many generations, making the interconnectedness between the two groups such that they have created their own SRs of the aspects that separate them from their neighboring villages, such as deafness, sign language and inclusive community adaptations. Thus creating a *village* identity in which the *koloks* and the *normals* are perceived as being, the "same", or "equal", members who participate fully in all community events. The following paragraphs will present the data collected from the *koloks* in regards to three instances that put forth the equality between the *koloks* and the *normals* in the village, whether it be the relationships fostered between the deaf and the hearing, the inclusion of the *kolok* children in the local school or the equal work-related opportunities for all members of the village.

As much as the *koloks* tend to gather together, this is always done alongside the hearing villagers with whom they share everything from the local sign language, the compounds in which they live, the temples where they celebrate or the gardens where they work. By being so intertwined, the *koloks* and the *normals* share a common outlook on village life that represents both hearing and deaf villagers as the "same". And so, during the interviews, the *koloks* shared that, in Bengkala, the "*koloks* and *normals* sign together". This "shared" nature of *Kata kolok* is perceived as being something very positive from the *koloks*' perspective as it is representative of a common communication system that has been held in the village for many decades. Without communication, it would be impossible for the *koloks* to form the bonds that have been created within this *village ingroup*. Living so close to each other and spending so

much time together, the *koloks* and the *normals* have grown up alongside each other from the time they were born making their social identity process linked with that of their hearing peers. For this reason, there are no discriminatory or dismissive distinctions between the deaf and the hearing in the village.

In more recent years, the relationship between the *koloks* and the *normals* has been even more interlaced due to the fact that they now attend the same school. It was, however, not so long ago that the *koloks* were not allowed in the local school. In Bali, deaf children usually attend "Deaf schools" where they are taught using the national sign language. These schools are found in a number of the larger cities around the island with the closest one to Bengkala being in Singaraja, approximately 15 km from the village. Although this distance might not seem like much of a burden, it must be put into the context of rural Bali where there is no public transportation and the traffic is overwhelming due to the state of the roads as well as the number of people travelling on motorbikes. But with the integration of the *kolok* children in one of the two local primary schools since 2007, the *koloks* now have access to education in their native village. This has triggered a major shift in the *koloks*' social identity as the younger generation does not use the same derogatory terms used as the older *koloks* who gave answers such as " I can't do…", "I am stupid/an idiot", "I don't understand", or "I am uneducated" to describe themselves. They now consider themselves as equal members of society who have access to the same education as their peers.

In addition to now having access to the same education as the *normals*, the *koloks* have access to the same employment opportunities as well. Considering the older generations of *koloks* did not have any type of formal education, they were all taught the importance of work at a very young age and so they take much pride in the fact that they can provide for themselves

and support their families regardless of their lack of hearing and education. That said, with the *kolok* children now going to school, this focus on work is not as prevalent as early in life as it used to. Regardless, a good work ethic is still a very sought out aptitude in the village, whether you are deaf or hearing. The most common jobs for the *koloks* and the *normals* to obtain revolve around agriculture, farming or manual labour. These jobs are mostly dependent on the seasons and offer very few stable, full-time, employment opportunities. For these reasons, the villagers must be very flexible and willing to do many different types of jobs. That being said, there are a few jobs that require communication and/or training outside of the village, such as the village security or political and governing jobs. The *koloks* cannot occupy these positions due to communication issues. However, when it comes to the vast majority of the local jobs, the *koloks* and the *normals* have been working as equals for generations.

Exceptions

Although the *koloks* shared many stories of happiness and equality, there are certain aspects which were brought up by the participants that reflected a certain feeling of inferiority in the village. As was mentioned, the newly married *koloks* who were born to hearing parents outside of the village have shared stories of sadness and loneliness stemming from their childhood. But there are also a few exceptions from native adults that have shared certain issues pertaining to their interactions with the hearing villagers of Bengkala. One participant in particular stated during the one-on-one interview that he has made the decision not have any hearing friends. That being said, he continued by adding a few exceptions to this rule, all of whom are *normal* villagers who spend much of their time helping the *koloks* either by translating or accompanying them when needed. Additionally, he regularly interacts with his grandchildren, his daughter in-law and her family, all of which are hearing. These discrepancies

are indicative of the individuals' difficulty to manage both the *kolok identity* and the *village identity* that serve him in different contexts.

In addition, there were rare instances where a few *koloks* mentioned having issues regarding their education or their communication skills. Considering the inclusive school in the village only started accepting *koloks* in its classrooms in 2007, the majority of the *koloks* have not had any formal education. This has had negative effects on the older generations who, as children, were separated from their peers on the basis of their hearing impairment. Reflecting on these memories brought out sadness for the older *koloks* who remember their fathers, as well as village authorities, not allowing them to go to school. However, they are very happy that their children and grandchildren now have access to education.

As for issues with communication, some of the older participants shared feelings of sadness and loneliness due to the fact that their interactions with their hearing family members are limited. Although there have been many adaptations within the village in hopes of minimizing the segregation and the isolation of the *koloks*, the data collected from these participants indicates that there are still mixed feelings about being born into an all-hearing family, even within the village. However, it is clear that the younger generations have a much more positive outlooks on deafness as they are continuously being included in more and more of the village activities. Thus, this is indicative of a change taking place in the social representation of deafness in the village.

Discussion

In Bengkala, the *koloks* identify as members of both the *kolok ingroup* and the *village ingroup*. This dual identity is what makes Bengkala so intriguing to outsiders who have a tendency to associate deafness with being non-compatible with the majority hearing group

identity. Meaning that, in most societies, a Deaf person is either integrated into the hearing society through medical intervention, or they are integrated into a Deaf community which organizes itself in the fringes of society. And once individuals identify themselves in either of these groups, they absorb and accept, over the course of time, their prevailing SRs (Howarth, 2004, 2006 ; Duveen, 2001). Thus limiting the contacts between the two groups. In fact, it is rare to find anything in between as both dominant currents have strong conflicting SRs of deafness which discredits the other as a way of favoring their own group identity and self-esteem ; such is described in Tajfels' (1974) Social Identity Theory.

However, deafness does not represent a medical nor does it represent a cultural event in Bengkala. Therefore, neither of the dominant SRs of deafness has yet to be adopted in the village even though in recent years there has been increasing amounts of contact between Bengkala and the Western d/Deaf debate. In fact, the *koloks*' SR of deafness was created through generations of close contact and communication between the *koloks* and the *normals* and it has stood the test of time. That said, the *koloks* are no strangers to outside influence when it comes to representing deafness. They acknowledge the different SRs of deafness around the world that have made their way, to varying degrees, in the village. But they stand strong against the segregation of the Deaf which comes from these Western approaches. Thus, the *koloks*' SR of deafness offers a more neutral alternative to this state of cognitive polyphasia as it encourages the development of their sense of identity within both the *kolok* and the *village* ingroups instead of having to choose one or the other.

When deafness appeared in Bengkala, instead of focusing on what the *koloks* could not do, which was hear, the focus was put on what they could do, which was physical work. The *koloks* were known not to get distracted at work and not to get frightened. Thus, they got

labelled as being strong and brave, which was perfect for manual labour jobs. That said, in the past decades, the *koloks* have begun to represent themselves as being more than just labourers by getting involved in more and more of the village activities and identifying as equal members of the *village* ingroup. But the fact that the social representation of deafness in Bengkala was not influenced by the dominant Western approaches to deafness is a testament to the importance of not only focusing on the process of categorization when thinking about social identity, but also to question why these categories were made in the first place (Duveen, 2001).

Left to their own devices, the villagers of Bengkala adopted a community-based approach to deafness by focusing on what brings these two groups together and how they can accommodate each other's needs. By implementing a local signed language, the communication issue was solved quite early in the process. From then on, the *koloks* and the *normals* were able to understand each other and their needs and they worked out their other differences by utilizing each other's strengths. Since the *koloks* were represented as being stronger and braver than the *normals*, they were made responsible for taking care of the cemetery and the water system in the village. Both of which are important jobs in all Balinese villages. In return, seeing as the *koloks* had fewer job opportunities as they couldn't go looking for work outside of the village and access to important information on merchant prices and techniques was not as easily accessible at the time (these conditions have since been improved upon), they were exempt from paying certain villages dues required of the *normal* villagers. All of these adaptations, which are still in place in the village after many generations, were generated from the ground up. They did not come from governing entities or legislatures, such is the case in Western societies where decisions that influence the fate of the Deaf are imposed from outside sources (Anmad & al., 2002). Thus, the fact that the *koloks* are born into a village

where they are accepted into their native society from birth makes their identity process no different than any of their *normal* friends.

What remains unknown, however, is how much longer the village of Bengkala will withstand the outside influence. It is already apparent in the data collected that the *koloks*' SR of deafness has changed in the last thirty years or so with the older generation having a much more negative outlook on life and the young adults feeling much more included in the local community. Still, Bengkala is at risk of losing its unique outlook on deafness as it is threatened by multiple different outside sources (Zeshan, 2007 ; Groce, 1985). For example, the fall of this inclusive SR of deafness could come from the diversification of the gene pool due to inter-village marriages, or *kolok* and *normal* marriages. Or the *koloks* could decide to leave the village to go find a Deaf community in a larger city where they will meet Deaf people from all over the island. It could also be due to the overturning of the local sign language by the dominating national sign language which could be encouraged by a nationalist approach looking to unifying all villages. In short, the future of Bengkala is unsure and could face some big changes in its coming generations. What would be interesting would be to conduct a longitudinal study that would monitor changes in the SR of deafness in the village to understand the process and explore where these changes are coming from.

Conclusion

Social representations are always evolving. And with outsiders' influence in the village being more and more frequent, through tourist visits, research projects and government grants, the *koloks* are brought to question their own social representations when confronted with Western beliefs on how the Deaf and hearing should interact. I believe that this has had a major effect on the way in which the *koloks* view their interactions both inside and outside of the village as the interactions between the two different social identities are constantly having the *koloks* question their representation of themselves. On the one hand, the *koloks* identify with each other as they share a common characteristic. This is seen as something positive as deafness has brought the *koloks* together and it has brought tourism into the village, all of which have positive social and economic effects on the community. On the other hand, the *koloks*' *village* identity finds its frame of reference in the SR that all villagers of Bengkala are the "same" and it gives the *koloks* access to all levels of community activities instead of being kept in the fringes due to their *disability* or their *difference*. Thus, by identifying as part of the *village* identity, the *koloks* acknowledge their native culture as it includes the *koloks*' history as well as the hearings.

Thus, following the internalization of the groups' social representations (Duveen & Lloyd, 1986), and with social identity being an always evolving "dynamic, flexible and situational" state in which the individuals must find themselves (Tajfel, 1974), the multi-generational relationships between the *koloks* and the *normals* testify to their long-standing ability to find cohesion between the two groups. That said, while the aim of this article was not to do a historical look into the evolution of the SR of deafness in Bengkala, the data collected shows that the older generation of participants shared more stories of social exclusion when

compared to the younger generations. Some of the older *koloks* shared not being able to attend school, not being able to communicate much with their hearing families, not having many *normal* friends and not having many interactions out of the village. These statements provide insight into how the *koloks*' SR of the normals has evolved into what it is today.

References

Ahmad, W. I., Atkin, K., & Jones, L. (2002). Being deaf and being other things: Young Asian people negotiating identities. *Social Science & Medicine*, *55*(10), 1757-1769.

Bath, P. M. C. (2012). Perspectives from the Deaf Community: Representations of Deaf Identity in the" Toronto Star" Newspaper (2005–2010). University of Ottawa (Canada).

Breakwell, G. (1993). Social representations and social identity. *Papers on social representations*, *2*, 198-217.

Dagron, J. (2006). Représentations sociales de la surdité. Dans : Benoît Virole éd., *Psychologie de la surdité* (pp. 239-252). Louvain-la-Neuve, Belgique: De Boeck Supérieur.

De Clerck, G. A. (2016). Deaf epistemologies, identity, and learning: A comparative perspective. Gallaudet University Press.

de Vos, C. (2012). Sign-spatiality in Kata Kolok: How a village sign language in Bali inscribes its signing space (Doctoral dissertation, Radboud University Nijmegen). Book.

Dodier, N., & Baszanger, I. (1997). Totalisation et altérité dans l'enquête ethnographique. *Revue française de sociologie*, 37-66.

Duveen, G. (2001). Social representations. *Introducing social psychology*, 268-287.

Duveen, G., & Lloyd, B. (1986). The significance of social identities. *British Journal of Social Psychology*, *25*(3), 219-230.

Epstein, S. (1973). The self-concept revisited: Or a theory of a theory. *American psychologist*, *28*(5), 404.

Furham, A., & Lane, S. (1984). Actual and perceived attitudes toward deafness. *Psychological Medicine*, *14*, 417-423.

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

Geertz, C. (1973). *The interpretation of cultures* (Vol. 5019). Basic books.

Golos, D. B., & Moses, A. M. (2011). Representations of deaf characters in children's picture books. *American Annals of the Deaf*, *156*(3), 270-282.

Groce, N. (1985). Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard. Cambridge, MA: Harvard University Press.

Hall, S. (1991). Ethnicity: Identity and difference. *Radical America*, *23*(4), 9-20.

Hammersley, M., & Atkinson, P. (2007). The process of analysis. *Ethnography: Principles in practice*, 158-190.

Holcomb, T. K. (1997). Development of deaf bicultural identity. *American annals of the deaf*, *142*(2), 89-93.

Howarth, C. (2004). Re-presentation and resistance in the context of school exclusion: Reasons to be critical. *Journal of community & applied social psychology*, *14*(5), 356-377.

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.

Howarth, C. (2011). Representations, identity, and resistance in communication. In *The social psychology of communication* (pp. 153-168). Palgrave Macmillan, London.

Jodelet, D. (1994). Le corps, la personne et autrui. *Psychologie sociale des relations à autrui*, 41-68.

Jodelet, D. (2002). Les représentations sociales dans le champ de la culture. *Social Science Information*, *41*(1), 111-133.

Lane, H. (1995). Constructions of deafness. *Disability & Society*, *10*(2), 171-190.

Lavigne, C. (2010). Surdités, représentations du corps, identités: corps biologique, corps social et corps à soi. *La nouvelle revue de l'adaptation et de la scolarisation*, (2), 67-75.

Marsaja, I. G. (2008). Desa Kolok - A Deaf Village and its Sign Language in Bali, Indonesia. Nijmegen: Ishara Press.

Marschark, M., & Clark, M. D. (2014). *Psychological Perspectives on Deafness: Volume II*. Psychology Press.

Maxwell-McCaw, D. L., Leigh, I. W., & Marcus, A. (2000). Social identity in Deaf culture: A comparison of ideologies. *JADARA-ROCHESTER NY-*, *33*(3), 14-28.

McLeod, S. (2008). Social identity theory. *Simply Psychology*.

McQuarrie, L., & Parrila, R. K. (2009). Deaf children's awareness of phonological structure: Rethinking the "functional-equivalence" hypothesis. *Journal of Deaf Studies and Deaf Education*, *14*(2), 137-154.

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

Palmonari, A. & Emiliani, F. (2017) Le modèle sociodynamique. In Lo Monaco, G., Delouvée, S. & Rateau, P. Les représentations sociales. Bruxelles : De Boeck

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

Schroedel, J. G., & Schiff, W. (1972). Attitudes towards deafness among several deaf and hearing populations. *Rehabilitation Psychology*, *19*(2), 59.

Tajfel, H. (1974). Social identity and intergroup behaviour. *Information (International Social Science Council)*, *13*(2), 65-93.

Tajfel, H., Turner, J. C., Austin, W. G., & Worchel, S. (1979). An integrative theory of intergroup conflict. *Organizational identity: A reader*, *56*, 65.

Thayer, S., & Schiff, W. (1974). Observer judgment of social interaction: Eye contact and relationship inferences. *Journal of Personality and Social Psychology*, *30*(1), 110.

Vergès, P. (1992). L'evocation de l'argent: Une méthode pour la définition du noyau central d'une représentation. *Bulletin de psychologie*.

Wang, A., Liang, Y., Fridell, R. A., Probst, F. J., Wilcox, E. R., Touchman, J. W., ... & Friedman, T. B. (1998). Association of unconventional myosin MYO15 mutations with human nonsyndromic deafness DFNB3. *Science*, *280*(5368), 1447-1451.

Zeshan, U. (2007). The ethics of documenting sign languages in village communities.

Second article

The inclusive Deaf community of Bengkala : the *Koloks*' Social Representation of the hearing

Abstract

Deaf communities have been existing in the margins of hearing societies for centuries. Forming in larger cities and urban centers, Deaf communities allow Deaf people from all neighboring villages to meet, share experiences, make connections, have fun and learn, all while using sign language. That said, a more recent interest in smaller isolated villages with a high incidence of multi-generational deafness has resulted in numerous publications on "shared signing communities" (Kisch, 2008). Located in the thick forest of Bali's mountainous northern coast, the small isolated village of Bengkala has been considered to be one of very few remaining shared signing communities in the world. Putting the shared use of a local sign language in the forefront of many of the publications on the subject, not much is known about the deaf populations' perspective. Thus, the aim of this ethnographical research is to analyze the *koloks*' social representation of the hearing, known locally as the *normals*, with whom they share their community in order to offer a better understanding of their participation in the public sphere as well as the types of relationships that are formed between the two groups. Having found that the data collected in this study finds the *koloks*' social representation of the *normals* includes both a sense of sameness between the groups and a sense of support from the *normals* towards the *koloks*, the acceptance of deafness, the adaptation of community events and the allegiance between the *koloks* and the *normals* were discovered as being the three conditions that have led to the mutual existence in the village.

Keywords : Social Representations, Social Inclusion, Deaf Community, Shared Signing Community

Introduction

Bengkala is a small village in the thick forest of Bali's mountainous northern coast where a high incidence of genetic deafness has been present for over 7 generations (Liang, 1999). Known locally as the *koloks*, the deaf villagers have piqued the interest of many academics in the fields of genetics and linguistics since the 1990s (Winata & al., 1995 ; Marsaja, 2008 ; de Vos, 2012). However, the *koloks* are not the only ones earning the attention of researchers. The hearing villagers, or *normals*, have also been praised by academics and journalists from all over the world for they have adopted the widespread use of the local sign language, *Kata kolok. Kata kolok* was developed by the deaf villagers more than five generations ago (de Vos, 2012), and with such high numbers of deaf births within the village due to the mutation of the DFNB3 gene, it was implemented and then improved upon by many hearing family members and friends. From then on, more and more people started to learn the language, and now, the majority of the local signers are hearing villagers who have grown up in close contact with the *koloks* and were naturally immersed in the language (de Vos, 2011).

As a result of the extensive use of *Kata kolok* in the village, the *koloks* do not face any of the communication barriers usually associated with being deaf as they are able to communicate freely and effectively within the boundaries of their community. Thus, the *koloks* have been included in all aspects of the local community and have developed meaningful relationships with their hearing family members, friends and neighbors. Being so unique, the relationship between the *koloks* and the *normals* has yet to be studied. And so, the aim of this article is to explore how the village of Bengkala has become the epitome of Deaf communities through inclusive community practices by studying the *koloks*' social representation of the *normals* with whom they share the public sphere.

Research Context

In Bengkala, the *koloks* and the *normals* have been living together for over 200 years. During this time, they have worked together in order to adapted to meet each other's needs, all the while keeping a sense of community. In saying so, there has been much debate on whether or not Bengkala, or other similar villages where there has been a multi-generational high incidence of deafness and a widespread use of a local sign language, should be considered as Deaf communities, or if they should be considered as "shared signing communities" (Kisch, 2008 ; Woll & Ladd, 2003 ; Rayman, 2009 ; Kusters, 2014). In order to weigh in on the debate, it is important to have a clear understanding of what is considered a Deaf community and what characterizes a shared signing community.

Deaf Communities

For a start, Deaf communities are almost exclusively established in the margins of hearing communities as a way for Deaf people to connect with each other. Forming in larger cities and urban centers, Deaf communities allow Deaf people from all neighboring villages to meet, share experiences, make connections, have fun and learn, all while using a signed language. Another important characteristic of Deaf communities all over the world is that they allow for basic socialization of its members (Gaucher, 2009). While socialization of children usually begins within the family, in the case of Deaf children, 90% of them are born into hearing families (Lane, 1995). In these instances, the child's socialization may be negatively impacted by the difficulties revolving around communication. And so, exchanges with members of the Deaf community, with whom they can communicate openly and easily, may be warranted as a way to initiate the child's socialization.

Seeing as there are thousands of Deaf communities around the world, Woll and Ladd (2003) were interested in creating a classification system which would allow them to determine the level of integration of the Deaf within these communities. According to Woll and Ladd (2003), the main factors to consider in determining the type of community in which one or more Deaf people are integrated are : 1) the number of deaf people, 2) the equal opportunities of deaf people and 3) the perception of sign language. While most Deaf communities would be situated somewhere in the middle of these three axes, there are a few exceptions that successfully place themselves in the utopian front, bottom right corner of the imagined cube. These are the most inclusive and well adapted Deaf communities around the world. Woll and Ladd (2003) refer to, among others, Martha's Vineyard and Bengkala, as being prime examples of these communities where there are many Deaf people living in a community which has equal opportunities for the Deaf and the hearing as well as a widespread use of sign language. However, some authors who have been particularly interested in these communities have claimed that these should not be categorized as Deaf communities, but rather as "shared signing communities" (Kisch, 2008; Rayman, 2009).

Shared Signing Communities

Following a stay in the Al-Sayyid community in Israel, Kisch (2008) proposed the use of the term "shared signing community" to describe the isolated community with a high incidence of deafness and an exceptional use of sign language. The number of these communities currently in existence is not known, but Kusters (2009), Rayman (2009) and Zeshan (2007) state that it is possible to find works from various disciplines (linguistics, anthropology, history) conducted in similar communities around the world, including Adamorobe, Ghana (Nyst, 2007; Kusters, 2009), Al-Sayyid, Israel (Aronoff, Meir, Padden and

Sandler, 2008; Kisch, 2004, 2008), Bengkala, Indonesia (Branson, Miller, Marsaja and Negara, 1996; de Vos, 2012; Winata & al, 1995 and Zeshan, 2007), Mayan Yucatec, Mexico (Escobedo-Delgado, 2008; Johnson, 1994; Shuman, 1980), Ban Khor, Thailand (Nonaka, 2004), Kosindo, Surinam (Van den Bogaerde, 2005) and Saint Elizabeth, Jamaica (Cumberbatch, 2008; Dolman, 1986). That being said, it is not known how many of these communities have stood the test of time, as many of them have been dispersed, such was the story of the most well-known shared signing community of Martha's Vineyard in the United States (Groce, 1985).

Although shared signing communities can, by most standards, be considered Deaf communities, there are specific characteristics that must be met for a Deaf community to in turn be considered a shared signing community. Similarly to Woll and Ladd's (2003) cube analogy, shared signing communities are identified through their relationship with sign language, the number of deaf people and the equality of opportunities between the deaf and the hearing, but they must also meet genetic, geographical and organizational criteria. By combining several author's description of shared signing communities, a list of characteristics which must be met in order for a community to be considered a shared signing community will be described in the following paragraphs.

First of all, there are three linguistic characteristics that must be met. First, the sign language must be indigenous to the area, and not spoken anywhere other than within the shared signing community. Sign language is central to both Deaf communities and shared signing communities. Therefore, it is important to distinguish whether or not it is indigenous to the local Deaf community. According to Padden (2010), sign language can emerge in two distinct ways. Either sign language emerges as a result of grouping Deaf people from different regions

through Deaf organizations such as schools for Deaf children, sports leagues, social events, etc. This is the case for most Deaf communities around the world where an already established sign language, such as American Sign Language (ASL), is transmitted to members of a group or association. Or sign language can emerge in a remote village where the deaf villagers do not have any contact with an already existing sign language. In these villages, the deaf create their own sign language by first gesturing or miming certain actions which then eventually evolved into their own indigenous sign language that is passed on through generations. De Vos and Zeshan (2012) have identified 11 of these "village sign languages" around the world.

The second linguistic characteristic of shared signing communities is that in addition to the sign language being "shared" by both deaf and hearing people, it must also be used in all village activities (Zeshan, 2007; Rayman, 2009). Whether it be social activities, professional exchanges, political debates, religious ceremonies, or any other interactions, all activities must have the ability to include the local sign language when a deaf person is involved. This leads us to the third and final linguistic characteristic of shared signing communities which is that most signers are in fact hearing. Not only does this allow for the socialization of the deaf, but it favors the integration of sign language in all levels of local activities. This is far from being the norm in urban Deaf communities where very few hearing people are comfortable using even the most basic of signs. On the contrary, de Vos (2011) states that within a shared signing community, less than 10% of signers are deaf. That being said, it is not uncommon for hearing signers to not only sign with the deaf villagers but to also use sign language among themselves in a noisy or busy environment.

Secondly, concerning the number of deaf individuals within a shared signing community, unlike Deaf communities where there are no specifics on the ratio of the deaf to

hearing people, Rayman (2009) states that between 1 and 4 % of the population is deaf. This higher than average proportion of deaf people is necessary to account for all of the adaptations made in these villages, such as the adoption of the local sign language, the creation of an inclusive school program, the formation of deaf social groups, etc. Thirdly, given the high incidence of deafness in these areas, the deaf presence in social interactions is inevitable and therefore cannot be ignored or set in the background. As a consequence, deaf people have access to the same opportunities as hearing people in terms of social status, employment opportunities, marriage, etc. (Rayman, 2009 ; de Vos, 2011). Even though a few very specific tasks may be reserved for deaf people while others are reserved for hearing people, there is no judgment or large disparities between statutes. The deaf and hearing members of a shared signing community are, for all intents and purposes, equals.

As for the genetic, geographical and organizational criteria, these are what really distinguishes the shared signing communities from the Deaf communities around the world. First, in shared signing communities, deafness is always the result of a genetic mutation (Sundstrom & al, 1999; Morton, 1991). That being said, deaf people are therefore often born into deaf families, where there is already a significant deaf presence and use of the local sign language are well ingrained into the social setting. This creates strong socialization for the deaf child who, in most other areas of the world, would not create such relationships with their hearing family members. Also, shared signing communities always emerge in small rural villages of about 1000 to 2000 people with limited contacts to neighboring villages (de Vos, 2011). These villages are self-sufficient and isolated from large urban centers, as well as Deaf communities, which could influence social interactions and diversify the gene pool. And so, in these smaller populations, research shows that the genetic transmission of deafness is fortified

through endogamous marriage practises (Zeshan, 2007; Rayman, 2009). Therefore, the high incidence of deafness is not easily threatened and the contact with other, more prestigious, sign languages is minimal.

Finally, according to Kisch (2008), in shared signing communities, there is no Deaf community which exists in the margins of the hearing community. This is due to the fact that in these communities, deaf and hearing people share the same opportunities, the same values, the same culture and the same language. Therefore, there is no need for marginal groups, associations or committees to form. Although the absence of a Deaf community could be seen as assimilative, Rayman (2009) states that this is not the case as shared signing communities do not consist of majority and minority groups ; it is simply a community in which deaf and hearing people have evolved together to value the use of a sign language in order to make community living accessible to all.

Dotted with its local sign language, multi-generational deafness, isolated location and the participation of the *koloks* in all levels of community activities, Bengkala is often considered as being both a Deaf community and a shared signing community, depending on the individuals' preference and theoretical background. That said, with a background in social work and an affinity towards the social representations theory, this study explores the *koloks*' social representations of the *normals* with the purpose of providing insight into how these two groups work alongside each other to go beyond the shared use of *Kata kolok* and influence community adaptations promoting social inclusion from the ground up.

Theoretical Framework

Social Representation Theory

The social representation theory (SRT) finds its roots in social psychology, but has proven itself in several fields of social sciences such as sociology, anthropology, history and social work (Rateau and Lo Monaco, 2013). Social representations (SR) are a system of cognitive elements, values, ideas and practices, shared within a social group and allowing individuals to position themselves *vis-à-vis* a social object or situation with which they are faced (Palmonari & Emiliani, 2017 ; Jodelet, 1994). The founder of the social representation theory, Moscovici (2013), states that social representations have a twofold function. The first aims to establish certain parameters which will help the individuals orient themselves in their material and social worlds. And the second aims to enable communication to take place among members of a community.

Jovchelovitch (2019) has taken quite an interest in theorizing the concept of community within the SRT framework. Communities, which have boundaries and a social memory, organize themselves around the creation of a public sphere in which "Self and Other meet, interact and construct representations of themselves, others and issues that matter for their communities" (Jovchelovitch, 2019). Thus, this social arena, where all communication takes place, is at the center of all SR formation. By acknowledging the importance of community in the process of social representations, it also shines a light on the emotional, social and cultural process, for scientific knowledge is not the only form of knowledge that can bring people together. According to Jovchelowitch (2019),

> "Thinking together is for humans a major driver of togetherness itself, a dynamic cycle of mutual constitution in which sociality forms cognition and builds a system of shared meaning that in turn builds the social representations that connect participants and establish specific cultural communities."

And so, being a member of a community, or having a sense of community encompasses the multifaceted relations between individuals and community, including membership, shared emotional connection, needs fulfillment and influence (McMillan and Chavis, 1986). Thus, social inclusion, or being included as a member of a community that shares a history, memories, experiences and social representations, is an important part of the human development from a very young age.

Social inclusion is almost always negatively defined and understood as the opposite state of social exclusion, or, all that is *not socially excluded* (Rawal, 2008). However, in the field of disability studies, social inclusion has been largely defined as "greater participation in community-based activities and a broader social network" with talking to people, being socially accepted, having access to community facilities and having access to opportunities all promoting inclusion (Abbot & Mcconkey, 2006). Even more so, citizen participation, as described by Rochira & al. (2019) is an individual's "active and voluntary involvement" in their community. Seeking to influence problematic conditions, such as policies and programs in their communities, individuals will go beyond social inclusion and turn to citizen participation to try and change the circumstances that are causing issues by actively voicing their opinions, voting, volunteering, protesting, etc. (Ohmer, 2007 ; Mannarini & al., 2009). That said, social inclusion is not all-encompassing. Individuals, or groups of individuals, can be included in one domain all the while being excluded in another (Rawal, 2008).

To summarize, SRs are referred to by individuals throughout their day to day activities as they act as references that help them navigate their environment (Jodelet, 2002). And these frames of reference represent both the process and the result of individuals' citizen participation in their community. And so, by analyzing the *koloks*' SR of the *normals* with

whom they share their community, this study will offer a better understanding of their participation in the public sphere as well as the types of relationships that are formed between the two groups. Thus, answering the research question : how can the *koloks'* social representation of the *normals* give insight into the community-based approach which has led to the inclusion of the *koloks* in all levels of community activities?

Methodology

This ethnographical research was conducted between 2017 and 2019 and was divided into two field studies for a total of six months in the village. During this time, participant observation and semi-structure interviews were chosen as data collection methods. Firstly, participant observations were documented in both written and electronic journal entries using objective running descriptions, first impressions, feelings, questions, hypotheses as well as pictures and videos. The intention was to create what Geertz (1973) referred to as a "thick description" of the *koloks'* involvement in the community. Thus, by participating in many cultural events, such as religious ceremonies, rituals, dances and sacrifices, as well as administrative and political duties, such as a national presidential vote, community meetings and tourism management, I was able to document the *koloks'* interactions, whether it be with each other, with their local culture and environment or with the outsiders who visit Bengkala,

In addition to documenting participant observations by participating in many daily activities, such as working in the fields, cooking and visiting family and friends, I was able to collect a first-hand understanding of the *koloks'* social interactions and practices. In doing so, relationships were formed between the *koloks* and I, leading to more in depth conversations moving forward. These close interactions are what lead to having a better sense of local culture and values. By creating these relationships with the *koloks* and participating in their daily,

mundane, activities, as well as more significant, cultural, events, I gained insight into the way the *koloks* process new information, through objectivation and anchoring, thus forming their social representations.

In addition to participant observation, 30 one-on-one semi-structured interviews were conducted with all the *koloks* who were capable of doing an interview, keeping in mind their age and linguistic abilities. In order to have a format to follow during the interviews, Verges' (1992) evocation method was chosen. In its complete version, this technique incites the participants to share the first five words that come to mind when given a stimulus word, in this case "*normal*". Since there is no sign to attest to the concept of importance in Bengkala, the shorter, non-hierarchical, form, where the data is collected in order of appearance only, as opposed to being subsequently ranked by importance, was chosen for the interview. In addition, the *koloks* were encouraged to elaborate on their one word in order to provide context to the data. In return, the data collected resembled a mix between Verges' non-hierarchical evocation method and a typical semi-structured interview, resulting in a list comprised of representational elements complete with a rich body of discursive data.

Considering the combination of descriptive data collected through participant observation and the more structured elements of representation gathered during the semi-structured evocational interviews, the iterative analysis process was done so in two stages. Firstly, the data analysis began as soon as the participant observation started by reading through the data often and generating concepts which make sense of it. By familiarizing myself with the data and the identification of recurring themes, attitudes and contradictions, this ethnographical analysis (Hammersley and Atkinson, 2007) revealed two major elements of the *koloks*' social representation of the *normals*. Be it that the *koloks* represent the *normals* as

being the "same" as the *koloks* while also allowing them to be fully integrated in the community as they help them through challenging situations. Having identified these two elements of the *koloks'* social representation, I proceeded with the content analysis of the semi-structured qualitative evocational data which complemented the data collected through participant observation by giving the *koloks* the opportunity to share their own narrative on the situation.

Thus, knowing that the *koloks* are included in all levels of community activities in Bengkala, the major limit of this research project was the distance needed between myself and the Western adaptation of the idea of social inclusion. Social inclusion in the sense that it relates to social processes related to a social construct which considers that some people can be excluded from society is prevalent in Western societies. However, the local culture of Bengkala does not revolve around the idea of inclusion/exclusion. Instead, it revolves around the idea that everyone is the "same". Meaning that the *koloks*, the *normals*, and all the other groups in the village are portrayed and treated in the same way. And so, although I ultimately decided to use the concepts of inclusion to describe what I believe to be an inclusive Deaf community as it provides a familiar concept to a unique situation, the relationship between the *koloks* and the *normals* is not formed as a way to counter the exclusion of the *koloks* but rather as a way to maintain traditional community activity.

Results

Bengkala is known for being a village where the deaf and the hearing communicate with each other using a local sign language. Thus, eliminating the communication issue usually associated with deafness. This community-based adaptation has encouraged the *koloks'* interactions with their hearing family members, friends and neighbors and their inclusion in many of the local community events. By doing so, the *koloks'* relationships with the *normals*

represents an idealistic view of deaf and hearing interactions in most Western societies. The following section will present the data collected on the *koloks*' social representation of the *normals* in two main sections. First, the *koloks* shared answers describing the similarities between themselves and the *normals* in regards to their roles in the village. Second, the *koloks* spoke about the supportive role the *normals* play in the *koloks*' lives as they rely on them to mitigate certain situations where deafness interferes in their ability to accomplish specific tasks.

Normals : "Same" as Koloks

Over the years, the *koloks* have developed strong relationships with the *normals* through their mutual use of *Kata kolok*. These relationships are what distinguish Bengkala from other Deaf communities around the world where the Deaf have been excluded from the hearing community and forced to organize themselves in the fringes of society. During the one-on-one interviews, the *koloks* identified five instances where their interactions with the *normals* characterize the equality that reigns between the two groups in the public sphere : 1) at home, 2) at work, 3) at school, 4) in the temple and 5) during community events.

Shared Living Compounds

Bengkala is home to just over 3,000 villagers and with its geographical area being only one square kilometre in size, the living arrangements are quite dense. Living compounds, as they are referred to in the area, are therefore shared between three or four multi-generational families who have built small living areas and bedrooms around a communal outdoor space dotted with a small temple. These compounds also share one or more kitchens and bathrooms where the families take their turns in doing their tasks. These homes have been passed down through generations and, although there are some areas that are more densely populated by

kolok families due to the number of deaf children living at home, there is no such thing as an all deaf or a deliberately all hearing compound. And so, the *koloks* often refer to their *normal* neighbors as being close family friends with whom they have grown up with and with whom they share many resources and fond memories.

Shared Workplace

When they are not at home, the *koloks* are more often than not working in or around the village. The *koloks*' work ethic is a subject that is near and dear to their heart as they have a great sense of pride in being able to provide for their families. And so, the *koloks* shared many stories of their work, whether it be cutting trees, doing construction, working in the gardens, weaving sarongs, etc. However, work can be scarce in Bengkala and so the villagers must have a flexible skill set and be ready and willing whenever an employment opportunity comes around. That being said, working offers a sense of inclusiveness and belonging in the village that encompasses both the *koloks* and the *normals* as being important members of the community. After all, the relationships that are formed between the deaf and hearing coworkers often lead to friendships and socializing outside of work.

Inclusive School

Since 2007, the *kolok* children have been included in one of the two local primary schools in the village. Before this change in policy, very few *koloks* had any form of formal education as it required them to leave Bengkala to go to a special Deaf school in the city. That said, the inclusion of *kolok* children in the local school has given the *koloks* a significant rise in terms of equality. Not only do the deaf children now have the basic skills they need to read and write, but they also gained access to a much more normalized socialization by multiplying their interactions with other children instead of being taught to work in the fields surrounded

by their parents and other adults from a very young age, as was tradition. Now, the expectations put on the *kolok* children are the same as the expectations put on any other child in the village.

Cultural Events

As for religion, it plays a central role in all Balinese villages. While Indonesia is the most populated Muslim country in the world, the majority of the Balinese, including all of the *koloks*, are Hindu. Following Hindu tradition, daily offerings are made to the gods and temple ceremonies are an important part of community activities as they mark milestones in each individual's life as well as special community events. During temple ceremonies, the *koloks* and the *normals* are included equally in all the same events, they wear the same temple clothes, they follow along with the same prayer movements and they offer the same offerings to the gods. Thus, there is no segregation, or exclusion, of the *koloks* based on the inability to hear. The *koloks* have learned to follow along with the many traditions in the area. And so they participate in all the same ceremonies as everyone else in the village does.

Community Events

Outside of religious ceremonies, Balinese culture is also filled with smaller scaled community events, such as birthdays, wedding receptions, social gatherings, etc. These social events highlight the inclusivity of the relationships between the *koloks* and the *normals* as they regularly involve gatherings of both groups. During these community events, the interactions between the *koloks* and the *normals* are reminiscent of all other social interactions between the two groups. The conversation flows freely through the use of *Kata kolok* and the relationships flourish through the sense of community. In regard to marital practices, it was said that keeping marriages between the *koloks* was a factor in the high incidence of deaf births in the village. However, with the increase in marriages between *koloks* and deaf people from other villages,

many of the young deaf couples are now having hearing children. This is creating even more intricate relationships between the deaf and the hearing as more and more *kolok* and *normal* families are being merged.

Normals : Supportive Members of the Community

In addition to considering the *normals* as being the "same" as them, the *koloks* shared many stories about having received valuable help and support from their hearing family members, friends and neighbors during their one on one interviews. Of course, there is plenty of mutual help shared between the *koloks* and the *normals* during regular village activities, whether it be lending a helping hand in the fields, sharing information, food or other resources, or showing support for a friend. This is representative of the holistic approach to community living which is common practice in the area. That being said, there is sometimes an extra level of help required from the *normals* in order to accommodate for the *koloks*' lack of hearing. This support comes from both local hearing villagers and outsiders who have shown an interest in the *kolok* population.

Community-Based Support

On the one hand, the *koloks* rely on their hearing friends and neighbors for help when they have errands to run outside of the village. Since *Kata kolok* is so prevalent within the village, the *koloks* are very independent in their day-to-day activities. But when it comes to doing business outside of the village, the *koloks* inevitably run into communication issues if they are not accompanied by a trusted, *normal*, friend who can act as an informal interpreter. For example, when a *kolok* gives birth to a child that must be registered, or when they want to apply for a loan at the bank, they must rely on someone to fill out the appropriate documentation. Also, when researchers come to the village with questionnaires to be filled out

by the *koloks*, they rely heavily on the help of hearing locals to act as impromptu interpreters. And so, although they are completely independent in the confines of their village, once they step outside of the large gate that limits the village boundaries, the *koloks* face all the same barriers as any other Deaf person would when they are faced with the hearing world. However, they are surrounded by supportive family members, friends or neighbors that can help them in their endeavors.

Outside Sourced Support

On the other hand, the *koloks* have also received quite a bit of support from the Indonesian government as well as local and international organizations in the form of financial grants, equipment and training resources which helped create many job opportunities and infrastructure. For example, a state-owned oil company has been subsidizing the *kolok* dance group by donating their costumes, they have supplied start-up equipment for the weaving of sarongs and they have paid for the construction of the *kolok kemp*, a covered area for the *koloks* to gather, dance, eat, work, etc. There are also many tourists who visit the area that give financial support to the *koloks* in the form of donations as a way to thank them for showing them their village. In some cases, these tourists become close friends with the *koloks* and they send regular gifts, such as clothing, appliances or money to cover medical bills, schooling, food, etc. These relationships with hearing people from outside of the village showcase a practical social representation of the hearing as the relationship seems to be much more one-sided, with the *normals* doing most of the giving and the *koloks* doing much more of the receiving. However, in the village, the social representation of the *normals* is far from being utilitarian.

Discussion

The data collected in this study finds the *koloks*' social representation of the *normals* includes both aspects of sameness and disparity. The complex relationship between the two groups emerged within the context of a small isolated village where a sudden appearance and subsequent rapid increase in deaf births prompted community based adaptations over 200 years ago. Now, Bengkala is known worldwide for being an example of how the Deaf and hearing can live together. By including the *koloks* in the public sphere, be it in informal gathering, religious ceremonies, the classroom, etc., the inclusive Deaf community of Bengkala was created. However, this was not done overnight and it was much more than a shared sign language that initiated the process. The data collected in this study brought forth three conditions that have led to the current situation in which the *koloks* and the *normals* live as equals in Bengkala : 1) the acceptance of deafness, 2) the adaptation of community events and 3) the allegiance between the *koloks* and the *normals*.

Acceptance of Deafness in Bengkala

The data collected, describing the sense of sameness between the *koloks* and the *normals* is the perfect testament to the widespread acceptance of deafness in the village. The acceptance of deafness in Bengkala, although not tangible, is at the forefront of all other adaptations that have taken place in order to maintain inclusivity in the community. When thinking of acceptance in relation to deafness, it is most often associated with grief in the arduous task of accepting the unknown (Skelton & Valentine, 2003 ; Jepson, 1991 ; Pelchat, 2009). With the majority of Deaf children being born to hearing parents (Lane, 1995), there is often no frame of reference for the hearing family to refer to when trying to understand, in order to eventually accept, the faith of their child (Pelchat, 2009 ; Fitzpatrick & al., 2008). The

same can be said for the Deaf persons themselves who are surrounded by a hearing world in which they do not fit in. For this reason, the quest to connect with other Deaf people, or even more so a Deaf community, in hopes of finding themselves and creating their Deaf identity is part of so many narratives shared by the advocates for the cultural Deaf movement (McIlroy & Claudine, 2011 ; Anmad & al., 2002 ; Holcomb, 1997).

However, in Bengkala deafness has been present for many generations and everyone in the village has had, at one point or another, to accept deafness as part of the local culture. And so, when a *kolok* child is born, the framework needed to navigate the situation is readily available. Being as deafness in Bengkala is mostly genetic, the family usually already has a good understanding of what it entails. Hence, the parents are not required to go through the process of creating their own social representation of deafness because they already have close relationships with other *koloks* and they are familiar with deafness. During his time in Bengkala, Hinnant (2000) described the lack of surprise when a deaf child is born in the village because it is usually born to *kolok* parents who expect their child to be like them. In the case of deaf children being born to *normal* parents, it may come as a surprise, but they quickly get the support they need to accept the deafness and embrace the local sign language from the *koloks*. And so, deafness does not represent the *unknown* in Bengkala.

This familiarity with deafness surely has had an effect on the acceptance of deafness, but the strong religious beliefs and cultural values also aided in the process. The vast majority of the Balinese are avid practitioners of Hinduism. That being said, while the southern part of the island had held on the hierarchical beliefs, dominated by ritual and elite secular castes, for longer, the northern half of the island has evolved to adapt a more egalitarian approach to

Hinduism (Branson & Miller, 2004). Geertz (1959) described the caste system in Bali as follows :

> "The Balinese, like the Indians from whom they have borrowed (and reformulated) so much, have commonly been described as having a caste system. They do, in the sense that social status is patrilineal inherited, that marriage is fairly strictly regulated in terms of status, and that, save for a few unusual exceptions, mobility between levels within the prestige system is in theory impossible and in practice difficult. But they do not in the sense of possessing a ranked hierarchy of well-defined corporate groups, each with specific and exclusive occupational, social, and religious functions all supported by elaborate patterns of ceremonial avoidance and commensality and by a complex belief system justifying radical status inequality. Where the term "caste" is not so deeply ingrained in the literature on Bali, it might be less confusing to speak of the Balinese as having a "title system," for it is in terms of a set of explicit titles, passing from father to child and attached to the individual's name as a term both of address and reference, that prestige is distributed."

And so, the lack of a caste hierarchy in Bengkala, which propagates the idea that everyone is equal, combined with the belief in the reincarnation of the familial ancestors (Hinnant, 2000), work in the favour of the *koloks* as they are not expected to be anything other than themselves and they are accepted as such. Thus, deafness has become an integral part of the village culture.

Adaptation of Community Events

In addition to the acceptance of deafness in Bengkala, many community-based adaptations have been put forth to promote the inclusion of the *koloks* in the public sphere. The most talked about adaptation in the village is the shared sign language that emerged over five generations ago making it possible for the *koloks* and the *normals* to foster meaningful relationships for generations to come (de Vos, 2012). Similarly, adaptations to deafness have emerged in all societies. But in most cases, the debate on whether deafness should be represented as a disability or a linguistic minority, dictates the actions taken. And so, the adaptations usually consist of either assimilating the deaf into the hearing society through

medical intervention or excluding the deaf from the hearing society and sequestering them to Deaf communities that operate in the fringes (Branson and Miller, 2002). However, the widespread use of *Kata kolok* as a way to include the *koloks* into all levels of community activities is indicative of the SR of deafness in Bengkala not being representative of either a medical or a cultural deviance. Instead, the *koloks* and the *normals* are seen as being the "same" and sharing a common language.

Also, the inclusion of the *kolok* children in the local primary school has been a major community based adaptation. Although the impacts of this inclusion have not been studied nearly as much as the shared nature of *Kata kolok* has in Bengkala, education has always been, and will continue to be, a point of contention within Deaf studies, and disability studies in general (Luckner & al., 2005 ; Moog & Geers, 2003). Branson & Miller (2004) described how the Western influence has played a central role in the schooling of deaf children all over Indonesia as all of the schools that cater to deafness are classified as "*Sekolah Luar Biasa*", or "schools outside the normal". All of these schools for the Deaf adopt the "total communication" approach which aims to have the deaf children learn how to lipread the national language, *Bahasa Indonesia*, and sign using signed Indonesian (SIBI) or Indonesian Sign Language (BISINDO) (Rohmani & Rohmani, 2018 ; Branson & Miller, 2004). The issue with this approach is that it does not provide the students with any applicable skills for village life. In Bali, none of the villagers speak *Bahasa Indonesia* in their daily activities. However, the government of Indonesia has unified all teachings by implementing *Bahasa Indonesia* in all school curriculums. The fact that the *kolok* children in Bengkala are able to get away from the divisive approach to schooling by attending the local inclusive school, which uses the local sign language, is a testament to the distinction between Bengkala's approach to deafness and

the rest of the islands, or most of the worlds', approach to deafness. This is important as schools play a central role in the promotion of inclusive communities in the context of diversity (Andreouli & al., 2014).

Allegiance of the Koloks and the Normals

The adoption of *Kata kolok* and the inclusion of the *koloks* in the local school are examples of large scaled, community-wide, adaptations that have been made in order to promote the social inclusion of the *koloks* in Bengkala. However, there are many more adaptations that have been done on a much smaller, more individual, level that showcases the allegiance that has been formed between the two groups. In the data presented, the participants mention how much they value the friendships they have created with the *normals*, whether it be their work colleagues, their neighbors, their family members, etc. Without these relationships, the *koloks* would be forced to live outside of the public sphere, such is the reality in most Deaf communities around the world (Lane, 1995, 2005 ; Holcomb, 1997). However, by maintaining these relationships with the *normals*, the *koloks* are able to refer to them in their times of need and vice versa.

Bengkala : the Inclusive Deaf Community

The *koloks* and the *normals* have created, over many generations, a community in which the two groups have been able to participate equally in the public sphere. In doing so, the *koloks* and the *normals* have been living together as opposed to forcing the *koloks* to congregate in separate locations or to claim a different culture. For this reason, it may seem as though there is no "Deaf community" in Bengkala, making it more of a shared signing community (Kisch, 2008). But in reality, the fact that the Deaf community of Bengkala does not resemble the Western Deaf communities does not reflect the absence of a sense of

community among the *koloks*. It simply reflects the fact that included in their sense of community are the *koloks'* *normal* family members, friends and neighbors. This is the result of the inclusive Deaf community being built from the ground up, through communication between the two groups, and not from the imposition of outside scientific knowledge trying to explain social and emotional connections.

The *koloks*, through their social inclusion and their citizen participation, began to foster meaningful relationships with the *normals* who believed them to be equal members of society a long time ago. Thus, the isolated nature of the village not only contributed to the rapid multiplication of deaf births in the village, but it also created a blank canvas for the members of the community to create their own social representations as there was no outside influence in the village. This was long before international researchers and tourists came to visit the village. That said, now that the Western approaches to deafness have entered the village by way of tourists, it is possible to see how much the *koloks'* SR of the *normals* was important in maintaining the equality between the groups. Because although the *koloks* know about the distance generally maintained between the Deaf and the hearing in most societies, they have kept working towards building event stronger relationship with the *normals* over the last few decades.

And so, I believe it to be a missed opportunity if we do not promote the inclusive measures taken in such communities by considering them as inclusive Deaf communities. In promoting the acceptance of deafness, the adaptation of community events and the allegiance between the *koloks* and the *normals*, it might provide some inspiration to other communities where Deaf and hearing people are trying to find their way. Having said that, in order to have an even better understanding of how Bengkala has become such an inclusive Deaf community,

we should also explore the *normals*' SR of the *koloks*. This would be an interesting angle to study in a subsequent research project as it would provide an opportunity to discuss both the *koloks* and the *normals*' perspective on their community, thus having a better understanding of their similarities and their differences.

Conclusion

Bengkala's unique history with deafness has resulted in the creation of an inclusive Deaf community which encourages the *koloks*' participation in all levels of community events. Through the analysis of the *koloks*' SR of the *normals*, it was possible to extract three conditions that have led to the current situation in which the *koloks* and the *normals* live as equals in Bengkala : 1) the acceptance of deafness, 2) the adaptation of community events and 3) the allegiance between the *koloks* and the *normals*. All of these conditions testify to the benefits of having the Deaf and the hearing working together in building and inclusive community where everyone can flourish instead of promoting the exclusive practices in most Western societies. Although Bengkala represents a small scale isolated community, larger Deaf communities could benefit from trying to promote this successful, unifying, story in what seems to be a divided world.

That said, the debate surrounding Deaf communities and shared signing communities has its merits, especially when it comes to the field of linguistics as the shared nature of a local sign language is definitely noteworthy (Kisch, 2008 ; Zeshan, 2007; Rayman, 2009 ; de Vos, 2012). However, I fear that by creating a divide between traditional Western Deaf communities and shared signing communities, we miss out on the learning opportunities that might be had from what could be better known as an inclusive Deaf community. Thus, the *koloks*' social representation of the *normals*, which portrays the equal standing between the groups all the while acknowledging the support being offered, gives insight into the importance of creating a community which promotes acceptance, adaptability and allegiance in order to insure the inclusion of all its members.

References

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of intellectual disabilities*, *10*(3), 275-287.

Ahmad, W. I., Atkin, K., & Jones, L. (2002). Being deaf and being other things: Young Asian people negotiating identities. *Social Science & Medicine*, *55*(10), 1757-1769.

Andreouli, E., Howarth, C., & Sonn, C. (2014). The role of schools in promoting inclusive communities in contexts of diversity. *Journal of health psychology*, *19*(1), 16-21.

Aronoff, M., Meir, I., Padden, C. A., & Sandler, W. (2008). The roots of linguistic organization in a new language. *Interaction studies*, *9*(1), 133-153.

BBC, (2019). A town where most speak sign language. Retrieved at : http://www.bbc.com/travel/story/20190221-a-town-where-most-speak-sign-language

Branson, J., & Miller, D. (2002). Damned for their difference: the cultural construction of deaf people as" disabled": a sociological history. Gallaudet University Press.

Branson, J., & Miller, D. (2004). The cultural construction of linguistic incompetence through schooling: Deaf education and the transformation of the linguistic environment in Bali, Indonesia. *Sign Language Studies*, *5*(1), 6-38.

Branson, J., Miller, D., Marsaja, I. G., & Negara, I. W. (1996). Everyone here speaks sign language, too: A deaf village in Bali, Indonesia. *Multicultural aspects of sociolinguistics in deaf communities*, *2*, 39-57.

Cumberbatch, K. (2008, February). Country sign: Jamaica. Paper presented at the 3rd conference for Cross-Linguistic Research and International Cooperation in Sign Language Linguistics, Preston, England.

de Vos, C. (2011). Kata Kolok Color Terms and the Emergence of Lexical Signs in Rural Signing Communities. *Senses & Society*. 6(1), 68-76.

de Vos, C. (2012). Sign-spatiality in Kata Kolok: How a village sign language in Bali inscribes its signing space (Doctoral dissertation, Radboud University Nijmegen). Book.

de Vos, C., & Zeshan, U. (2012). Introduction: Demographic, sociocultural, and linguistic variation across rural signing communities. In *Sign languages in village communities: Anthropological and linguistic insights* (pp. 2-23). Mouton De Gruyter.

Dodier, N., & Baszanger, I. (1997). Totalisation et altérité dans l'enquête ethnographique. *Revue française de sociologie*, 37-66.

Dolman, D. (1986). Sign languages in Jamaica. Sign Language Studies, 52, 235–242.

Escobedo-Delgado, C. E. (2008, February). Culture and sign language in a Mexican Mayan deaf community. Paper presented at the 3rd conference for Cross-Linguistic Research and International Cooperation in Sign Language Linguistics, Preston, England.

Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, *17*(1), 38-49.

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

Geertz, C. (1959). Form and variation in Balinese village structure. *American anthropologist*, *61*(6), 991-1012.

Geertz, C. (1973). *The interpretation of cultures* (Vol. 5019). Basic books.

Groce, N. (1985). Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard. Cambridge, MA: Harvard University Press.

Hammersley, M., & Atkinson, P. (2007). The process of analysis. *Ethnography: Principles in practice*, 158-190.

Hinnant, J. T. (2000). Adaptation to deafness in a Balinese community. *Genetics and hearing loss*, 111-123.

Holcomb, T. K. (1997). Development of deaf bicultural identity. *American annals of the deaf*, *142*(2), 89-93.

Jepson, J. (1991). Some aspects of the deaf experience in India. *Sign Language Studies*, *73*(1), 453-459.

Jodelet, D. (1991). Madness and social representations: Living with the mad in one French community (Vol. 5). University of California Press.

Jodelet, D. (1994). Le corps, la personne et autrui. *Psychologie sociale des relations à autrui*, 41-68.

Jodelet, D. (2002). Les représentations sociales dans le champ de la culture. *Social Science Information*, *41*(1), 111-133.

Johnson, R. (1994). Sign language and the concept of deafness in a traditional Yucatec Mayan village. In C. Erting, R. Johnson, D. Smith, & B. Snider (Eds.), The Deaf way: Perspectives from the international conference on Deaf culture (pp. 103–109). Washington, DC: Gallaudet University Press.

Jovchelovitch, S. (2019). *Knowledge in context: Representations, community and culture*. Routledge.

Kisch, S. (2004). Negotiating (genetic) deafness in a Bedouin community. In J. V. Van Cleve (Ed.), Genetics, disability, and deafness (pp. 148–173). Washington, DC: Gallaudet University Press.

Kisch, S. (2008). "Deaf discourse": the social construction of deafness in a Bedouin community. *Medical Anthropology*, *27*(3), 283-313.

Kusters, A. (2009). Deaf Utopias? Reviewing the Sociocultural Literature on the World's "Martha's Vineyard Situations". *The Journal of Deaf Studies and Deaf Education*, *15*(1), 3-16.

Kusters, A. M. J. (2014). Deaf gain and shared signing communities. In *Deaf Gain: Raising the Stakes for Human Diversity* (pp. 285-305). University of Minnesota Press.

Lane, H. (1995). Constructions of deafness. *Disability & Society*, *10*(2), 171-190.

Lane, H. (2005). Ethnicity, ethics, and the deaf-world. *The Journal of Deaf Studies and Deaf Education*, *10*(3), 291-310.

Liang, Y. (1999). *Mapping, Mutation Identification and Expression Study of DFNB3, a Gene for Human Recessive Deafnes [ie Deafness]*. Michigan State University. Graduate Program in Genetics.

Luckner, J. L., Sebald, A. M., Cooney, J., Young III, J., & Muir, S. G. (2005). An examination of the evidence-based literacy research in deaf education. *American Annals of the Deaf*, *150*(5), 443-456.

Mannarini, T., & Fedi, A. (2009). Multiple senses of community: The experience and meaning of community. *Journal of Community Psychology*, *37*(2), 211-227.

Marsaja, I. G. (2008). Desa Kolok - A Deaf Village and its Sign Language in Bali, Indonesia. Nijmegen: Ishara Press.

McIlroy, G., & Storbeck, C. (2011). Development of deaf identity: An ethnographic study. *The Journal of Deaf Studies and Deaf Education*, *16*(4), 494-511.

McMillan, D. W., & Chavis, D. M. (1986). Sense of community: A definition and theory. *Journal of community psychology*, *14*(1), 6-23.

Moog, J. S., & Geers, A. E. (2003). Epilogue: Major findings, conclusions and implications for deaf education. *Ear and hearing*, *24*(1), 121S-125S.

Morton, N. E. (1991). Genetic epidemiology of hearing impairment. *Annals of the New York Academy of Sciences*, *630*(1), 16-31.

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

Nonaka, A. M. (2004). The forgotten endangered languages: Lessons on the importance of remembering from Thailand's Ban Khor Sign Language. Language in Society, 33, 737–767.

Nyst, V. (2007). A descriptive analysis of Adamorobe Sign Language (Ghana). Utrecht, The Netherlands: LOT.

Ohmer, M. L. (2007). Citizen participation in neighborhood organizations and its relationship to volunteers' self-and collective efficacy and sense of community. *Social Work Research*, *31*(2), 109-120.

Padden, C. (2010). Sign language geography. *Gaurav y Napoli (Eds.)*, 19-37.

Palmonari, A. & Emiliani, F. (2017) Le modèle sociodynamique. In Lo Monaco, G., Delouvée, S. & Rateau, P. Les représentations sociales. Bruxelles : De Boeck

Pelchat, D. (2009). Comment les pères et les mères réinventent-ils leur vie avec un enfant ayant une déficience ? *Frontières*, *22*(1-2), 58-68.

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

Rawal, N. (2008). Social inclusion and exclusion: A review. *Dhaulagiri Journal of Sociology and Anthropology*, *2*, 161-180.

Rayman, J. (2009). Why doesn't everyone here speak Sign Language? Questions of language policy, ideology and economics. *Current Issues in Language Planning*, *10*(3), 338-350.

Rochira, A., De Simone, E., Mannarini, T., & Salvatore, S. (2019). What Do We Talk About When We Talk About Participation? Sense of Community and Social Representations of Participation. *Europe's Journal of Psychology*, *15*(2), 312-328.

Rohmani, I., & Rohmani, C. (2018). The Communication Methods in English Classroom for Indonesian Deaf Students. *Theory and Practice in Language Studies* 8.1 : 9–16.

Shuman, M. (1980). The sound of silence in Nohya: A preliminary account of sign language use by the deaf in a Maya community in Yucatan, Mexico. Language Sciences, 51, 144–173.

Skelton, T., & Valentine, G. (2003). 'It feels like being Deaf is normal': an exploration into the complexities of defining D/deafness and young D/deaf people's identities. *Canadian Geographer/Le Géographe Canadien*, *47*(4), 451-466.

Sundstrom, R. A., Van Laer, L., Van Camp, G., & Smith, R. J. (1999). Autosomal recessive nonsyndromic hearing loss. *American journal of medical genetics*, *89*(3), 123-129.

Van den Bogaerde, B. (2005). Everybody signs in Kosindo also? Deaf Worlds, 21, 103–107.

Vergès, P. (1992). L'evocation de l'argent: Une méthode pour la définition du noyau central d'une représentation. *Bulletin de psychologie*.

Vice, (2015). In Bali's Deaf Village, Everyone Speaks Sign Language. Retrieved at : https://www.vice.com/en_ca/article/8gkjag/theres-a-village-in-bali-where-everyone-knows-sign-language-511

Winata, S., Arhya, I. N., Moeljopawiro, S., Hinnant, J. T., Liang, Y., Friedman, T. B., & Asher, J. H. (1995). Congenital non-syndromal autosomal recessive deafness in Bengkala, an isolated Balinese village. *Journal of medical genetics*, *32*(5), 336-343.

Woll, B., & Ladd, P. (2003). Deaf communities. *Oxford handbook of deaf studies, language, and education*, 151-163.

Zeshan, U. (2007). The ethics of documenting sign languages in village communities.

Third article

The koloks' Social Representation of Kata kolok : the Unifying Local Sign Language of Bengkala

Abstract

Known as Bali's Deaf village, Bengkala has been the object of many media and academic publications praising the shared use of *Kata kolok*, the village sign language, by the deaf and hearing villagers. Sign language is a vital component of all Deaf communities around the world as they allow the Deaf to overcome the communication issues usually associated with deafness. However, while the cultural approach to deafness endorses the use of sign language as a way to counter the assimilation of the Deaf into the hearing society and encourage their membership to the Deaf community, the medical approach promotes an oralist approach with the goal of integrating the deaf population into the hearing society through speech acquisition. That said, in both of these dominant approaches to deafness, sign language is represented as being a barrier to the relationship between the Deaf and the hearing. Thus, this article aims to study the *koloks*' social representation of *Kata kolok* and how sign language perceived as being the unifying factor in the village. The data collected indicates that in Bengkala, the *koloks* represent *Kata kolok* as being part of the local culture. This is why the local sign language is believed to be what unifies the *koloks* and the *normals*. And, by having such a positive social representation of *Kata kolok* as unifying the *koloks* and the *normals* in the village, the *koloks*' social identity which is derived from their membership to a social group (Tajfel, 1974), is created in parallel rather than in opposition with the *normals*' social identity. This eliminates the *koloks* need to seek out Deaf communities to find others who are like them as well as the need to adopt an oralist approach in order to enter the hearing society.

Keywords : Social Representations, Social Identity, Deafness, Sign Language

Introduction

Although a popular misconception, there is no such thing as a universal sign language. On the contrary, there are hundreds of sign languages around the world with varying numbers of signers ranging from a few family members, such is the case in a small Indian village (Jepson, 1991), to American Sign Language, the most widely used sign language with hundreds of thousands of signers in the United States of America and Canada. In any case, Deaf signers from around the world depend on the use of sign language in their daily activities. And although most deaf people are born to hearing parents who do not have any pre-existing knowledge of sign language (Morton, 1991), there are a few remote villages where a long-standing high incidence of genetic deafness has brought forth community-wide acceptance of deafness and a shared use of a local sign language by deaf and hearing villagers alike. This is the case in Bengkala, a small farming village in the northern regency of Bueleleng on the island of Bali, Indonesia.

Indonesia is a country in South East Asia comprised of over seventeen thousand islands with over 700 different native languages, 19 of which are used by over one million speakers (Cohn & Ravindranath, 2014). Not surprisingly, many Indonesians speak several dialects as well the national language, *Bahasa Indonesia*, which is usually only used in formal settings such as education and politics. In addition, native Balinese will often learn foreign languages in order to access a career in tourism or international commerce. More specifically, the Bengkala natives communicate with each other using Balinese and *Bahasa Indonesia* when appropriate. That said, it is also possible to hear Malay, Dutch, English, French, Italian, Japanese and many other international languages in the village. But what is truly unique to Bengkala is that there is a local sign language known as *Kata kolok* which is known by more

than half of the villagers. In this article, the *koloks*' social representation of *Kata kolok* will be studied as a way to explore its significance in the community.

Research Context

In Bengkala, there has been a high incidence of deafness due to the transmission of a genetic mutation in the village for more than 7 generations (Winata & al., 1995 ; Liang, 1999). Having appeared in a small isolated village in Northern Bali, the transmission of this genetic deafness was maintained for many generations by traditional marriage practises and the fact that until very recently, intervillage travelling was quite rare. Therefore, there were very little changes in the gene pool and multi-generational deafness became part of the village constitution. However, with the arrival of motorized scooters on the island making travelling more accessible in recent years, there has been an increase in intervillage travelling. As a result, there has been mixing of the native *koloks* with deaf people from surrounding villages resulting in the diversification of the gene pool and a decrease in the number of *kolok* births. All things considered, the *kolok* population has stayed relatively stable due to the influx of deaf adults from around the island moving to Bengkala and compensating for the decrease in deaf births.

In conjunction with the high incidence of deafness in the village, a local sign language was created over 5 generations ago in order to accommodate the *koloks* communication needs. Sign language is a vital component of all Deaf communities around the world, but they are not all created in the same way. For this reason, it is important to discover the context in which sign languages have emerged in order to better understand their historical and cultural value. According to Padden (2010), there are two possible ways in which sign languages can emerge. On the one hand, sign languages emerge and are transmitted as a result of the grouping of Deaf people from different regions through the formation of Deaf communities. This is the case for

the vast majority of sign languages, such as American Sign Language (ASL), British Sign Language (BSL), Indonesian Sign Language (BISINDO), etc. On the other hand, sign languages can emerge indigenously in remote villages where the local deaf population has no contact with any preexisting Deaf communities. Thus, in rural villages such as Bengkala where deaf individuals do not have the necessary exposure to a pre-existing sign language, they tend to become home signers who develop elaborate gestural communication systems through their interactions with other deaf and hearing people (de Vos & Zeshan, 2012). And, as was the case with *Kata kolok*, these gestures can evolve into an independent, yet complete, sign languages if need be (de Vos, 2016).

Having identified 11 village sign languages around the world, de Vos and Zeshan (2012) discovered that they were generally shared by deaf and hearing people who live together in a small, isolated, communities. Further analysis into these sign languages brought de Vos and Zeshan (2012) to make the distinction between village sign languages which are mostly, if not exclusively, used in home settings with only close family members of the deaf, and shared sign languages which are used by a larger portion of the hearing population in all levels of village activities. And so, shared sign languages such as *Kata kolok* are the result of signing varieties emerging indigenously from the local population in rural communities where a high incidence of deafness and a lack of exposure to pre-existing sign languages created the need for such development (Kisch, 2012).

The concept of shared sign languages is closely related to Kisch's (2008) concept of shared signing communities which is used to distinguish small isolated communities with a high incidence of genetic deafness passed down through generations and a local sign language shared by deaf and hearing villagers, from the traditional Deaf communities which are created

in the margins of the hearing society. Deaf communities are the result of Deaf people leaving their rural home towns where they did not have many opportunities to socialize and become an integrated member of society in hopes of finding a community that will accept them as they are. At first, the concept of Deaf community was the by-product of the institutionalization of the deaf. In fact, both the notions of Deaf community and the first true sign language were introduced in the *Institut National de Jeunes Sourds de Paris*, the first Deaf school which welcomed some seventy students in 1780 (Buton, 2008 ; Encrevé, 2009 ; Gaucher, 2009).

However, this driving force created by the grouping and the education of Deaf people was not without opposition. As much as this cultural approach to deafness was developed through the use of sign language and valued the common reality of the Deaf, an opposing oralist approach which had strong ties with the medical field was promoting the inclusion of the deaf into the hearing society by making them communicate orally instead of gesturally. The rise of the oralist movement made waves as it passed legislature at *the Second International Congress on the Education of the Deaf* held in Milan in 1880, making it obligatory for all deaf children to have an exclusive oralist education. This meant that the Deaf children were forced to lip-read and use speech to communicate through countless hours of therapy. This approach to deafness dominated the public sphere until the 1960s when there was a renewal of the Deaf movement.

Although detrimental, the Deaf population succeeded in maintaining some form of group membership and Deaf identity through the transmission of their signed language during clandestine social interactions in spite of the suppression of Deaf culture during much of the 19 and 20th[th] century,. That said, during the second half of the 20th century, the Deaf movement, like a multitude of other social movements, underwent a period of renewal and the

prohibition period of sign language was reversed (Lachance, 2007 ; Gaucher, 2009). And so, from the 1960s on, the Deaf space in society began to change drastically because until then, the Deaf space was largely linked to the institutional and school systems that acted as meeting places for the Deaf (Lachance, 2007).

However, once Deaf children were integrated into public schools, they began to form a *new* Deaf space in the margins of society by creating sports and recreation associations to satisfy their need for a Deaf community (Lachance, 2007). This is known as the *Deaf awakening* (Gaucher, 2009). Deaf people were finally free from state constraints and becoming responsible for decisions that were made on their behalf. They were also inspired by the disability movement, the civil rights movement, the consumer movement, the *self-help* movement, the demedicalization movement and the deinstitutionalization movement, that were all having their own uproar during this period (Gaucher and Saillant, 2010). But what distinguished the Deaf movement from all these other movements is that they were rallying around the recognition of the importance of sign language as a way to counteract the communication issues usually associated with deafness.

In short, the act of grouping deaf people together and giving them access to formal education for the first time created an irreversible bond and has influenced the fate of Deaf people around the world to this day. This bond has been maintained for centuries through the use of sign language. In Bengkala, however, there were no such organized efforts into having the *koloks* form their own Deaf community as they were not sent to specialized institutions like was the case in other parts of the island. In fact, before World War II, under the Dutch rule, special schools for the deaf, which are still operating today, were created in Bali's larger cities (Branson & Miller, 2004).That said, these Deaf schools that offer a "total communication"

approach to education (Branson & Miller, 2004) have never had much success in recruiting the *koloks*. Nevertheless, their popularity on the island is a testament to the influence of the Western approach to deafness in Bali.

Seeing as neither of the dominant Western approaches to deafness, be it the oralist or the gestural approach, have integrated the village of Bengkala, it's reality is quite different from its neighboring villages. The fact that there was such a high incidence of deafness in the village made it so the *koloks* were able to bond and create enough momentum to initiate a community-wide usage of a village sign language. The implementation of this shared sign language being at the forefront of all subsequent adaptations, this article will study the *koloks* social representation of *Kata kolok* and how sign language, which is usually perceived as being a barrier for the deaf and hearings' interaction, is the unifying factor between the *koloks* and the hearing villagers of Bengkala known as the *normals*.

Theoretical Framework

The Social Representation Theory

Social representations (SRs) are a system of cognitive elements, values, ideas and practices, shared within a social group and allowing individuals to position themselves *vis-à-vis* a social object or situation with which they are faced (Palmonari & Emiliani, 2017 ; Jodelet, 1994). Moscovici (1973), the founder of the theory, states that social representations serve two main functions : to establish order and to enable communication. And so, SRs are referred to by individuals throughout their day to day activities as they act as reference grids that help them navigate their environment (Jodelet, 2002).

The Theory of Social Representations (TSR) is concerned with both the process of formation of social knowledge, by transforming objects that are unusual into something

familiar through associating said objects with well-known images, concepts and languages, and the social representations that ensue (Moscovici, 1973). In Jodelet's sociogenic approach to the SRT, she seeks to study the environment in which social representations emerge. This is done by adopting an ethnographical approach that promotes the researchers active participation in the research context. As SRs are the result of an individual's encounter with an unknown object, the sociogenetic approach considers both processes of objectivation and anchoring as integral to the understanding of the genesis of SRs (Moscovici, 1976). In using this theoretical framework to study how, and in what context, the *koloks*' SR of *Kata kolok* was created and maintained, this study will provide insight into the role of *Kata kolok* on the *koloks*' social identity and social inclusion.

Social Identity and Social Inclusion

In addition to helping individuals navigate social settings, social representations have a role to play in the construction of social identity (SI). Howarth (2002) states that SRs act as the "scaffolding" that supports the always changing construction of social identity since individuals always refer back to their SRs as they navigate this process. In return, she also believes that SI is an essential component in understanding how people represent their reality as it allows the individuals to question their views on such reality (Howarth, 2014). SI is defined as "the part of an individual's self-concept which derives from his knowledge of his membership of a social group (or groups) together with the emotional significance attached to that membership" (Tajfel, 1974).

Individuals seek out others who are like them. For the members in a group to preserve their self-esteem, they must compare favorably to their rivals, suggesting that these groups may compete with each other in order to gain social status. This is why so many Deaf communities

emerge in urban cities around the world. The majority of deaf children are born to hearing parents (Lane, 1995), and so they have the tendency to make their way into larger cities in hopes of finding Deaf clubs or associations for them to become members of. In doing so, they are constructing their own Deaf Identity by internalizing the groups' ideologies and SRs. Ahmad & al. (2002), define the Deaf Identity as follows :

> "Deaf identity offers an alternative framework for conceptualizing the experience of being deaf; it is potentially reaffirming, signifies normalcy rather than deviance, emphasizes language skills, provides confidence and support and locates the stigma and disadvantage associated with deafness in the oppressive hearing society's attitudes towards deaf people and their language. Deafness is thus not an impairment or deficit, it has a linguistic minority status" (Ahmad & al., 2002).

In fact, a sense of identity to the Deaf community is usually prompted by the use of sign language and the emphasis of the shared oppression of Deaf people by a hearing society (Gaucher & Vibert, 2010). And though it might come later in life, once a person finds their way into the Deaf community, it has the tendency of becoming their primary identity (Lane, 1995). As a result of external categorization as much as internal self-identification (Jenkins, 2014), members of an *ingroup* (Deaf) will seek to find the positive aspects of the *ingroup* (Deaf) and negative aspects of an *outgroup* (hearing), in the belief that it will enhance their self-image (McLeod, 2008). It is through these group memberships, which provide encouragement and positive role models, that individuals will garter a more positive self-esteem. And so, the more integrated the Deaf person becomes into a Deaf group, the lesser are the chances for them to become isolated and began to internalize the negative attitudes shared by society towards the Deaf. That being said, individuals belong to many different groups, and thus social identity is comprised of multiple identity claims, such as ethnicity, gender, age, religion and ability status, etc.

In the field of disability studies, social inclusion has been largely defined as "greater participation in community-based activities and a broader social network" (Abbot & Mcconkey, 2006). Abbot & Mcconkey (2006) discovered that talking to people, being socially accepted, having access to community facilities and having access to opportunities are four main themes which promote social inclusion. However, social inclusion is not all-encompassing. In fact, individuals, or groups of individuals, can be included in one domain all the while being excluded in another (Rawal, 2008). And so, social inclusion is almost always negatively defined and understood as the opposite state of social exclusion, or, all that is *not socially excluded* (Rawal, 2008). That said, changes in attitudes towards deafness and disability have come primarily from the Deaf and disabled people themselves as they have questioned the focus on impairment and shed light on the discriminatory practices of institutions and societies (Brennan, 2003).

Knowing the extent to which *Kata kolok* is shared in the village, the *koloks* have fostered meaningful relationships with hearing members of their society for many generations. This has had an important impact on their social inclusion in all levels of community activities. In order to discover to the *koloks*' perspective on their community involvement, this study aims to document their social representation of *Kata kolok* as it is at the center of all subsequent community based adaptations. Thus, this will provide an answer to the research question : how has the *koloks*' social representation of *Kata kolok* facilitated their social inclusion into the community?

Methodology

Following Jodelet's sogiogenetic approach to the SRT, this research project adopted an ethnographical method spanning two field studies for a total of six months, spread over two

years, in the village of Bengkala (2017-2019). During this time, participant observation was chosen as the first data collection method. A field journal was kept in order to document observations by keeping notes and anecdotes, as well pictures and videos. These observations were documented in both written and electronic journal entries using objective running descriptions, first impressions, feelings, questions and hypotheses. Following Dodier and Baszangers' (1997) concept of "totalization", I gathered as much knowledge into the processes and conditions that influence the *koloks'* day-to-day interactions as possible. The intention was to create what Geertz (1973) referred to as a "thick description" of the use of *Kata kolok* in the village.

In addition to participant observation, semi-structured interviews were conducted with all the *koloks* who were capable of doing an interview, keeping in mind their age and linguistic abilities (n = 30). Verges' evocation method (1992) was chosen as a way to loosely format the semi-structured interviews. In its complete version, this technique results in the participants giving the first five words that come to mind when given a stimulus word, in this case "*Kata kolok*", and then ranking them in order of importance. In doing so, the participants prioritize their results rather than leaving them in their order of appearance, which is thought to be more indicative of the actual structure of the social representation. But in the case of the *koloks*, none of the answers were ranked as the concept of importance does not exist in *Kata kolok*. Since there is no sign to attest to such a task, the shorter, non-hierarchical, form, where the data is collected in order of appearance only, was chosen for the interview. In addition, the *koloks* were encouraged to elaborate on their answers which felt much more natural as it resembled more of our typical day-to-day conversations. In return, the data collected resembled a mix between Verges' non-hierarchical evocation method and a typical semi-structured interview,

resulting in a list comprised of representational elements complete with a rich body of discursive data.

Considering the combination of descriptive data collected through participant observation and the more structured elements of representation gathered during the semi-structured evocational interviews, the iterative analysis process was done so in two stages. Firstly, the data analysis began as soon as the participant observation started through familiarizing with the data and the identification of recurring themes, attitudes and contradictions. By reading through the corpus of data often and generating concepts which make sense of it, the ethnographical analysis revealed categories for organizing the data which emerged from the context (Hammersley and Atkinson, 2007). Secondly, I proceeded with the content analysis of the semi-structured qualitative evocational data which complemented the data collected through participant observation by giving the *koloks* the opportunity to share their own narrative on the situation. Thus, by combining all of the data, I was able to identify the three major elements of the *koloks*' social representation of *Kata kolok* and its unifying influence on their social identity and inclusion into all levels of community events.

Having identified *Kata kolok* as being the unifying factor between all villagers in Bengkala, it was also a limit to this research project as it required learning a new language which is unique to such a small geographical area. That said, the only way to learn the language was to be fully immersed in the *koloks* environment. Having gone to the village multiple times, I became fluent in *Kata Kolok* quite early in the project. However, even with the help of the local interpreter, some concepts, such as "importance" and "social representation" were not translatable as they do not exist in *Kata kolok*. This brought forth some methodological changes, mostly in the use of the word association interview as it was impossible to have the

participants rank their answers in order of importance. Having said that, the ethnographical approach chosen was very well suited for the context in which this research was held as it gave me the opportunity to adapt the data collection method over time as well as create meaningful relationships with the participants.

Results

The following section will look into what makes *Kata kolok* such an integral part of village life in Bengkala. Not only did the *kolok* participants discuss the importance of *Kata kolok* for them, but also for the *normals* as they are the ones responsible for the widespread use of the language in the village. Hence, the *koloks'* social representation of *Kata kolok* consists of three principles which were brought up during the one on one interviews combined with the participant observation on the matter. First, *Kata kolok* is, for all intents and purposes, the *koloks'* native language. Not only was it created by the *koloks*, but it has been their only means of communication for many decades. Second, *Kata kolok* is an indigenous language which is unique to the area and has been maintained within its boundaries even though the village is surrounded by Deaf communities which use the National sign language. And third, the *koloks* and the *normals* both use *Kata kolok* as a means to communicate with the deaf population in all levels of community activities. *Kata kolok* is not solely used in the margins of society as a way for the *koloks* to develop their Deaf identity ; it is used in all daily activities.

The Koloks' Native language

For the deaf population of Bengkala, access to *Kata kolok* is essential to their socialization and their integration into the public sphere as it annuls the most disabling characteristic of being deaf : the inability to communicate through traditional oralist methods. Although it is a shared sign language known by both deaf and hearing villagers, *Kata kolok* is

primarily used by the *koloks* who, until quite recently, had no other means of communication. Since 2007, the *koloks* have been integrated in one of the local primary schools where they learn to read and write *Bahasa Indonesia* with the help of a local interpreter who translates the teachers lessons in *Kata kolok*. However, in their day-to-day activities, the *koloks* communicate solely using sign language. Thus, even though the younger generation of *koloks* now have an intermediate level, at best, of written *Bahasa Indonesia*, *Kata kolok* remains the *koloks* preferred means of communication. After all, it is, as they say, "easy" for the *koloks* to communicate with each other through signs.

This ease with which the *koloks* communicate with each other using *Kata kolok* was discussed during the interviews by the participants who shared vivid descriptions of deaf gatherings. Bengkala is a small traditional Balinese village where many of the villagers' day-to-day activities revolve around communal activities such as working in the gardens, sharing meals, going to the temple and spending time with family and friends. Seeing as the living arrangements in the village consist of multiple generations of families sharing a compound, the *koloks* spend a lot of time sharing space with their family members and friends who are often deaf as well. These memories of spending time together at home or in the community are what the *koloks* refer to as being representative of their local sign language. It is what allows them to socialize and participate in their community.

As for the *koloks* who are born into hearing families, and therefore do not share a living compound with any other deaf people, they tend to spend a lot of their free time visiting their *kolok* friends. Sharing that they only go home to "eat" and "bathe", these *koloks* value their friendships as they share a little something extra in common with the other *kolok* villagers in comparison to their hearing family members with whom they communicate but they do not

share a *kolok* identity. And so, without excluding anyone, nor negating the fact that they consider themselves to be the "same" as the *normals*, the *koloks* tend to favour interactions among themselves rather than interactions with the hearing villagers. This is even more apparent when considering the input of the deaf villagers from around the island who move to Bengkala later in life.

Being born deaf in Bali, outside of Bengkala of course, means that these participants learned how to communicate using BISINDO or SIBI during their time in the Deaf school system. It also means that they have had very limited interactions with the hearing, whether it be their family, their neighbors, or the public in general as they were faced with the same communication issues that Deaf people all over the world face. However, having found Bengkala, these participants have learned, and some are still learning, *Kata kolok*. This has initiated a multitude of new opportunities for these participants who now have access to a whole new level of communication and socialization which they had never before experienced as the majority of their interactions had been with hearing non-signers. These new *koloks* are now able to maintain healthy relationships with both the deaf and hearing villagers of Bengkala and they have access to work and community activities. These secondary effects from having good communication skills can often be overlooked when visiting the village for only short periods of time.

In fact, many of the *koloks* simply, but effectively, expressed that one of the first words that came to mind when they thought of the term "*Kata kolok*" was the thumbs-up sign which represents "good". This positive association to the language that has given them their independence and their equal social status in the village is not to be glossed over as it is representative of a sense of pride for what has become an icon in local and international

publications. Having access to *Kata kolok* allows the *koloks* to communicate with each other as well as with many of their hearing family members, friends and neighbors. That being said, the participants also shared that from their use of *Kata kolok*, they have found joy as it is a way for them to express themselves. Thus, the use of *Kata kolok* also counters loneliness as it allows the *koloks* to connect with others. It alleviates stress as it provides work opportunities and it brings happiness as it fosters meaningful relationships and it allows for inclusion in the public sphere.

Unique to Bengkala

Kata kolok is known as a local, or shared, or village, sign language that is only used within the boundaries of the village of Bengkala. Being unique to the area is what got many researchers interested in studying its linguistics. But it is also what has made the *koloks* feel such pride in their native language as their ancestors are the ones who originated it. Having emerged indigenously in the village over five generations ago, and having been passed down through generations, *Kata kolok* is not related in any way to BISINDO or SIBI. Although these national sign languages are used in all state-led activities, such as Deaf schools and news broadcasting all over Indonesia, and in all Deaf community events held in the country, the *koloks* prefer to continue using *Kata kolok* as it enables them to communicate with their hearing family members, friends and family in the village. These relationships within their native community are represented as being more important than having access to the Balinese or other Deaf communities in the country. Thus, when comparing *Kata kolok* to the BISINDO interpreters they see on national news stations, the *koloks* represent the national sing language as being emotionless and lacking the facial expressions and dynamic movements that characterize *Kata kolok* and the deaf interactions in the village.

In their interviews, the *koloks* also acknowledged the distinction between *Kata kolok* and the Indonesian sign language by stating that the signs are "different" in Bengkala in comparison with the signs in Denpasar, the capital city of Bali located 90 km south of the village, as well as the signs that are used by their friends who attend special Deaf schools. They also compared their local language with the signs used by international tourists with some being very similar, for example signs for chicken or cow, and other being very different, like the sign for dog. In fact, when the alphabet for *Kata kolok* was implemented in conjunction with the inclusion of the *kolok* children in the local primary school in 2007, it was decided to go with the International Sign Language alphabet rather than the Indonesian sign language two handed alphabet which shows just how unrelated the two languages really are. It also shows the influence of international tourists in the area.

Shared With Normals and Tourists

Seeing as communication in Bengkala is not an issue due to the widespread use of *Kata kolok*, the *koloks* and the *normals* have been fostering strong relationships for many years. Whether they be friendships, intimate relationships, work partnerships or helping relationships, the connections between the two groups have made it possible for the *koloks* and the *normals* to overcome the divide and see themselves as being the same, regardless of their hearing loss. The *koloks* shared stories of themselves interacting with the *normals* in many different settings, be it as colleagues on a job site, as customers in local shops, as friends spending their evenings together or even just as friendly neighbors having small talk in the morning. Regardless of what their interactions are, the *koloks* are happy that communication with their hearing family members, friends and neighbors is also "easy". That being said, *Kata kolok* is not only used

between friends in the social setting. It is used in all aspects of village life either by direct use between two people, or through the use of informal interpreters.

The *koloks* rely on a few key villagers who act as interpreters when there are village meetings, work training activities offered by outside organizations, large events in the temple, research groups interested in studying the *koloks*, etc. These interpreters make it so the *koloks* are never excluded from any community events. Thus, the shared nature of *Kata kolok* represents an important characteristic of the local sign language as it is used not only by the *koloks*, but also by the local hearing population, some deaf villagers from neighboring areas and even tourists and researchers who visit the village. Although each of these groups, and individuals within them, may have differentiating levels of knowledge and use of *Kata kolok*, there is a sense of unity that rings true with everyone who shares an interest in the language. The *koloks* refer to this unity by stating that, thanks to the widespread use of *Kata kolok,* the *koloks* and the *normals* are the "same" ; they are "equals" in the village.

Discussion

Sign language has been at the center of the Deaf discourse for centuries. It has been the object of countless publications and it has been a point of contention between the two major approaches to deafness that dominate not only Western societies, but which have had an impact on d/Deaf people worldwide. By studying the *koloks*' SR of *Kata kolok*, it was discovered that sign language, more specifically *Kata kolok*, is represented as being what unifies the *koloks* and the *normals* in Bengkala. This provides an alternative approach to the inclusion of Deaf people within a hearing society since it opposes the *koloks* acquisition of speech through hearing aids and speech therapy. Instead, the shared reality of the sign language bridges the gap between the two groups. This was possible in Bengkala since linguistic variation is viewed

as something positive as it allows for broader interactions with the outside world. Thus, the adoption of a signed language by the majority hearing population is seen as being much more applicable as it follows the existing SR of other linguistic varieties in the area, rather than trying to get the *koloks* to adopt an oralist approach which is based on the medical SR of deafness and has no influence in Bengkala.

In saying so, *Kata kolok* has been able to unify the *koloks* and the *normals* as opposed to becoming a communication barrier between the two groups or creating a divide between two distinct communities, such is the case in most Western societies. Evidently, within traditional Deaf communities, sign language is perceived as being the "natural language of the prelingually deaf people" (Kemaloğlu, & Kemaloğlu, 2012), it is what unifies the Deaf and allows them to socialize, to build their identity, to share their culture (Gaucher, 2009), and it is what ultimately gives them access to the Deaf culture (Lachance, 2007). However, it does not usually serve the purpose of unifying the Deaf minority with the hearing majority. In fact, it has quite the opposite effect as it tends to create barriers between the two groups which then leads to the segregation of the Deaf in the margins of the hearing society.

The fact that *Kata kolok* promotes *kolok* and *hearing* relationships instead of becoming a barrier to the communication between the two groups is worth looking into. In general, communication issues are at the center of all Deaf interactions with the hearing. By claiming to be a linguistic minority, Deaf communities are looking to get public recognition (Kyle & al., 1988 ; Hogan-Brun & Wolff, 2003). But at the same time, by stating that their native language is different from the majority of their entourage's native language, it creates a certain barrier to their interactions. That said, the conditions in which *Kata kolok* emerged in Bengkala were favourable to the adoption of a shared sign language as the genetic deafness presented itself in

a small isolated village where language varieties were seen as the norm. In fact, with its successful application for over five generations, the participants now reflect on how easy it is for them to communicate in the village, with both the *koloks* and the *normals*. This is quite different from Deaf people around the world who struggle to form relationships with the hearing because of the difficulties regarding communication (Singleton& Tittle, 2000 ; Moores, 2010).

Also, the fact that *Kata kolok* fosters a sense of community that encompasses the *koloks* and the *normals* as opposed to creating a divide between the two groups is worth looking into. Although the data collected suggests that there are some tendencies for the *koloks* to gather together and form *kolok* social groups, these are all formed within the larger community. Thus, the *kolok* groups are comparable to any other social or cultural groups that forms within the larger village community. And so, this tendency for the *koloks* to group themselves together coincides with the belief that Deaf identity is usually prompted by the use of sign language (Lane, 2002). However, whereas members of Deaf communities usually organize themselves around the notion of shared oppression of Deaf people by a hearing society (Gaucher & Vibert, 2010), the *koloks* represent themselves as being the "same" as the hearing members of the community (see previous publications from this study). Therefore, they do not organize themselves in the fringes of society. On the contrary, they participate in all the same community events as the *normals.* Hence, the *kolok* identity, even though it is organized around deafness, is different than the Deaf identity as it is included into the larger, more encompassing, village identity which is shared by the *koloks* and the *normals*.

In Bengkala, the *koloks* represent *Kata kolok* as being one of many linguistic varieties in the area. It is also represented as being part of the village culture and as belonging to the

koloks and the *normals* alike. Thus, by having such a positive SR of *Kata kolok* that unifies the *koloks* and the *normals* in the village, the *koloks*' social identity which is derived from their membership to a social group (Tajfel, 1974), is created in parallel rather than in opposition with the *normals'* social identity. This eliminates the *koloks* need to seek out Deaf communities to find others who share a common language and a common oppression from the hearing society in order to construct their Deaf identity (Gaucher, 2009). The *koloks* are born within a community which has adapted to its population by adopting a shared sign language which has led to their social inclusion in all levels of community activities as well as the development of their social identity, which includes a *kolok* and a *village* identity (explored in a previous publication), all within their native community.

What is still unclear, however, is how the increase in intervillage travelling has influenced the *koloks*' SR of the village sign language. With more and more *koloks* leaving the village to go find work in larger cities, as well as more deaf people from around the island settling into Bengkala as adults, the proximity between *Kata kolok*, BISINDO and SIBI has never been greater. Without attempting to delve into the linguistic ramifications of these interactions between the languages, it would be interesting to explore the native *koloks* perspective on the outside influence on their local language and its unique unifying tendencies. More so, it would be interesting to explore whether or not the fact that the *koloks* share a language with the *normals* is represented as being an advantage, or if the fact that they do not share a language with all the other Deaf people of Indonesia makes *Kata kolok* more of a disadvantage for the *koloks*.

Conclusion

Indonesians are no strangers to having multiple dialects existing within a region, especially due to the geography of the area and its diverse history. That said, as one of the thousands of islands that make up Indonesia, Bali has its own language, Balinese, which is most commonly used in Bengkala. In addition, *Bahasa Indonesia* is used in all state-led activities in the village, i.e. education and politics, such is the reality of all Indonesian villages. However, what distinguishes Bengkala from these other villages is that more than half of the village population also communicates using *Kata kolok*. Thus, when a *kolok* is present, regardless of the context, the shared sign language is used to ensure communication. And so, whether it be at home, in the streets, in the temples or in school, whenever a *kolok* is present, hands start to move, facial expressions get bigger and sounds take over where words used to matter.

In Deaf communities around the world, sign language is represented as being what distinguishes the Deaf from the hearing. Whether it be that the Deaf believe that they are a linguistic minority, or that the hearing believe that in order to be integrated into society the deaf must adopt an oralist approach, sign language is not represented as being a unifying solution to the disparity between the Deaf and the hearing. Hence, within Deaf communities, sign language is simultaneously what unifies the Deaf and what opposes them to the majority hearing society as communication is at the center of all interactions. However, in Bengkala, *Kata kolok* is what makes the conversations between the *koloks* and the *normals* "easy" and it is what allows these two groups to share the public space equally. Thus, the shared use of *Kata kolok* promotes the social inclusion of the *koloks* in the community all the while respecting their *kolok* identity.

References

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of intellectual disabilities*, *10*(3), 275-287.

Ahmad, W. I., Atkin, K., & Jones, L. (2002). Being deaf and being other things: Young Asian people negotiating identities. *Social Science & Medicine*, *55*(10), 1757-1769.

Brennan, M. (2003). Deafness, disability and inclusion: The gap between rhetoric and practice. *Policy Futures in Education*, *1*(4), 668-685.

Buton, F. (2008). L'éducation des sourds-muets aux XIXe siècle. Description d'une activité sociale. *La Découverte*, 223(2), 69-82.

Cohn, A. C., & Ravindranath, M. (2014). Local languages in Indonesia: Language maintenance or language shift. *Linguistik Indonesia*, *32*(2), 131-148.

De Vos, C. (2016). Sampling shared sign languages. *Sign Language Studies*, *16*(2), 204-226.

De Vos, C., & Zeshan, U. (2012). Introduction: Demographic, sociocultural, and linguistic variation across rural signing communities. In *Sign languages in village communities: Anthropological and linguistic insights* (pp. 2-23). Mouton De Gruyter.

Dodier, N., & Baszanger, I. (1997). Totalisation et altérité dans l'enquête ethnographique. *Revue française de sociologie*, 37-66.

Encrevé, F. (2008). Réflexions sur le congrès de Milan et ses conséquences sur la langue des signes française à la fin du XIXe siècle. *Le Mouvement Social*, (2), 83-98.

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

Gaucher, C., & Saillant, F. (2010). 4. En Amérique du Nord, la perspective autonomiste et le mouvement sourd. In *Le handicap au risque des cultures* (pp. 95-109). ERES.

Gaucher, C., & Vibert, S. (Eds.). (2010). *Les Sourds: aux origines d'une identité plurielle* (No. 5). Peter Lang.

Geertz, C. (1973). *The interpretation of cultures* (Vol. 5019). Basic books.

Hammersley, M., & Atkinson, P. (2007). The process of analysis. *Ethnography: Principles in practice*, 158-190.

Hogan-Brun, G., & Wolff, S. (Eds.). (2003). *Minority languages in Europe: Frameworks, status, prospects*. Springer.

Howarth, C. (2002). Identity in whose eyes? The role of representations in identity construction. *Journal for the theory of social behaviour*, *32*(2), 145-162.

Howarth, C. (2014). Connecting social representation, identity and ideology: Reflections on a London "riot". *Papers on Social Representations*, *23*(1), 4-1.

Jenkins, R. (2014). *Social identity*. Routledge.

Jepson, J. (1991). Some aspects of the deaf experience in India. *Sign Language Studies*, *73*(1), 453-459.

Jodelet, D. (1994). Le corps, la personne et autrui. *Psychologie sociale des relations à autrui*, 41-68.

Jodelet, D. (2002). Les représentations sociales dans le champ de la culture. *Social Science Information*, *41*(1), 111-133.

Kemaloğlu, Y. K., & Kemaloğlu, P. Y. (2012). The history of sign language and deaf education in Turkey. *Kulak Burun Boğaz İhtisas Dergisi*, *22*(2), 65-76.

Kisch, S. (2008). "Deaf discourse": the social construction of deafness in a Bedouin community. *Medical Anthropology*, *27*(3), 283-313.

Kisch, S. (2012). *Deafness among the Negev Bedouin: an interdisciplinary dialogue on deafness, marginality and context*. Universiteit van Amsterdam [Host].

Kyle, J. G., Kyle, J., Woll, B., Pullen, G., & Maddix, F. (1988). *Sign language: The study of deaf people and their language*. Cambridge University Press.

Lachance, N. (2007). Territoire, transmission et culture sourde: perspectives historiques et réalités contemporaines. Presses Université Laval.

Lane, H. (1995). Constructions of deafness. *Disability & Society*, *10*(2), 171-190.

Lane, H. (2002). Do deaf people have a disability?. *Sign language studies*, *2*(4), 356-379.

Liang, Y. (1999). *Mapping, Mutation Identification and Expression Study of DFNB3, a Gene for Human Recessive Deafnes [ie Deafness]*. Michigan State University. Graduate Program in Genetics.

McLeod, S. (2008). Social identity theory. *Simply Psychology*.

Moores, D. F. (2010). The history of language and communication issues in deaf education. *The Oxford handbook of deaf studies, language, and education*, *2*, 17-30.

Morton, N. E. (1991). Genetic epidemiology of hearing impairment. *Annals of the New York Academy of Sciences*, *630*(1), 16-31.

Moscovici, S. (1973). Foreword. In C. Herzlich (Ed.), *Health and illness: A social psychological analysis* (pp. ix–xiv). London/New York: Academic Press.

Moscovici, S. (1976). *Social influence and social change* (Vol. 10). Academic Press.

Padden, C. (2010). Sign language geography. *Gaurav y Napoli (Eds.)*, 19-37.

Palmonari, A. & Emiliani, F. (2017) Le modèle sociodynamique. In Lo Monaco, G., Delouvée, S. & Rateau, P. Les représentations sociales. Bruxelles : De Boeck

Rawal, N. (2008). Social inclusion and exclusion: A review. *Dhaulagiri Journal of Sociology and Anthropology*, *2*, 161-180.

Singleton, J. L., & Tittle, M. D. (2000). Deaf parents and their hearing children. *Journal of Deaf studies and Deaf education*, *5*(3), 221-236.

Tajfel, H. (1974). Social identity and intergroup behaviour. *Information (International Social Science Council)*, *13*(2), 65-93.

Vergès, P. (1992). L'évocation de l'argent: Une méthode pour la définition du noyau central d'une représentation. *Bulletin de psychologie*.

Winata, S., Arhya, I. N., Moeljopawiro, S., Hinnant, J. T., Liang, Y., Friedman, T. B., & Asher, J. H. (1995). Congenital non-syndromal autosomal recessive deafness in Bengkala, an isolated Balinese village. *Journal of medical genetics*, *32*(5), 336-343.

Conclusion

The village of Bengkala has been the object of international academic and media publications since the 1990s as it is believed to be one of the last few remaining villages where a high incidence of multi-generational deafness and a shared local sign language have prompted the inclusion of the deaf population in all levels of community activities. Having said that, with the majority of the publications pertaining to issues of genetics and linguistics (Winata & al., 1995 ; Sundstrom & al., 1999 ; Marsaja, 2008 ; de Vos, 2012), only a few studies have provided insight into the *koloks*' social reality (Hinnant, 2000 ; de Vos, 2012 ; Marsaja, 2015). Thus, by adopting an ethnographical approach and the theory of social representations, the aim of this thesis was to explore the *koloks*' social representation of deafness, the hearing and the local sign language in hopes of finding an alternative approach to deafness which represents a middle ground to the two opposing dominant social representations of deafness in Western societies.

The SRT was chosen as the framework for this thesis as it values common sense knowledge (Moscovici, 2013). It takes into consideration how individuals, or groups of individuals, transform existing knowledge into information they understand as being representative of their unique context. Thus, the *koloks*' SRs are reflections of their own understanding of the community in which they live, of their deafness, of the people with whom they share their lives, and of the local sign language that has been created specifically for them. In addition, the influence SRs have on the construction of social identity as they characterize the way members of a group represent the objects with which they are faced and how these affect their interactions with said object provided insight into the *koloks* identity process. Deaf identity plays a crucial role in Western Deaf societies. Therefore, by gathering data describing

the *koloks*' social identity, this research was able to explore the existence of a possible alternative path to the two opposing dominant social representations of deafness in Western societies and offer new perspectives on the inclusion of deaf people in a hearing society as well as their social identity.

This alternative path finds its purpose in providing an approach to deafness that is not preoccupied with the Western beliefs revolving around social inclusion/exclusion. Without denying the presence of the medical and the cultural constructs of deafness in Bengkala since the arrival of outsiders in the village, the limits associated with this thesis project do not reflect the villagers' interpretation of these as much as they reflect the difficult task of distance myself from them. In order to compensate for this bias, many field studies were conducted over a long period of time giving me the opportunity to learn *Kata kolok* and learn about the local culture. As a result, I became familiar with local culture of Bengkala which does not revolve around the idea of inclusion/exclusion. Instead, it revolves around the idea that everyone is the "same". Meaning that the *koloks*, the *normals*, and all the other groups in the village are portrayed and treated in the same way. And so, the three articles provide an understanding on how the *koloks* represent the world around them with a loose comparison to the Western approaches.

In the first article, the *koloks*' SR of deafness was studied and it was found that the *koloks* have been navigating both a *kolok* social identity and a *village* social identity. The data collected showed that the *koloks* tend to spend a lot of time together. The relationships fostered between the *koloks*, whether they be between family members or not, are represented as being very important for the participants. The *koloks* rely on each other to be there when they need help providing food for their family due to illness. They rely on each other to be a friendly face when they need someone to talk to. They rely on each other to do activities together in the

village. In sum, the *koloks* rely on each other as they share a common reality that cannot be understood by the *normals*. However, the *koloks* do not organize themselves in the margins of the community. They do not represent themselves as being excluded, or segregated, from the *normal* society. In fact, they portray themselves as being the "same" as the *normals* in the village with whom they interact during all of their day-to-day activities.

Belonging to a community where the group is more important than the individuals within it, the *koloks*' social identity was created first within the larger *village ingroup*, but as the data shows, it did not come at the *koloks* expense as they have been able to navigate both a *village* identity and a *kolok* identity. Thus, the *koloks*' SR of deafness is very different from the SR of deafness that exists almost everywhere else in the world. Whereas deafness is usually represented as being either a *disability* or a *difference*, in Bengkala, the *koloks* represent deafness as being one of the many diverse characteristics that describe them. Therefore, the *koloks* do not only identify within the *kolok ingroup*, they also identify with the larger, more encompassing *village ingroup* which includes them in all levels of community activities.

In the second article, the *koloks*' SR of the *normals* was explored only to discover that the *koloks* represent themselves as being the "same" as the hearing members of the community all the while acknowledging that they rely on the support of the *normals* when their deafness impacts their ability to communicate. The data collected showed that the *koloks*' SR of the *normals* is divided in the sense that although they are represented as being equals in most areas, such as in the shared living compounds, the shared workplace, the inclusive school, as well as during cultural and community events, the *normals* also act as impromptu interpreters for the *koloks* when communication becomes an issue. This supportive role that the *normals* assume for the benefit of the *koloks* is usually only needed outside of the village, or when outsiders

come to the village. Thus, in their day-to-day activities, the *koloks* have a very balanced social representation of their hearing family members, friends and neighbors.

All of which led to the discovery of the three conditions that have led to the current situation in which the *koloks* and the *normals* form an inclusive Deaf community in Bengkala : 1) the acceptance of deafness, 2) the adaptation of community events and 3) the allegiance between the *koloks* and the *normals*. These three conditions are representative of how differently deafness is represented in the village. By not only accepting deafness, but also adapting to it and creating an alliance with the *koloks*, the *normals* have shown that they do not adhere to the idea that the *koloks* must organize themselves in the margins of society. In doing so, the *koloks* and the *normals* have created, over many generations, a community in which the two groups have been able to prosper together. Thus, the isolated nature of the village not only contributed to the rapid multiplication of deaf births in the village, but it also created a blank canvas for the members of the community to create their own social representations as there was no outside influence in the village.

In the third article, it was discovered the *koloks*' SR of *Kata kolok* as being the unifying force between the *koloks* and the *normals* which is a testament to the benefits of having long standing communication between the two groups. The data collected provided insight on the *koloks* perspective towards what they believe to be their natural language. *Kata kolok* was created by the *koloks* ancestors and it has been responsible for all of their interactions ever since. Also, the *koloks* acknowledge the fact that *Kata kolok* is unique to the village. And although the shared sign language might facilitate communication between the *koloks* and the *normals* in Bengkala, it does differ from the sign language of other Deaf communities in Bali and around the world, such is the case with all sign languages. Finally, the *koloks* represent

Kata kolok is being a shared sign language and therefore, it does not solely belong to them, but also to the over 1,800 *normal* villagers who use the local sign language in varying degrees. Because, in addition to having a high incidence of deafness in the village, with 44 of the 3,003 villagers being deaf, Bengkala is known for having a high incidence of hearing signers.

The widespread use of the local sign language as a way to include the *koloks* into all levels of community activities is indicative of an innovative way the locals have found to represent deafness in the community as it differs greatly from the behavior towards Deaf people and sign language in other areas of the world. By unifying the *koloks* and the *normals*, *Kata kolok* is more than just a sign language, it is more than just representative of a Deaf community, and it is more than just a way for the *koloks* to access all levels of community activities. *Kata kolok* is part of the village culture. Thus, by having such a positive SR of *Kata kolok* that unifies the *koloks* and the *normals* in the village, the *koloks*' social identity which is derived from their membership to a social group, is created in parallel rather than in opposition with the *normals* social identity.

*** Implications in the field of Social Work

Implications for Policy and/or Further Research

The aim of this thesis was to explore the *koloks*' social representations of deafness in order to determine how it was possible for the *koloks* to be included in all levels of community activities without having to either adopt an oralist approach to communication or having to create their own Deaf community in the fringes of the village. In Western societies it is believed that the Deaf and the hearing are different in that they do not share a language nor do they share a culture. However, by exploring the *koloks*' social representations, a critical reading of the two dominant approaches to deafness in Western societies could ensue from the fact that *Kata*

kolok is represented as a unifying language. Also, the idea that deafness is accepted as part of the local culture is something to aspire to. The *koloks* and the *normals* are not preoccupied in identifying the differences between the two groups. On the contrary, they tend to focus on what unifies them as being the "same" and from there they are able to find their place within the holistic society in which they share the public space.

The data collected in all three of the articles show that there is a great divide between the *koloks* SRs of deafness and all that it entails, and the two dominant SRs of deafness in the rest of the world. In summary, the *koloks* are proud to be deaf. They are happy and they are able to focus on the positive aspects of deafness as they are not constantly bombarded with obstacles to overcome. In addition, the *koloks* are able to participate in all levels of community activities, therefore giving them access to normal and age appropriate socialization. And finally, the *koloks* understand that they are perceived by the outside world as living in one the best Deaf communities and they take pride in showing their village, their dances and their sign language to tourists who come to visit the village.

However, the *koloks* current SRs are the result of years of community-based adaptations such as the implementation of a shared sign language, the inclusion of the *koloks* in village activities, the creation of the inclusive school program, etc. And so, considering all the factors that came into play in order to make Bengkala the inclusive Deaf community it is today, it would be difficult to recreate this scenario in modern Western societies. Still, knowing that there are possible alternatives to the dominant Western SRs of deafness and knowing that sign language can be used to unify the Deaf and the hearing instead of creating barriers between the two should give hope to d/Deaf people around the world. Thus, I believe that the implications of doing this research should be the acknowledgement that community-based adaptations can

withstand the influence of outside sources if and when the social representations in said communities are strong.

As for future research, there are so many other opportunities in Bengkala as this thesis only scratched the surface of the *koloks* SRs. Future publications from this research project will also include an analysis of the local children's SR of the *koloks* through drawings, the *normals*' SRs of the *koloks* as well as the *normals* and *Kata kolok,* and a photovoice activity which documented the *koloks*' inclusion in the public sphere. Possible collaborations with other researchers who share an interest in similar villages could also provide even more divers approaches to deafness. In short, the *koloks* represent a unique d/Deaf population which provides a more middle ground, yet culturally appropriate, approach to deafness by having the *koloks* organize themselves within the larger community instead of being pushed to the sidelines.

Bibliography

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of intellectual disabilities*, *10*(3), 275-287.

Ahmad, W. I., Atkin, K., & Jones, L. (2002). Being deaf and being other things: Young Asian people negotiating identities. *Social Science & Medicine*, *55*(10), 1757-1769.

Andreouli, E., Howarth, C., & Sonn, C. (2014). The role of schools in promoting inclusive communities in contexts of diversity. *Journal of health psychology*, *19*(1), 16-21.

Aronoff, M., Meir, I., Padden, C. A., & Sandler, W. (2008). The roots of linguistic organization in a new language. *Interaction studies*, *9*(1), 133-153.

Barnett, S., Klein, J. D., Pollard Jr, R. Q., Samar, V., Schlehofer, D., Starr, M., ... & Pearson, T. A. (2011). Community participatory research with deaf sign language users to identify health inequities. *American journal of public health*, *101*(12), 2235-2238.

Bath, P. M. C. (2012). Perspectives from the Deaf Community: Representations of Deaf Identity in the" Toronto Star" Newspaper (2005–2010). University of Ottawa (Canada).

BBC, (2019). A town where most speak sign language. Retrieved at : http://www.bbc.com/travel/story/20190221-a-town-where-most-speak-sign-language

Branson, J., & Miller, D. (2002). Damned for their difference: the cultural construction of deaf people as" disabled": a sociological history. Gallaudet University Press.

Branson, J., & Miller, D. (2004). The cultural construction of linguistic incompetence through schooling: Deaf education and the transformation of the linguistic environment in Bali, Indonesia. *Sign Language Studies*, *5*(1), 6-38.

Branson, J., Miller, D., Marsaja, I. G., & Negara, I. W. (1996). Everyone here speaks sign language, too: A deaf village in Bali, Indonesia. *Multicultural aspects of sociolinguistics in deaf communities*, *2*, 39-57.

Breakwell, G. (1993). Social representations and social identity. *Papers on social representations*, *2*, 198-217.

Brennan, M. (2003). Deafness, disability and inclusion: The gap between rhetoric and practice. *Policy Futures in Education*, *1*(4), 668-685.

Brueggemann, B. J. (1999). *Lend me your ear: Rhetorical constructions of deafness*. Gallaudet University Press.

Buton, F. (2008). L'éducation des sourds-muets aux XIXe siècle. Description d'une activité sociale. *La Découverte*, 223(2), 69-82.

Cohn, A. C., & Ravindranath, M. (2014). Local languages in Indonesia: Language maintenance or language shift. *Linguistik Indonesia*, *32*(2), 131-148.

Cumberbatch, K. (2008, February). Country sign: Jamaica. Paper presented at the 3rd conference for Cross-Linguistic Research and International Cooperation in Sign Language Linguistics, Preston, England.

Dagron, J. (2006). Représentations sociales de la surdité. Dans : Benoît Virole éd., *Psychologie de la surdité* (pp. 239-252). Louvain-la-Neuve, Belgique: De Boeck Supérieur.

Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. Verso.

De Clerck, G. A. (2016). Deaf epistemologies, identity, and learning: A comparative perspective. Gallaudet University Press.

de Vos, C. (2011). Kata Kolok Color Terms and the Emergence of Lexical Signs in Rural Signing Communities. *Senses & Society*. 6(1), 68-76.

de Vos, C. (2012). Sign-spatiality in Kata Kolok: How a village sign language in Bali inscribes its signing space (Doctoral dissertation, Radboud University Nijmegen). Book.

de Vos, C. (2016). Sampling shared sign languages. *Sign Language Studies*, *16*(2), 204-226.

de Vos, C., & Palfreyman, N. (2012). Mathur Gaurav & Napoli Donna Jo (eds.), Deaf around the world : The impact of language. Oxford: Oxford University Press, 2011. Pp, xviii 398. *Journal of Linguistics*, 48(3), 731-735.

de Vos, C., & Zeshan, U. (2012). Introduction: Demographic, sociocultural, and linguistic variation across rural signing communities. In *Sign languages in village communities: Anthropological and linguistic insights* (pp. 2-23). Mouton De Gruyter.

Delaporte, Y. (2000). Être sourd dans un monde entendant: destin, rencontre, transmission et rupture. *Ethnologie française*, 389-400.

Dodier, N., & Baszanger, I. (1997). Totalisation et altérité dans l'enquête ethnographique. *Revue française de sociologie*, 37-66.

Dolman, D. (1986). Sign languages in Jamaica. Sign Language Studies, 52, 235–242.

Duman, D., & Tekin, M. (2012). Autosomal recessive nonsyndromic deafness genes: a review. *Frontiers in bioscience: a journal and virtual library*, *17*, 2213.

Duveen, G. (2001). Social representations. *Introducing social psychology*, 268-287.

Duveen, G., & Lloyd, B. (1986). The significance of social identities. *British Journal of Social Psychology*, *25*(3), 219-230.

Encrevé, F. (2008). Réflexions sur le congrès de Milan et ses conséquences sur la langue des signes française à la fin du XIXe siècle. *Le Mouvement Social*, (2), 83-98.

Epstein, S. (1973). The self-concept revisited: Or a theory of a theory. *American psychologist*, *28*(5), 404.

Escobedo-Delgado, C. E. (2008, February). Culture and sign language in a Mexican Mayan deaf community. Paper presented at the 3rd conference for Cross-Linguistic Research and International Cooperation in Sign Language Linguistics, Preston, England.

Fédération Francophone des Sourds de Belgique (FFSB), (2004). À la découverte de la surdité. *Centre d'Information et de Documentation sur la Surdité*, 18 pages.

Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, *17*(1), 38-49.

Furham, A., & Lane, S. (1984). Actual and perceived attitudes toward deafness. *Psychological Medicine*, *14*, 417-423.

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

Gaucher, C., & Saillant, F. (2010). 4. En Amérique du Nord, la perspective autonomiste et le mouvement sourd. In *Le handicap au risque des cultures* (pp. 95-109). ERES.

Gaucher, C., & Vibert, S. (Eds.). (2010). *Les Sourds: aux origines d'une identité plurielle* (No. 5). Peter Lang.

Geertz, C. (1959). Form and variation in Balinese village structure. *American anthropologist*, *61*(6), 991-1012.

Geertz, C. (1973). *The interpretation of cultures* (Vol. 5019). Basic books.

Golos, D. B., & Moses, A. M. (2011). Representations of deaf characters in children's picture books. *American Annals of the Deaf*, *156*(3), 270-282.

Groce, N. (1985). Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard. Cambridge, MA: Harvard University Press.

Hall, S. (1991). Ethnicity: Identity and difference. *Radical America*, *23*(4), 9-20.

Hammersley, M., & Atkinson, P. (2007). The process of analysis. *Ethnography: Principles in practice*, 158-190.

Hinnant, J. T. (2000). Adaptation to deafness in a Balinese community. *Genetics and hearing loss*, 111-123.

Hogan-Brun, G., & Wolff, S. (Eds.). (2003). *Minority languages in Europe: Frameworks, status, prospects*. Springer.

Holcomb, T. K. (1997). Development of deaf bicultural identity. *American annals of the deaf*, *142*(2), 89-93.

Howarth, C. (2002). Identity in whose eyes? The role of representations in identity construction. *Journal for the theory of social behaviour*, *32*(2), 145-162.

Howarth, C. (2004). Re-presentation and resistance in the context of school exclusion: Reasons to be critical. *Journal of community & applied social psychology*, *14*(5), 356-377.

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.

Howarth, C. (2011). Representations, identity, and resistance in communication. In *The social psychology of communication* (pp. 153-168). Palgrave Macmillan, London.

Howarth, C. (2014). Connecting social representation, identity and ideology: Reflections on a London "riot". *Papers on Social Representations*, *23*(1), 4-1.

Jenkins, R. (2014). *Social identity*. Routledge.

Jepson, J. (1991). Some aspects of the deaf experience in India. *Sign Language Studies*, *73*(1), 453-459.

Jodelet, D. (1994). Le corps, la personne et autrui. *Psychologie sociale des relations à autrui*, 41-68.

Jodelet, D. (2002). Les représentations sociales dans le champ de la culture. *Social Science Information*, *41*(1), 111-133.

Johnson, R. (1994). Sign language and the concept of deafness in a traditional Yucatec Mayan village. In C. Erting, R. Johnson, D. Smith, & B. Snider (Eds.), The Deaf way: Perspectives from the international conference on Deaf culture (pp. 103–109). Washington, DC: Gallaudet University Press.

Jovchelovitch, S. (2019). *Knowledge in context: Representations, community and culture*. Routledge.

Kemaloğlu, Y. K., & Kemaloğlu, P. Y. (2012). The history of sign language and deaf education in Turkey. *Kulak Burun Boğaz İhtisas Dergisi*, *22*(2), 65-76.

Kisch, S. (2004). Negotiating (genetic) deafness in a Bedouin community. In J. V. Van Cleve (Ed.), Genetics, disability, and deafness (pp. 148–173). Washington, DC: Gallaudet University Press.

Kisch, S. (2008). "Deaf discourse": the social construction of deafness in a Bedouin community. *Medical Anthropology*, *27*(3), 283-313.

Kisch, S. (2012). *Deafness among the Negev Bedouin: an interdisciplinary dialogue on deafness, marginality and context*. Universiteit van Amsterdam [Host].

Kusters, A. (2009). Deaf Utopias? Reviewing the Sociocultural Literature on the World's "Martha's Vineyard Situations". *The Journal of Deaf Studies and Deaf Education*, *15*(1), 3-16.

Kusters, A. M. J. (2014). Deaf gain and shared signing communities. In *Deaf Gain: Raising the Stakes for Human Diversity* (pp. 285-305). University of Minnesota Press.

Kyle, J. G., Kyle, J., Woll, B., Pullen, G., & Maddix, F. (1988). *Sign language: The study of deaf people and their language*. Cambridge University Press.

Lachance, N. (2007). Territoire, transmission et culture sourde: perspectives historiques et réalités contemporaines. Presses Université Laval.

Lane, H. (1995). Constructions of deafness. *Disability & Society*, *10*(2), 171-190.

Lane, H. (2002). Do deaf people have a disability?. *Sign language studies*, *2*(4), 356-379.

Lane, H. (2005). Ethnicity, ethics, and the deaf-world. *The Journal of Deaf Studies and Deaf Education*, *10*(3), 291-310.

Lane, H. L., Hoffmeister, R., & Bahan, B. J. (1996). *A journey into the DEAF-WORLD*. Dawn Sign Press.

Lavigne, C. (2010). Surdités, représentations du corps, identités: corps biologique, corps social et corps à soi. *La nouvelle revue de l'adaptation et de la scolarisation*, (2), 67-75.

Liang, Y. (1999). *Mapping, Mutation Identification and Expression Study of DFNB3, a Gene for Human Recessive Deafnes [ie Deafness]*. Michigan State University. Graduate Program in Genetics.

Luckner, J. L., Sebald, A. M., Cooney, J., Young III, J., & Muir, S. G. (2005). An examination of the evidence-based literacy research in deaf education. *American Annals of the Deaf*, *150*(5), 443-456.

Mannarini, T., & Fedi, A. (2009). Multiple senses of community: The experience and meaning of community. *Journal of Community Psychology*, *37*(2), 211-227.

Marsaja, I. G. (2008). Desa Kolok - A Deaf Village and its Sign Language in Bali, Indonesia. Nijmegen: Ishara Press.

Marsaja, I. G. (2015). Desa Kolok and its Deaf people. *Learning Communities: International Journal of Learning in Social Contexts*, *16*.

Marschark, M., & Clark, M. D. (2014). *Psychological Perspectives on Deafness: Volume II*. Psychology Press.

Maxwell-McCaw, D. L., Leigh, I. W., & Marcus, A. (2000). Social identity in Deaf culture: A comparison of ideologies. *JADARA-ROCHESTER NY-*, *33*(3), 14-28.

Mayberry, R. I. (2007). When timing is everything: Age of first-language acquisition effects on second-language learning. *Applied Psycholinguistics*, *28*(3), 537-549.

McIlroy, G., & Storbeck, C. (2011). Development of deaf identity: An ethnographic study. *The Journal of Deaf Studies and Deaf Education*, *16*(4), 494-511.

McLeod, S. (2008). Social identity theory. *Simply Psychology*.

McMillan, D. W., & Chavis, D. M. (1986). Sense of community: A definition and theory. *Journal of community psychology*, *14*(1), 6-23.

McQuarrie, L., & Parrila, R. K. (2009). Deaf children's awareness of phonological structure: Rethinking the "functional-equivalence" hypothesis. *Journal of Deaf Studies and Deaf Education*, *14*(2), 137-154.

Metzger, M. (2000). *Bilingualism and identity in deaf communities* (Vol. 6). Gallaudet University Press.

Mitchiner, J. C. (2015). Deaf parents of cochlear-implanted children: Beliefs on bimodal bilingualism. *Journal of deaf studies and deaf education*, *20*(1), 51-66.

Moog, J. S., & Geers, A. E. (2003). Epilogue: Major findings, conclusions and implications for deaf education. *Ear and hearing*, *24*(1), 121S-125S.

Moores, D. F. (2010). The history of language and communication issues in deaf education. *The Oxford handbook of deaf studies, language, and education*, *2*, 17-30.

Morton, N. E. (1991). Genetic epidemiology of hearing impairment. *Annals of the New York Academy of Sciences*, *630*(1), 16-31.

Moscovici, S. (1973). Foreword. In C. Herzlich (Ed.), *Health and illness: A social psychological analysis* (pp. ix–xiv). London/New York: Academic Press.

Moscovici, S. (1976). *Social influence and social change* (Vol. 10). Academic Press.

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

Nonaka, A. M. (2004). The forgotten endangered languages: Lessons on the importance of remembering from Thailand's Ban Khor Sign Language. Language in Society, 33, 737–767.

Nyst, V. (2007). A descriptive analysis of Adamorobe Sign Language (Ghana). Utrecht, The Netherlands: LOT.

Ohmer, M. L. (2007). Citizen participation in neighborhood organizations and its relationship to volunteers' self-and collective efficacy and sense of community. *Social Work Research*, *31*(2), 109-120.

Padden, C. (2010). Sign language geography. *Gaurav y Napoli (Eds.)*, 19-37.

Palfreyman, N. B. (2011). Variation in Indonesian sign language. In *Book of abstracts*.

Palmonari, A. & Emiliani, F. (2017) Le modèle sociodynamique. In Lo Monaco, G., Delouvée, S. & Rateau, P. Les représentations sociales. Bruxelles : De Boeck

Pelchat, D. (2009). Comment les pères et les mères réinventent-ils leur vie avec un enfant ayant une déficience ? *Frontières*, *22*(1-2), 58-68.

People Groups. (2018). People Name : Deaf Indonesians of Indonesia. Retrieved at : http://www.peoplegroups.org/explore/groupdetails.aspx?peid=47768

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

Rawal, N. (2008). Social inclusion and exclusion: A review. *Dhaulagiri Journal of Sociology and Anthropology*, *2*, 161-180.

Rayman, J. (2009). Why doesn't everyone here speak Sign Language? Questions of language policy, ideology and economics. *Current Issues in Language Planning*, *10*(3), 338-350.

Rochira, A., De Simone, E., Mannarini, T., & Salvatore, S. (2019). What Do We Talk About When We Talk About Participation? Sense of Community and Social Representations of Participation. *Europe's Journal of Psychology*, *15*(2), 312-328.

Rohmani, I., & Rohmani, C. (2018). The Communication Methods in English Classroom for Indonesian Deaf Students. *Theory and Practice in Language Studies* 8.1 : 9–16.

Schroedel, J. G., & Schiff, W. (1972). Attitudes towards deafness among several deaf and hearing populations. *Rehabilitation Psychology*, *19*(2), 59.

Shuman, M. (1980). The sound of silence in Nohya: A preliminary account of sign language use by the deaf in a Maya community in Yucatan, Mexico. Language Sciences, 51, 144–173.

Singleton, J. L., & Tittle, M. D. (2000). Deaf parents and their hearing children. *Journal of Deaf studies and Deaf education*, *5*(3), 221-236.

Skelton, T., & Valentine, G. (2003). 'It feels like being Deaf is normal': an exploration into the complexities of defining D/deafness and young D/deaf people's identities. *Canadian Geographer/Le Géographe Canadien*, *47*(4), 451-466.

Sundstrom, R. A., Van Laer, L., Van Camp, G., & Smith, R. J. (1999). Autosomal recessive nonsyndromic hearing loss. *American journal of medical genetics*, *89*(3), 123-129.

Tajfel, H. (1974). Social identity and intergroup behaviour. *Information (International Social Science Council)*, *13*(2), 65-93.

Tajfel, H., Turner, J. C., Austin, W. G., & Worchel, S. (1979). An integrative theory of intergroup conflict. *Organizational identity: A reader*, *56*, 65.

Thayer, S., & Schiff, W. (1974). Observer judgment of social interaction: Eye contact and relationship inferences. *Journal of Personality and Social Psychology*, *30*(1), 110.

Van den Bogaerde, B. (2005). Everybody signs in Kosindo also? Deaf Worlds, 21, 103–107.

Vergès, P. (1992). L'evocation de l'argent: Une méthode pour la définition du noyau central d'une représentation. *Bulletin de psychologie*.

Vice, (2015). In Bali's Deaf Village, Everyone Speaks Sign Language. Retrieved at : https://www.vice.com/en_ca/article/8gkjag/theres-a-village-in-bali-where-everyone-knows-sign-language-511

Wang, A., Liang, Y., Fridell, R. A., Probst, F. J., Wilcox, E. R., Touchman, J. W., ... & Friedman, T. B. (1998). Association of unconventional myosin MYO15 mutations with human nonsyndromic deafness DFNB3. *Science*, *280*(5368), 1447-1451.

World Health Organization (WHO), (2014). Surdité et déficience auditive. Retrieved at : http://www.who.int/mediacentre/factsheets/fs300/fr/

Winata, S., Arhya, I. N., Moeljopawiro, S., Hinnant, J. T., Liang, Y., Friedman, T. B., & Asher, J. H. (1995). Congenital non-syndromal autosomal recessive deafness in Bengkala, an isolated Balinese village. *Journal of medical genetics*, *32*(5), 336-343.

Woll, B., & Ladd, P. (2003). Deaf communities. *Oxford handbook of deaf studies, language, and education*, 151-163.

Zeshan, U. (2007). The ethics of documenting sign languages in village communities.

Appendices

Certificate of Ethics Approval

31/01/2019

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE l CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	S-11-18-1226
Titre du projet / Project Title	Social Representation of deafness in Bengkala
Type de projet / Project Type	Recherche de professeur / Professor's research project
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	31/01/2019
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	30/01/2020

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Lilian NEGURA	École de service social / School of Social Work	Chercheur Principal / Principal Investigator
Jessica BREAU	École de service social / School of Social Work	Étudiant-chercheur / Student-researcher

Conditions spéciales ou commentaires / Special conditions or comments

550, rue Cumberland, pièce 154   550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada   Ottawa, Ontario K1N 6N5 Canada

613-562-5387 ·   613-562-5338 ·   ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie l www.recherche.uottawa.ca/ethics

Consent form

Title of the study

Social Representation of Deafness in Bengkala

Introduction

The purpose of this form is to provide you with information that may affect your decision whether or not to participate in this research study. Please read the information below and ask any questions you might have before deciding whether or not you agree to take part in this study.

Invitation to Participate

You are invited to participate in the above-mentioned research study. This document provides information on the terms and conditions of this research. If there are words or paragraphs you do not understand, do not hesitate to ask questions. In order for you to participate in this research project, you must sign two copies of this document. You may keep one copy for your records and the other will be safely kept by the researchers.

The interview will consist of a word association task where you will be asked to name the first five (5) words that come to mind after hearing four (4) stimulus words. You will then be asked to rank the words in order of importance (1 – 5) and assign each one with a positive, neutral or negative attitude, as well as a brief explanation. This interview will be approximately one hour long.

Researchers

The researchers responsible for this research project are Lilian Negura, professor at the School of Social Work of the University of Ottawa, Canada, and Charles Gaucher, professor at the School of Social Work of the University of Moncton, Canada. For any additional information or to address any concerns related to the research project, you can reach Lilian Negura by phone at 1-613-562-5800 ext. 2020 or by email at

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School of Social Work

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lilian.negura@uottawa.ca ; or Charles Gaucher by phone at 1-506-858-4172 or by email at charles.gaucher@umoncton.ca.

The student researcher responsible for this research project is Jessica Breau. She is enrolled in the PhD in Social Work at the University of Ottawa and can be reached by email at jbrea035@uottawa.ca.

Purpose of the study

The purpose of this study is to understand the Social Representations of deafness in the village of Bengkala.

Voluntary participation

You are under no obligation to participate and it is important for you to know that if you choose to participate, you can withdraw from the study at any time. If you choose to withdraw, you may ask for all data gathered not to be used or to be destroyed.

Given the subject nature, it is possible that you may experience some emotional/psychological discomfort while participating in this research. In order to minimize the risk of discomfort, it is possible to pause the interview or move on to a different question at any time during the interview. The researcher might also suggest that you talk further about your situation with someone who the researcher feels could be helpful in the situation.

Confidentiality and Anonymity

All data collected (transcripts, audio recordings, video recordings, photos, drawings, questionnaires and notes) will be kept in a secure manner. All collected data will be identified only by a alphanumerical code associated with each participant. The correspondence between the alphanumerical code and the names of the participants will be kept in an encrypted document protected by a password only accessible by the researchers and the student researcher.

During the field study all electronic data will be stored on a password-protected computer and all hard copies or paper documents will be kept under lock and key by the student researcher (Jessica Breau). Once the

field study completed, all data (hard copy and electronic data) will be stored safely at the University of Moncton and destroyed 10 years after the end of this research.

Results and Publication

All data collected during this research project will be used for research purposes only in order to fulfill the purpose of the study described in this consent form. The results of this research will make up the subject matter for conferences, publications in scientific and professional journals as well as a PhD thesis. The data collected, such as transcripts, photos and videos, could be used in such conferences and publications.

Research funding

This research is funded by The Social Sciences and Humanities Research Council of Canada and received the Insight Development Grant for the years of 2018-2020.

Monitoring of ethical aspects

The Ethics Committees of the University of Ottawa and the University of Moncton have approved this research project. In addition, they will approve in advance any revisions and modifications to the consent form and to the research protocol. If you have any comments or concerns, you can talk about any ethical problems regarding the conditions in which your participation in this project took place with either of the researchers or the Protocol Officer for Ethics in Research of the University of Ottawa (in English or French only) by phone at 1-613-562-5387 or by email at ethics@uottawa.ca ; or the Faculty of Graduate Studies and Research of the University of Moncton by phone at 1-506-858-4310 or by email at fesr@umoncton.ca.

Free and Informed Consent

I, _____ (print name), declare that I have read and / or understood this form and have received a copy. I understand the nature and the purpose of my participation in the project. I had the opportunity to ask questions that were answered. I hereby agree to participate freely in the research project

Signature: _____

Date : _____

Declaration of the person responsible for obtaining consent

I, _____, certify to have explained to the participant the terms of this form, to have answered the questions that they asked me in this respect and to have clearly indicated to them that they remain, at any time, free to put a term to participate in the research project described above. I commit myself to guarantee the respect of the objectives of the study and to respect the confidentiality.

Signature: _____

Date : _____

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Lembar Persetujuan

Judul Penelitian

Representasi Sosial Tuli – Bisu di Bengkala

Latar Belakang

Tujuan dari formulir ini adalah untuk menyediakan anda informasi yang mungkin mempengaruhi keputusan anda untuk ikut atau tidak dalam penelitian ini. Silahkan membaca informasi dibawah ini dan tanyakan apapun yang anda mau sebelum memutuskan setuju atau tidak untuk ikut dalam studi ini.

Undangan Untuk Ikut Serta

Anda diajak untuk ikut berpartisipasi dalam penelitian seperti disebut diatas. Dokumen ini akan memberikan anda informasi tentang syarat dan ketentuan yang berlaku dalam penelitian ini. Jika ada kata-kata yang tidak anda mengerti, jangan khawatir untuk bertanya. Untuk ikut berpartisipasi dalam studi ini, anda harus menandatangani 2 lembar dokumen. Anda boleh menyimpan salah satunya dan lainnya akan disimpan oleh peneliti.

Proses wawancara akan terdiri dari kegiatan berbicara dimana anda akan diminta untuk menyebutkan lima (5) kata yang muncul dalam pikiran anda setelah mendengar empat (3) kata-kata stimulus. Anda kemudian akan diminta untuk memilah kata tersebut sesuai tingkat pentingnya (1 – 5) dan menunjukkan masing-masing kata tersebut dengan sebuah sikap positif, netral atau negative, dan juga penjelasan singkat. Interview ini kira-kira akan berlangsung selama satu jam.

Para Peneliti

Para Peneliti yang bertanggung jawab terhadap studi ini adalah Lilian Negura, seorang profesor dari Jurusan Kegiatan Sosial Universitas Ottawa, Kanada, dan Charles Gaucher, Profesor dari Jurusan Kegiatan Sosial Universitas Moncton, Kanada. Untuk informasi tambahan atau apapun terkait proyek penelitian ini, anda bisa menghubungi Lilian

Negura dengan telepon: 1-613-562-5800 ekstensi 2020 atau email lilian.negura@uottawa.ca ; atau Charles Gaucher dengan telepon: 1-506-858-4172 atau email charles.gaucher@umoncton.ca.

Mahasiswa yang bertanggungjawab untuk proyek penelitian ini adalah Jessica Breau. Dia terdaftar sebagai mahasiswa Doktoral di Jurusan Kegiatan Sosial di Universitas dan bisa dihubuingi pada email jbrea035@uottawa.ca.

Tujuan Penelitian

Tujuan penelitian ini adalah untuk mengerti tentang Representasi Sosial Tuli – Bisu di Desa Bengkala.

Ikut Serta Secara Sukarela

Anda tidak dipaksa untuk berpartisipasi dan penting untuk diketahui bahwa jika anda memutuskan untuk ikut, anda bisa keluar/berhenti dari studi ini kapanpun. Jika anda memutuskan untuk menarik diri, anda boleh meminta data yang sudah diperoleh untuk tetap digunakan atau dihapuskan.

Secara alami, ada kemungkinan anda akan mengalami beberapa kondisi emosional/psikis yang kurang nyaman selama ikut serta dalam penelitian ini. Untuk meminimalisir resiko ketidaknyamanan, boleh untuk mengambil jeda saat wawancara atau berpindah ke pertanyaan yang lebih nyaman selama proses interview berlangsung. Peneliti juga memberi saran bagi anda untuk berbagi perasaan kepada orang yang anda percayai dan membantu bagi peneliti dalam studinya.

Anonimitas dan Kerahasiaan

Semua data yang diperoleh (transkrip, rekaman audio (suara), foto, gambar-gambar, kuesioner dan catatan) akan disimpan dengan baik. Semua data yang terkumpul akan diidentifikasi hanya dengan kode alfanumerik sesuai dengan masing-masing peserta. Korespondensi antara kode alfanumerik dan nama peserta akan disimpan dalam dokumen yang terkunci dengan password yang hanya bisa diakses oleh peneliti dan mahasiwa yang sedang melakukan penelitian ini.

Selama studi lapangan, semua data elektronik akan disimpan dalam komputer/laptop yang tersandi dan semua cetakan atau dokumen kertas akan disimpan dalam lemari dan terkunci oleh mahasiswa itu sendiri (Jessica Breau). Setelah studi lapangan selesai, semua data (cetakan dan elektronik data) akan disimpan secara aman di Universitas Moncton Kanada dan akan dihancurkan 10 tahun setelah penelitian ini selesai.

Publikasi dan Hasil Penelitian

Semua data yang terkumpul selama proses penelitian ini akan digunakan dalam tujuan penelitian saja untuk memenuhi aspek tujuan penelitian yang sudah disebutkan dalam lembar persetujuan diatas. Hasil dari penelitian ini akan digunakan sebagai materi dalam konferensi, terbit dalam publikasi ilmiah dan jurnal professional dan juga dalam thesis gelar doctoral. Data yang terkumpu seperti transkrip, foto dan video dapat digunakan dalam berbagai publikasi dan konferensi.

Sumber Dana Penelitian

Penelitian ini didanai oleh Dewan Penelitian Ilmu Sosial dan Humanisme Kanada dan memperoleh Beasiswa Pengembangan Wawasan untuk tahun 2018 – 2020.

Pengawasan Aspek Etik

Komite Etik Universitas Ottawa dan Universitas Moncton telah menyetujui penelitian ini. Lebih lanjut, mereka akan menyetujui segala bentuk revisi dan modifkasi/perubahan lainnya terkait dengan lembar persetjuan dan protocol penelitian ini. Jika anda memiliki komentar atau pendapat, anda bisa berbicara tentang masalah kode etik menurut kondisi dimana anda ikut serta dalam proyek penelitian ini dengan peneliti langsung atau menghubungi kantor protokol etik penelitian di Universitas Ottawa (hanya dalam bahasa Inggris & Prancis saja) dengan telepon: 1-506-858-4310 atau email fesr@umoncton.ca.

Persetujuan Bebas & Diinformasikan

Saya, _____ (nama anda), menyatakan bahwa saya telah membaca dan/atau mengerti formulir ini dan telah menerima salinannya. Saya mengerti tujuan serta maksud dari partisipasi saya dalam proyek ini. Saya mempunyai kesempatan untuk bertanya dan dijawab. Saya dengan ini menyatakan SETUJU untuk ikut secara bebas/sukarela dalam penelitian ini.

Tanda Tangan : _____

Tanggal : _____

Pernyataan Sumber Yang Bertanggungjawab Atas Lembar Persetujuan

Saya,_____,
menyatakan telah menjelaskan kepada peserta kondisi/ketentuan dalam formulir ini, telah menjawab pertanyaan yang diajukan oleh mereka untuk secara jelas bahwa mereka tetap, kapanpun, bebas untuk menyatakan keikutsertaan dalam proyek penelitian yang disebutkan diatas. Saya menyatakan dengan jujur dan sebagai penjamin tujuan penelitian ini dan sifat kerahasiaannya.

Tanda Tangan : _____

Tanggal : _____

Evocations – Interview Grid

<div align="right">

ID # : _____

Date : _____

</div>

Deaf

Evocations	Rank 1 – 5	Attitude - / 0 / +

Normal

Evocations	Rank 1 – 5	Attitude - / 0 / +

Sign

Evocations	Rank 1 – 5	Attitude - / 0 / +