

Editorial

Thinking About Immigration and Disability

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The state and the body are always connected. In times of crisis (political and economic), there is often increasing concern with borders, both of the nation and of the body. It becomes “urgent” to protect the state from contagions and threats, real or imagined. With increasing urgency, leaders often attempt to unify their base by clearly articulating what it means to be a “normal citizen,” identifying which bodies are included and which are not. We can see this connection between body and state both in the present and in the past.

History is replete with examples, and the lessons are not subtle. As the Third Reich consolidated power in 1933, among their first actions was to identify people with disabilities as enemies of the state. Just six months after assuming power, they passed the Law for the Prevention of Progeny with Hereditary Diseases. On one hand, the physically strong and independent *Übermensch* (superman) served as powerful symbol of a strong independent German state. On the other hand, there was perhaps no more inconvenient sign than people with disabilities: inconvenient truths of the vulnerability of bodies, of their needs and undeniable interdependence. Eliminating these inconvenient bodies became an important early step in nation-building, and the muted national response to their elimination became a tragic rehearsal for much larger atrocities. (See Liz Crow’s short film *Resistance* (2009) and David Mitchell and Susan Snyder’s upcoming *Disposable Humanity*.)

Our present moment reflects a great deal of border anxiety. There’s rhetoric of literal wall building to protect and reify imaginary and geographic borders and a troubling rise of isolationist/anti-immigrant rhetoric in the United States and Europe. The rising chorus of voices saying which bodies should be citizens and which should not marks a shift that has taken many in the world by surprise: there was near global shock to the assumption of power by the current POTUS in the US and to the passage of Brexit in Great Britain, as well as to the recent near-miss in closely watched elections in France.

At least in the United States, this rise in border anxiety appears to coincide with increasing government disdain (or at least apparent disinterest) in the needs of those with disabilities. The current POTUS, who as a candidate famously mocked a reporter with disabilities, has a pattern of choosing appointees with apparent disinterest in the needs of people with disabilities. It was widely reported that now Secretary of Education Betsy DeVos appeared confused about basic legal protections afforded to all students with disabilities. As recently as May 24th, Ms. Devos refused to say she would refuse federal funds to schools that discriminated against students with special needs. The confirmation hearing of Supreme Court nominee Neil Gorsuch, revealed a seemingly similar lack of concern: a case showed him unnecessarily ruling against a student with autism, a questionable ruling the Supreme Court

subsequently rebuked (during his actual confirmation hearings). Some rhetoric in current efforts at immigration reform has also evoked the danger posed by immigrants drawing on public services in ways that could easily target those with disabilities for exclusion.

While this particularly anxious moment has taken many by surprise, immigration and disability have long been tied in the history of the United States. Two centuries ago, with the Immigration Act of 1882, the country identified people with disabilities as potential “threat to the nation” and has since had a long history of using disability as criteria for immigration exclusion (See Daniel J. Wilson’s “‘No Defectives Need Apply’: Disability and Immigration.” *OAH Magazine of History* 23 [July 2009]: 35-40.) Today, the ‘ideal’ citizen has been more explicitly tied to religion and ethnicity than to issues of ability, with Islamic people the immediate subject of particularly intense suspicion. At the same time, history suggests it’s wise for us to keep mindful of possible slippages of otherness, slippages that frequently allow these fears to bleed to the body and to disability. With a view shared by many, embattled former National Security Advisor Michael Flynn famously described Islam in biological terms, as a “cancer” threatening national security and as a “sick” ideology that, per his tweet, “needs to B [sic] healed.” The US administration’s recent attempt at a Muslim ban attempted to “cure” this “sickness.”

As the effects of early exclusion policies still echo and debates rage over who belongs, who does not belong, who is worthy of entrance, who is not, a great deal of attention is rightly paid to the ethnic and religious dimensions of the debate. Perhaps we should give more attention to also considering the ways in which disability may intertwine with these. In a time when nations are actually increasingly interdependent, with a variety of bodies—with a variety of needs—often living in flow between nations, perhaps the greatest threat is pretending this isn’t so. And in this chain of bodies that need one another and have the power to speak out for one another, now more than ever, as Martin Niemöller reminded us, it doesn’t matter who they come for first.

Research Article

The Changing View of Physical Recreation for People with Disabilities in the USA: A More Inclusive Perspective?

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Abstract: Historically, people with disabilities have had limited access to physical recreation. However, as society's view of people with disabilities and their rights has been in transition, so has physical recreation activities for people with disabilities. The purpose of this study is to examine the transition of physical activity for people with disabilities in the United States. A three-fold search process of databases, ancestral, and descendent searches were conducted, yielding sixteen studies for inclusion in this historical literature review. The results show that the earliest physical recreational opportunities for people with disabilities were based in medical response to physical needs. Today, opportunities for physical recreation for people with disabilities include therapeutic and non-therapeutic activities. Nonetheless, there is still a division in how society views recreation for people with disabilities, represented by major recreation organizations holding either medical or sociopolitical views of people with disabilities.

Keywords: people with disabilities, recreation, history

Introduction

Physical recreation activity is valuable for all people (World Health Organization, 2015). Research shows that physical recreation activities provide many health benefits, such as reducing the risk of many types of diseases, cancers, and diabetes (World Health Organization, 2015). Other benefits of physical recreational activity include reducing hypertension, reducing depression, and controlling weight (World Health Organization, 2015). Moreover, many people engage in physical recreation activities due to its intrinsic benefits, such as relaxation and social interactions (Bullock & Mahon, 2001; Hurd & Anderson, 2011; Nesbitt, 1979).

Physical recreation activities are a fundamental human right, according to the United Nations' Declaration of Human Rights (UDHR), "Everyone has the right to rest and leisure" (Universal Declaration of Human Rights, 2006). Article 30 also recognizes that people with disabilities have the right to partake in recreation activities: "[...] Participate on an equal basis with others in recreational, leisure, and sporting activities" (UDHR, 2006).

Society's dominant view of people with disabilities and their rights has been in transition (Linton, 1998; Palmer & Harley, 2012; Smart, 2009b). Linton (1998) highlights six ways that society has classified people with disabilities, ranging from denying people with disabilities any of their civil rights to limiting people with disabilities' role in society to

providing people with disabilities opportunities to participate in all areas of their communities. Historically, the United States has held a medical view of people with disabilities, where the individual with the disability was responsible for fixing his/her disability, and doctors were viewed as the experts in helping people with disabilities overcome their disability (Palmer & Harley, 2012; Smart, 2009a; Smart, 2009b; US Commission on Civil Rights, 2000). Moreover, this medical view of disabilities views disability as a problem, deviance, or something abnormal (Palmer & Harley, 2012; Smart, 2009b). This suggests that people with disabilities may be excluded from areas such as recreation, thereby reducing their integration into communities and their quality of life.

The Civil Rights movements of the 1960s in the U.S. represented a major change in society's view of people with disabilities (DePauw & Gavron, 2005; Smart, 2009a; Smart, 2009b; US Commission on Civil Rights, 2000). Society began to shift from a predominantly medical view of disability toward a sociopolitical view of disability (Smart, 2009b). From the sociopolitical perspective, people with disabilities are no longer seen as deviant, but rather as people who are entitled to their rights in society. Rather than delegating the responsibility of disability to the medical profession, the sociopolitical view posits that all members of society are responsible for including people with disabilities in the mainstream (Palmer & Harley, 2012; Smart, 2009b). But it was not until 1990 with the passage of the Americans with Disabilities Act that people with disabilities' civil rights were affirmed and it became illegal to discriminate against people with disabilities in the public sector (ADA.gov, n.d.).

As society's understanding of people with disabilities' fundamental human rights has shifted in the past century, physical recreation activities for people with disabilities have also changed. Current research explains the shift from the therapeutic to non-therapeutic recreation, but it appears outdated and does not examine how this parallels the shift from a purely medical model of disabilities to a sociopolitical view of disabilities (e.g., Blas, 2007; Nesbitt, 1983; Szyman, 1993). It also fails to explain how recreation is viewed from recreation providers for people with disabilities. The purpose of this study is to examine the transition of physical recreation for people with disabilities in the United States. This historical literature review examines when/how has physical activity for people with disabilities in the USA transitioned?

Definitions

For more than thirty years, physical activity has been defined as "any body of movement produced by skeletal muscles that requires energy expenditure" (Caspersen, Powell, & Christensen, 1985; World Health Organization, 2015). Recreational therapy's long-standing definition is "a treatment service designed to restore, remediate and rehabilitate a person's level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restriction to participation in life situations caused by an illness or disabling condition" (American Therapeutic Recreation Association, 2015). All of which are redeeming values. Recreation is defined as

“an activity that people engage in during their free time, that people enjoy, and that people recognize as having socially redeeming values” (Hurd & Anderson, 2011), in addition to secondary physically redeeming values. The definition of sport in the literature varies, but it is commonly recognized that sport is a type of physical activity that has rules, is a competition, and is performed for enjoyment (e.g., Hurd & Anderson, 2011; Wheelchair & Ambulatory Sports, USA, n.d.).

Therefore, the key difference between recreational therapy and recreation is that recreational therapy is a service provided to a person, whereas recreation is something that a person chooses to engage in during his/her free time. Also, recreation can be done without a therapist and without specific habilitation goals in mind (Bullock & Mahon, 2001). Sports are considered as part of recreation, except when those who engage in the sports are paid. Therefore, this article does not include the history of Paralympics, as many of these athletes receive some sort of payment (e.g., sponsorship) for their participation. Notably, the Paralympics parallel the development of other recreation opportunities for people with disabilities. That is, the first athletes in the opening 1960 Paralympics were individuals with spinal cord injuries, and slowly other types of disabilities began to join (DePauw, 2013).

Methods

Inclusion/Exclusion Criteria

Since this is a historical literature review, there were no date limits set for this search process. A three-fold search process of databases, ancestral, and descendent searches were systematically conducted according to inclusion and exclusion criteria outlined below. In order to narrow the focus on this review, the authors chose to focus on only the history of physical recreation in the USA. Articles were included if they contained information about physical recreation opportunities for people with disabilities. No specific limits were set on the types of disabilities; that is, articles were included if they only focused on one type of disability (e.g., physical) or on multiple types of disabilities (e.g., physical and intellectual). Due to the language limitations of the authors, only sources that were available in the English language were included. Books, chapters from books, peer-reviewed journal articles, and articles from recreation publications were included in this review. Exclusion criteria included: no people with disabilities mentioned, countries other than the USA, and source not available in English.

Search Methods

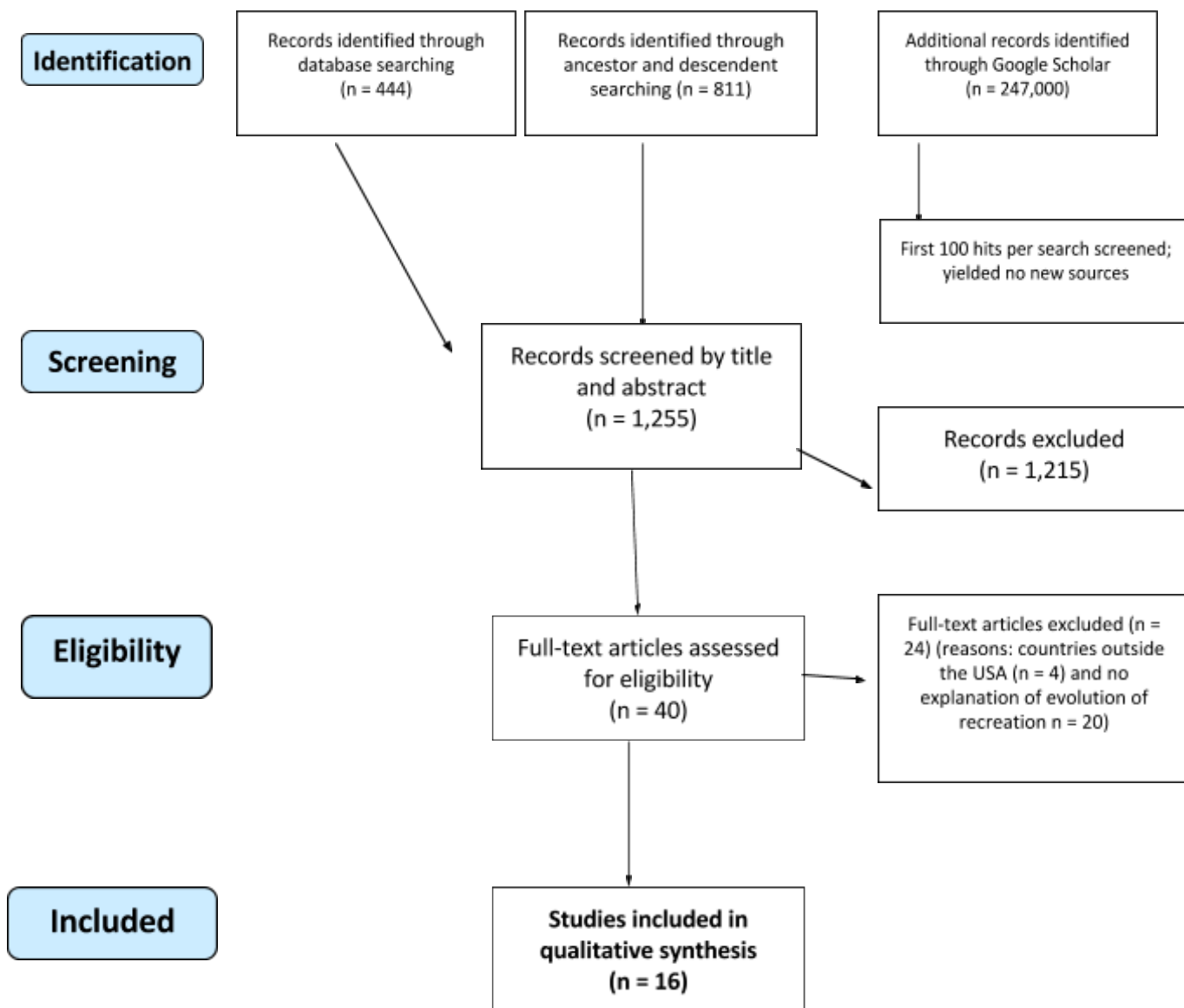
The following databases were searched during September, 2015: Psych Info, Hobbies & Crafts Reference Center, Psych & Behavioral Sciences, and Sport Discuss. Psych Info and Psych & Behavioral Sciences were chosen because of their robust inclusion of studies with people with disabilities. Hobbies & Crafts Reference Center was chosen because it includes many types of recreational activities. Likewise, Sports Discuss was chosen because it focuses on research related to sports. These databases captured such journals as the American Journal

of Sports Medicine, Therapeutic Recreation Journal, and Adapted Physical Activity Quarterly.

The following combinations of search terms were used: “disability + recreation + history,” “disability + recreation therapy + history,” “recreation therapy + history,” and “disability + history + therapeutic recreation.” This yielded 444 sources, and their titles and abstracts were screened for relevance. Sources were deemed relevant if they included historical information on either recreation or therapeutic recreation for people with disabilities in the USA. For example, the title of one study excluded during title screening was, “The story of sport for children and youth with disabilities in Latvia.” Likewise, the majority of studies were excluded because they either focused on countries outside the USA or because they merely explained types of recreation for people with disabilities without explaining the history of how this type of recreation evolved. An example of an included article is, “Thirty-seven years of community recreation for people with disabilities.” This article was included because it covered the history of recreation for people with disabilities, and the abstract revealed that it focused on the USA.

The ancestors (i.e., references) of the articles that passed this initial screening were also screened for relevance. Additionally, each of the articles obtained through the database searches and ancestral searches were screened for their descendants (i.e., later publications that cited an obtained article). When new descendant articles were obtained, their references also were screened. The combined ancestor and descendent searches yielded an additional 811 citations that were screened. Google Scholar was also searched using the aforementioned search terms to capture relevant gray literature, which yielded over 247,000 hits. Therefore, only the first 100 hits per set of search terms were screened. The Google Scholar searches yielded no new sources. Overall, 16 articles and books were selected for inclusion in this literature review. Figure 1 gives an overview of the systematic historical literature search and screening process.

Figure 1 Flow-chart of the systematic historical literature review and screening process.



Alternative text description – The image depicts flow chart of the systematic historical literature review and screening process. The flow chart categorized in four sections and labeled “Identification”, “Screening”, “Eligibility”, and “Included” in the flow chart. In the identification category there are three different starting point boxes, the first box includes description “Records identified through database searching (n=444)”, the second box includes description “Records identified through ancestor and descendent searching (n=444)”, and the third box includes description “Additional records identified through Google Scholar (n = 247,000).” In the screening category, there are two different boxes. The first and second box in the identification section flows into the screening section’s first box that includes description “Records screened by title and abstract (n = 1,255).” The third box in the

identification section flows into the screening section second box that includes description “First 100 hits per search screened; yielded no new sources.” In the eligibility category there are two different boxes. The first box in the screening section flows into two different box, the first box includes description “Full-text articles assessed for eligibility (n = 40)” and the second box includes description “Full-text articles excluded (n = 24) (reasons: countries outside the USA (n = 4) and no explanation of evolution of recreation n = 20).” In the included category there is one box in which box one from the edibility box one flows into a box with the description includes “Studies included in qualitative synthesis (n = 16).”

Discussion of Results

Overview

Because the majority of the literature on the evolution of physical recreation for people with disabilities is qualitative in nature, a thematic synthesis was used to analyze the literature to identify the themes and present the themes in narrative, chronological format (Barnett-Page & Thomas, 2009). Specifically, the following themes were identified: therapeutic recreation, non-therapeutic recreation, society’s changing perspective on physical activity for people with disabilities, major recreational organizations’ role in this changing perspective, and the expansion of non-therapeutic recreation. Each of these themes will be discussed below.

Therapeutic Recreation

As one researcher explains, recreation is “as old as recorded history” (Nesbitt, 1979, p. 12). Notably, the earliest formal recreation programs that included individuals with disabilities were therapeutic in nature. Some of the earliest roots of recreational therapy can be traced to the 1880s in the USA. During this time, physical activity and sports began out of a “medical concern” for the “correction of physical disabilities” (Mason, 2002, p. 82). Beginning in the 1900s, there is growing evidence of recreation for people with disabilities that was seen as having benefits other than just therapeutic. Many institutions, services for veterans, and options for children with disabilities began to offer recreational opportunities for people with disabilities. During the 1930s, the United States’ Veterans Administration created and provided recreational therapy services for veterans (Nesbitt, 1983). In the Works Progress Administration, the USA’s government stated the purpose of therapeutic recreation as “all activities, regardless of type, carried on for the benefit of disabled, maladjusted, or other institutionalized persons” (WPA Gov Docs, 1938). This definition reflects the widely held therapeutic mindset of the time, which viewed recreation for people with disabilities as rehabilitative in nature.

The 1940s brought an increase in therapeutic recreational services. During World War II, the American National Red Cross provided many therapeutic services to veterans in military hospitals and clinics (Austin, 2004; Nesbitt, 1983). As with many aspects of disability history, veterans were an early catalyst for societal acceptance and investment in

individuals with disabilities (Smart, 2009a). Following this historical pattern, therapeutic recreation services moved slowly from veterans' programs to public programs. In 1948, the Hospital Recreation Section of the American Recreation Society became the first professional organization for recreational therapy (Austin, 2004). The 1950s and 1960s ushered in a rise of recreational therapy organizations (Austin, 2004; Nesbitt, 1983). Generally, these were associated with medical institutions or associations, reflecting the emphasis on society's "medical concern" for people with disabilities.

As highlighted above, the earliest formal efforts in the USA of recreation for people with disabilities emphasized the therapeutic benefits of recreation. Nevertheless, access to recreational opportunities was generally only available through veterans and disability service institutions and organizations as a "service." It was not until the mid-twentieth century that organizations began to publically recognize recreation as having benefits beyond therapeutic.

Non-Therapeutic Recreation

As early as 1906, records of institutions for people with disabilities in the USA indicate that many institutions had designated staff in charge of recreation (Nesbitt, 1983). From 1906-1909, the Playground Association of America surveyed institutions such as orphanages and homes for people with disabilities and found that many of these homes had appointed key people to provide recreational services. In the 1910s, the Hospital for Crippled Children and School for Crippled Children provided recreational options for people with disabilities, such as camp experiences. Mirroring that seen for therapeutic recreation, in 1917, the American National Red Cross provided recreation for veterans (Nesbitt, 1983). These institutional programs, camp experiences, and recreation for veterans outside of hospital settings demonstrate some of the USA's earliest physical activities without therapeutic purposes for people with disabilities.

The types of non-therapeutic recreational opportunities provided for people with disabilities increased in the 1920s, though most of these options were targeted for children with disabilities. This marked a shift from prior services that were targeted for veterans. In the Northeastern USA, disability camps for children with diabetes began (Eells, 1986). From 1921 to 1926, the Russell Sage Foundation provided training on recreation and physical education for many schools and institutions for children with disabilities (Nesbitt, 1983). In 1924, the Deaf Olympics formed (Legg, Emes, Stewart, & Steadward, 2004). These children's programs and the Deaf Olympics were non-therapeutic recreation options, as their purpose was to provide people with disabilities opportunities to engage in activities during their free time that did not have rehabilitative purposes.

During the 1930s, non-therapeutic recreational opportunities for people with disabilities began to expand beyond just options for children with disabilities. Specifically, the Recreation Center for the Adult Physically Handicapped in New York and the Recreation Department of Akron, Ohio opened (Nesbitt, 1983). Throughout the 1930s and 1940s, summer camp programs for children with disabilities continued to expand (Blas, 2007). Just

as the camps and programs for people with disabilities in the 1920s did not have therapeutic purposes, so Akron's Recreation Center and these new summer camp programs did not have therapeutic goals. Instead, the goals of these camps were to provide camping options for children with disabilities that were similar to their nondisabled peers (Blas, 2007; Nesbitt, 1983).

The 1940s saw an increase in non-therapeutic recreational options for people with disabilities that were a direct response to the WWII veterans with physical disabilities returning from war. In particular, many types of wheelchair sports, such as wheelchair bowling and basketball, became popular during this time (Neishloss, 1973; Szyman, 1993). In 1945, the first wheelchair basketball games for veterans were held, and in 1948, the first wheelchair games for civilians formed (Szyman, 1993). These new sports and recreational options were purely recreational in nature as opposed to having therapeutic purposes.

During the 1950s, non-therapeutic recreational opportunities for people with disabilities continued to increase. During this time, the San Francisco Recreation Center for the Handicapped, one of the first major recreation centers for children and adults with disabilities, opened (Nesbitt, 1983; Pomeroy, 1990). This Center included many types of recreational activities, such as outdoor environmental activities, aquatics, physical education, and theatre (Pomeroy, 1990). The first national wheelchair games, which exemplified non-therapeutic recreational opportunities for people with disabilities in the USA, were held in 1957 (DePauw & Gavron, 2005). These wheelchair games were organized by Wheelchair Sports, USA; the Paralyzed Veterans of America; and Adelphi College in New York (DePauw & Gavron, 2005; Wheelchair & Ambulatory Sports, n.d.).

The 1960s brought continued growth of non-therapeutic recreational options for people with disabilities (Nesbitt, 1979). In 1960, the USA wheelchair sports team competed internationally for the first time (DePauw & Gavron, 2005). The US government began to see the rising need for professionals who were trained in recreation for people with disabilities, and so the US Office of Vocational Rehabilitation offered grants for "training master's-level specializations in recreation for the ill and handicapped" (Nesbitt, 1983, p. 101). Likewise, the Physical Education and Recreation for Handicapped Children Section of the Mental Retardation Act Amendments provided research and training funds for recreation for children with disabilities (Nesbitt, 1983). In 1968, Special Olympics, which provided competitive sports opportunities for people with intellectual disabilities, was founded (Legg et al., 2004; Orelove, Wehman, & Wood, 1982).

Throughout the twentieth century, recreation opportunities for people with disabilities continued to expand. Most importantly, these opportunities reflected a change in society's view of people with disabilities. That is, recreation activities were no longer viewed as primarily therapeutic; rather, many of these activities allowed people with disabilities to engage in recreation at their own discretion during their free time. For example, children's camping options and competitive wheelchair sports were just a few of the growing number of

recreational activities for people with disabilities in the USA.

Society's Changing Perspective

While the origins of recreation options for people with disabilities were rooted in the medical model, as the twentieth century progressed, recreation for people with disabilities expanded to include purposes beyond just therapy, reflecting a societal shift towards a sociopolitical view of disabilities. One author explains, “[t]he origins of physical activities and sport for people with disabilities are rooted in medical concern...for the ‘correction’ of physical disabilities through the use of exercise and physical therapy” (Mason, 2002, p. 82). The first individuals with disabilities who accessed physical recreation activities that were not seen as mainly therapeutic were veterans of WWII who had acquired physical disabilities (Mason, 2002; Stein, 1983).

The Civil Rights Movements in the 1960s sparked dramatic changes not only in African-Americans seeking their civil rights, but people with disabilities began to seek their civil rights as well (DePauw & Gavron, 2005; Smart, 2009a). This era was a turning point for recreation and people with disabilities as several new pieces of legislation formally recognized people with disabilities’ rights (DePauw & Gavron, 2005). Legislation that opened up doors for people with disabilities’ recreational options included the Education of All Handicapped Children Act of 1975 (renamed IDEA in 1990) and the Amateur Sports Act of 1978. Specifically, IDEA mandated a free, appropriate education for children with disabilities in public schools, which allowed these children access to physical education activities as well. The Amateur Sports Act recognized athletes with disabilities as part of the United States Olympic Committee (DePauw & Gavron, 2005). These laws reflect society’s shift towards inclusion of people with disabilities in recreational activities.

Major Organizations’ Influences on Recreation

Just as laws began to reflect society’s shifting view of people with disabilities, several key organizations in the USA began to reflect this shift away from the medical model of disability. For example, towards the end of WWII, the Red Cross issued a statement that “recreation is an end unto itself” and further stated that their organization’s activities were not therapeutic (James, 1980, p. 14). This statement may have been the result of economic and other pressures; specifically, at the end of WWII, the Red Cross had a lack of funds which decreased the number of workers who could provide services to veterans. Also, around this time, the Surgeon General challenged the Red Cross that their untrained workers were providing occupational therapy services (James, 1980). Therefore, in an effort to eradicate any responsibility of their dwindling number of workers from providing therapeutic services, the Red Cross announced that their recreational services were “an end unto itself” and not therapeutic (James, 1980, p. 14). The Red Cross workers shifted from providing recreation services that were therapeutic to providing services that were for diversionary or enjoyment purposes (Bullock & Mahon, 2001; James, 1980). This marked a shift from seeing recreational opportunities as being always therapeutic to being seen as having other purposes

(James, 1980).

Another key turning point in the shift from viewing recreation as only therapeutic occurred with the formation of the National Therapeutic Recreation Society (NTRS) in 1966 (Austin, 2004). This organization posited that recreation could have nonclinical purposes for all people, and that recreation could also be used as clinical therapy (Austin, 2004). During this time, there was a growing debate between major recreation and therapeutic recreation organizations about the use and meaning of the term “therapeutic recreation” (Austin, 2004). In 1970, these major organizations came together in a meeting at Indiana State University to try to come to a consensus on the meaning of “therapeutic recreation.” However, Austin points out that no agreement could be reached during this meeting, and the organizations continued to debate the meaning of the term “therapeutic recreation” well into the 1980s.

In 1984, the American Therapeutic Recreation Association (ATRA) was formed with the sole focus on defining therapeutic recreation as providing clinical therapy purposes only. This organization’s philosophy reflects the medical model of disabilities, which views people with disabilities in need of fixing. The formation of the ATRA marked a division into two ideas of therapeutic recreation. That is, the NTRS maintained their stance that recreation could be for all people with or without having therapeutic benefits, while the ATRA held that therapeutic recreation had clinical purposes (Austin, 2004). Thus, these two organizations’ philosophies of recreation highlight the opposite perspectives of people with disabilities from the sociopolitical model and the medical model, respectively.

Currently, the NTRS is a branch of the National Recreation and Park Association. The NTRS provides recreational services in both the clinic and community setting (NTRS, 2005). The NTRS posits that everyone has a right to leisure and that engaging in leisurely (i.e., non-therapeutic) activities increases one’s quality of life, which demonstrates their position that recreation can be therapeutic and non-therapeutic in nature (NTRS, 2005). The NTRS’s perspective on recreation reflects a sociopolitical mindset, in that people with disabilities are not viewed merely as in need of medical rehabilitation. Rather, NTRS’s view of recreation for people with disabilities is a more inclusive view, as most people without disabilities also engage in recreation for non-therapeutic reasons.

In contrast, the ATRA maintains their stance that therapeutic recreation has therapeutic, health-related benefits. The ATRA’s website states that their “services play a critical role in the comprehensive rehabilitation of individuals with illnesses and/or disabling conditions” (Welcome to the ATRA, 2015). Indeed, the ATRA views their services as primarily a health care treatment for people with disabilities, which is a direct contrast to the NTRS’s position that recreation can be therapeutic and non-therapeutic. Today, recreational opportunities for people with disabilities involve those that are both therapeutic and non-therapeutic, which reflects the perceived benefits of both as well as society’s still-divided views of people with disabilities.

Disability researchers note that society still holds contrasting views of people with disabilities, such as seeing people with disabilities as deficits in need of medical fixing to seeing people with disabilities as being limited only by the barriers society puts in place (Linton, 1998; Palmer & Harley, 2012; Smart, 2009a; Smart, 2009b). For example, recreational therapy reflects the medical viewpoint of people with disabilities, which sees people with disabilities as needing treatment from medical experts to help alleviate the effects of their disabilities (Smart, 2009a). In contrast, recreational options for people with disabilities that are not therapeutic in nature reflect a sociopolitical view of disabilities, whereas people with disabilities are hindered from participating in recreation only because of the barriers imposed by other people (Palmer & Harley, 2012; Smart 2009b).

Expansion of Non-therapeutic Recreation

Today, there are literally hundreds of non-therapeutic recreational opportunities for people with disabilities. For example, the Christopher & Dana Reeve Foundation lists many recreational resources for people with disabilities on their website. This list exemplifies the vast array of different types of non-therapeutic recreational opportunities that are available, such as national park services, surfboarding, figure ice skating, geocaching, golf, and many more (Reeve Foundation, 2015).

Additionally, while there are many organizations that are specifically focused on providing recreation for people with disabilities, many organizations provide parallel recreation for people with and without disabilities. For example, the Chicago Park District (CPD) provides mostly separate services for people with and without disabilities. The CPD's website lists many recreation activities for people with disabilities under their "adapted sports" or "special recreation" sections, whereas it lists activities aimed at people without disabilities under other general categories by the name of the sport, such as "martial arts" or "ice skating." While the CPD's Special Recreation offers specialized programs for the following populations: blind or visually impaired, Deaf or hard-of-hearing, intellectual disabilities, physical disabilities, Special Olympics, and veterans, it unclear if these programs are integrated with people without disabilities (Chicago Park District, 2014).

Many parks and recreation programs across the USA offer similar programs as those in Chicago, although whether or not these programs are integrated reflects the continuing transition in how society views individuals with disabilities. For example, Special Olympics programs and Deaf and Hard-of-Hearing programs are presumably only for people with disabilities, which reflect the continued separation between people with and without disabilities. A typical posting of a Deaf event at a park on the CPD's website explains that the target population for this activity is "individuals whose primary disability is deafness or heard-of-hearing." Likewise, postings for the CPD's special recreation activities specify that these events target "individuals with a primary intellectual or developmental disability" (Chicago Park District, 2014). Postings on the CPD's website that do not target people with disabilities generally are categorized by age, but typically do not specify if these programs are

open to people with disabilities. While people with disabilities have access to many more types of recreational programs than in the past, these programs still largely run parallel to programs for people without disabilities.

Summary

Our review explored the historical trends of recreation for people with disabilities in the USA. As with any historical literature review, this account is subject to the interpretive lens of the authors. Also, the dearth of information available, especially information on early recreation and therapy options for people with disabilities, is another limitation. Additionally, the focus on the history of recreational therapy in the USA limits the scope of this review. Future research could comparatively explore the transition of recreational therapy to non-therapeutic options in other countries.

Though originally viewed as having purely therapeutic purposes, by the mid-twentieth century, alternative views of recreation began to form. Additionally, although recreational opportunities for people with disabilities began mainly with services for veterans, these options expanded to include children with disabilities, and eventually recreation for all ages and types of disabilities began to form throughout the USA.

Most of the literature still reflects a medical view of people with disabilities. That is, most of our sources emphasized people's disabilities and how recreation can help people with disabilities. Even sources that do not claim that recreation need always be therapeutic often stressed other health benefits of recreation, such as reducing the risk of diseases, cancers, and diabetes. While not specifically claiming that recreation must be therapeutic for people with disabilities, by highlighting these other benefits, the literature still reflects a medical mindset of trying to help improve the lives of people with disabilities through recreation. Furthermore, none of these sources discussed the development of recreation for people with and without disabilities, thus highlighting the division that society places between people with and without disabilities.

Another noteworthy fact is the types of disabilities that are discussed in the literature. That is, most of the literature on physical activities for people with disabilities focuses on people with physical disabilities, with a smaller amount of attention on physical activities for people with intellectual disabilities (e.g., Special Olympics). This current literature review revealed virtually no literature on the evolution of physical activities for people with sensory, learning, or emotional disabilities. Future research could compare the historical physical recreation experiences of people with different types of disabilities.

Just as society is still in transition (Linton, 1998; Palmer & Harley, 2012; Smart, 2009a), so too is recreation, as many recreational programs for people with disabilities are still segregated from people without disabilities. As society continues to shift its perspective in realizing that societal barriers hinder people with disabilities, this shift leads to including people with disabilities in all areas of the community. Therefore, as society becomes more

inclusive of people with disabilities, recreational opportunities will likely become more integrated. While recreation has tended to follow society's leading in its view of people with disabilities, recreation could shift from merely following society's lead to being a leader in societal change. By systematically creating more programs that include both people with and without disabilities, recreation can be a catalyst for further integration of people with disabilities.

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Research Article

Changing Disability Status of Immigrants in Australia - Three Cases

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Abstract: This paper examines the changing disability status over five years of those born overseas who have lived in Australia for various periods of time. Sourcing data from the 2006 and 2011 censuses it explores in-depth three distinctive immigrant groups: recent immigrants arriving between 2002 and 2006; Chinese students coming to Australia in the late 1980s; and Vietnamese refugees settling in Australia in the late 1970s and early 1980s. The analysis shows that age is the most important factor influencing the trajectories of disability profiles of immigrants, just like their local counterparts.

Keywords: Australia, immigrants, disability statistics

Introduction

This study deals with the changing disability profiles of immigrants to Australia.¹ Australia has a largely immigrant population and successive waves of migration since European settlement have resulted in a highly culturally diverse society. According to the Australian Bureau of Statistics (ABS), at 30 June 2014, 28% (6.6 million people) of the population was born overseas. About half of Australians are either immigrants themselves (overseas born), or children of immigrants (at least one parent born overseas). An understanding of the disability characteristics of immigrant communities is crucial to the continued improvement of support systems to meet the changing needs of Australians with disability. Using the latest population statistics over the period 2006-2011 this paper demonstrates that while immigrants generally have a lower rate of disability on arrival, they tend to acquire disability at a much faster pace as they age than other Australians.

Research Question

This study questions how the disability status of Australian immigrants has changed over the five-years between 2006 and 2011. The relationship between immigrants of particular origins, their length of residence in host countries, and their health, wellbeing and specific diseases has been a subject of many studies (Alter and Oris, 2005; Gray, Harding and Reid, 2007; Harding, 2004; Johansson, Helgesson, Lundberg, Nordquist, Leijon, Lindberg, and Vingard, 2012). A recent review of the literature on the health status of migrants in Australia concludes that “migrants in Australia are generally in better health compared with the Australian-born population”(Anikeeva, Bi, Hiller, Ryan, Roder. and Han, 2010). This so-called ‘healthy migrant effect’ has also been used to understand the disability of immigrants. When explaining the relatively low presence of people born overseas in the

specialist disability services, the Australian Institute of Health and Welfare (AIHW, 2010), for instance, state that:

“Immigrant populations often have lower death and hospitalisation rates, as well as lower rates of disability and lifestyle-related risk factors. To some extent, this can be explained by the fact that most migrants are partly selected on the basis of their health and, in some cases, their relatively high socioeconomic status.”

Zhou (2015) recently probed whether disability status of immigrants could be understood in the same way as that on the healthy migrant effect. Zhou revealed that Australians born overseas have the same level of disability and a greater level of profound and severe disability. In particular, immigrants who mainly speak a language other than English at home have relatively higher levels of need for assistance than English speaking groups.

However, Zhou’s study as a snapshot does not explore the issue of changes in disability status over time. Just like the health status of individual immigrants, disability is not static and will change over time through manifestation, acquiring, improving or deteriorating (Mutchler, Prakash, and Burr, 2007). These changes are embedded in an acculturation process which all immigrants experience to various degrees. In this process individuals or groups transition from living one lifestyle to the lifestyle of another culture, exposing them to a new physical and social environment, requiring them, at least to some extent, to adapt to new behaviours, values, customs, and language. Consequently, the trajectories of their disability status may be altered. The time factor also includes a natural process of aging that tends to result in a greater rate of disability.

Another factor associated with disability of immigrants is the selection processes by which people who voluntarily or involuntarily move to another country, and are filtered through immigration regulations of the host country. People settle in a different country for a variety of reasons, including family reunion, economic and political considerations, security necessity, lifestyle persuasion and access to government services. While both ‘self’ selection and ‘policy’ selection exist, it is debatable whether health status plays any significant role in the decision-making process (Findley, 1988; Kaestner and Malamud, 2014).

Relating to these self-selection processes is the factor of country of origin. It emphasizes the importance of disability profile of countries of origins of immigrants. Countries at different stages of development tend to have different levels of disability prevalence (World Health Organization and The World Bank, 2011). Countries that have suffered from major natural disasters or wars may have an increased prevalence of disability. Subsequently immigrants from these countries may have disability profiles that are different from their host country.

While the disability profiles of immigrants differ from their local population and this is a result of many intertwining factors, it is the impact of this time factor that this study attempts to explore. Each year, a certain number of immigrants arrive in Australia under a

variety of programs. What happens to these people over a five-year period in terms of their disability?

Data and Method

This study uses the disability definition adopted by the Australia Bureau of Statistics (Australia Bureau of Statistics, 2006) in the five yearly Census of Population and Housing (the Census hereafter) and sources the data from the two most recent censuses, 2006 and 2011.

Being a complex and difficult concept to define and measure, disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO, 2001). Interpretation of disability varies from person to person and is also likely to vary across time for individuals. On a personal level, individuals may be reluctant or unable to identify themselves as having particular types of disabilities. In a data collection setting, responses to a disability question may be sensitive to the survey context – for instance, asking questions about other topics before asking questions on disability may encourage or discourage a particular type of response. It is especially difficult to capture the full complexity of the experience of living with a disability and accurately assess the full range of disability severity with a limited number of questions (ABS, 2007a).

Recognising this complexity, and aiming to overcome the difficulties, the ABS developed a two-dimensional measure for disability data collection. The first dimension, reflecting the International Classification of Functioning Disability and Health (ICF) activities and participation domains, says that a person has a disability if the person has a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts a range of daily activities (Australia Bureau of Statistics, 2013). These daily activities are further divided into core activities, namely: self-care, mobility and communication, and non-core activities. The second dimension addresses how frequently – always or sometimes – a person needs assistance in these daily activities. People who have limitations in one of three core activities and always or sometimes require assistance in these areas are classified as having a profound or severe disability.

The 2006 Census, for the first time, implemented the two-dimensional measure through a short disability module. It asked each person four disability-related questions: Whether the person ever (always or sometimes) needs someone to help with, or be with for (1) self-care; (2) body movement and (3) communication activities (Questions 20–22), and whether the reasons for the need for assistance in these questions are (1) short-term health condition; (2) long-term health condition; (3) disability; (4) old or young age; (5) difficulty with English language and (6) other cause (Question 23) (Australia Bureau of Statistics, 2005). The ABS however was only able to release an aggregated variable of “having need for assistance” that is derived from these four questions. This variable categorises people as

needing assistance if they reported always or sometimes needing help in at least one of the three core areas of self-care, mobility or communication because of a disability, long-term health problem (lasting 6 months or more) or old age. Therefore, responses are coded to the category “does not have need for assistance with core activities”, when the response to Question 23 is only “difficulty with English language” (ABS, 2006). Needing assistance with one or more of these activities is interpreted as an indication that someone has significant difficulties with basic human functions. These questions were repeated in the 2011 Census. These questions identify a population that is conceptually comparable to those with severe or profound core activity limitation which is targeted by specialist disability services in Australia (CSTDA, 2003; Evidence Base Development Unit, 2010, COAG, 2009), although it has been widely recognised that the disability population identified through the Census could not be directly interpreted as the prevalence rate of disability. To avoid using a long description such as, “people who have core activity need for assistance” and for ease of reading, this study simply uses terms the “disability” and “disability rate” to refer to this population.

This study primarily relies on disability statistics from census data (2006 and 2011) because of its size and comprehensive coverage which enables the examination of small populations by demographic, geographic or economic characteristics.²

The statistics presented in this study are not only sourced from the ABS standard publications but are also derived from special runs from the ABS TableBuilder. The TableBuilder allows researchers to access and manipulate census information in an unprecedented way (ABS, 2014). However, statistics sourced from these products may often be slightly different from other ABS publications, primarily due to how TableBuilder deals with the small counts.

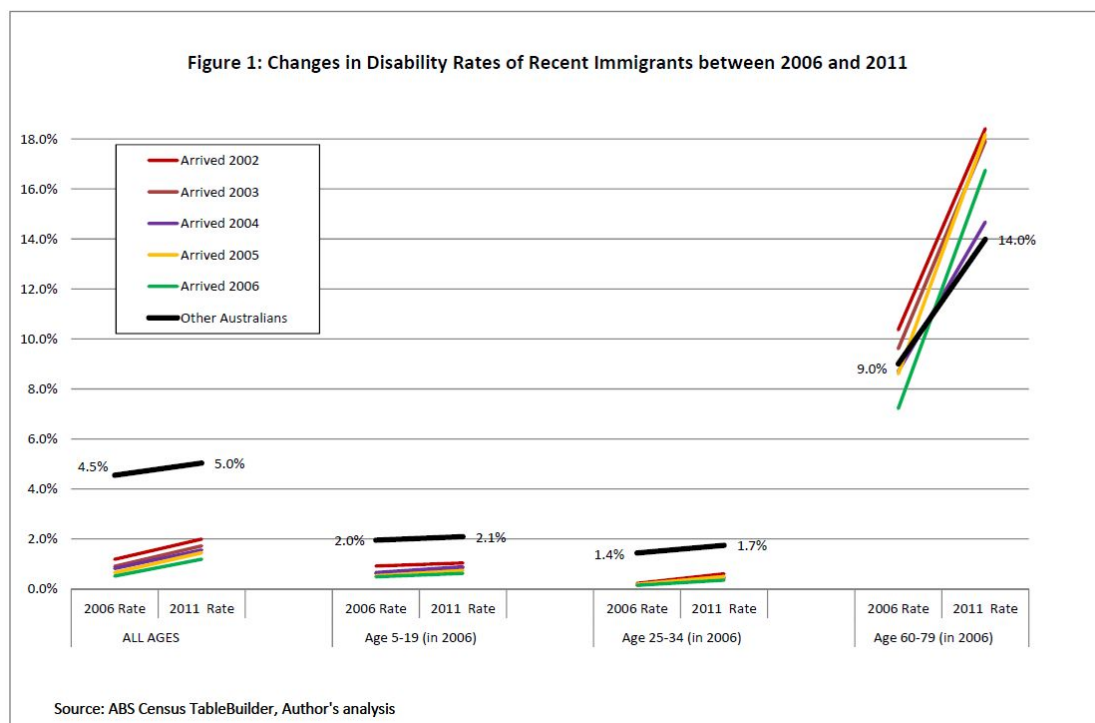
The study identifies three distinctive subpopulations of immigrants from the censuses. The first is the most recent arrivals who came to Australia during 2002-2006. The second is the Chinese students who had arrived in Australia between 1989 and 1991. The third are those Vietnamese who sought refuge in Australia between 1977 and 1986. When they came to Australia, these people had different disability profiles. The 2006 census collected information about their disability status at the time when they had lived within local communities for different durations. Their disability status is reported again five years later in the 2011 Census, using the exact same survey instrument. Changes in these subgroups over this five-year period are examined in turn within the context of when and from where they came.

Analysis Results

Recent Arrivals - Case One

The first group are those who were born overseas and settled in Australia in the five years (2002 to 2006) prior to the 2006 Census. This group was more than half a million from all over the world (ABS, 2007b). This section examines the disability rates for these people in 2006 and compares them with their disability rates reported in 2011 Census.

Figure 1 plots the changes in disability rates for immigrants who arrived in Australia in each of these five years. In addition to the all-age combined column, Figure 1 shows three other typically reported age cohorts: 5-19 years, 25-34 and 60-79 in 2006. Each colour represents a specific year of arrival and each line depicts the disability rates in 2006 and 2011 for approximately the same cohort. Meanwhile, for comparison purposes, the disability rates of other Australians who are not recent arrivals are presented by dark black lines.



Alternative text description – The image above depicts a line graph titled Figure 1: Changes in Disability Rates of Recent Immigrants between 2006 and 2011 and provides source ABS Census TableBuilder, Author’s analysis. The y-axis ranges from 0.0% to 14.0% and the x-axis provides 4 categories: all ages, age 5-16 (in 2006), age 25-34 (in 2006) and age 60-79 (in 2006). Each category provides line measurements between 2006 Rate and 2011 rate and each year is indicated by a color, pink represents arrived 2002, light purple represents arrived 2003, dark purple represents arrived 2004, yellow represents arrived 2005, green represents arrived 2006, black represents other. In addition, numbered measurements are provided on the graph in the all ages category measures 2006 at 4.5% and 2011 at 5.0%, age 5-19 category measures 2006 at 2.0% and 2011 at 2.1%, age 25-34 category measures 2006 at 1.4% and 2011 at 1.7%, and age 60-79 category measures 2006 at 9.0% and 2011 at 14.0%.

Figure 1 shows that while the new arrivals as a whole clearly have fewer disabilities than their local counterparts, they are not all without disabilities. Relatively higher proportions of older new arrivals have a disability than younger people, resulting in an age-related disability distribution. The later arrivals have a lower rate of disability than those coming a few years earlier, indicating that some immigrants had an acquired disability, or their disability conditions had manifested in just a few years after arriving in Australia. For

example, immigrants just arrived in 2006 as a whole reported the lowest rates of disability for all age cohorts, represented by the light green lines while those arrived in 2002 have much higher rates by 2006.

Furthermore, every cohort experienced an elevated rate of disability between 2006 and 2011, as indicated by the fact that the slopes of all lines go up. In other words, regardless of age at arrival and disability rate at arrival, more people acquired disability over the five years to 2011. However, older age cohorts acquire more disability at a much faster rate than younger ones, as shown by the varied degrees of the slopes for those aged 60-79. For instance, the upward trend of the lines for the youngest cohort (5-19 years in 2006) are minimal, meaning a very small increase over the five years as opposed to the older cohort of 60-79 year-olds for whom rates increase considerably regardless of arrival year. The sharpest rise is in the rates of those immigrants who arrived in 2006 when 60-79 years, from 7.2% to 16.8% over the five year reporting period.

Last, while recent arrivals overall have a lower rate of disability than other Australians, it may not be as clear-cut for older age cohorts. For example for those immigrants who were 60 to 79 years in 2006, only those who arrived in 2006, 2005 and 2004 have disability rates that are lower than that of other Australians. Nonetheless it is clear that older immigrants acquire disability at a much faster rate than both younger immigrants and other older Australians.

Chinese Students - Case Two

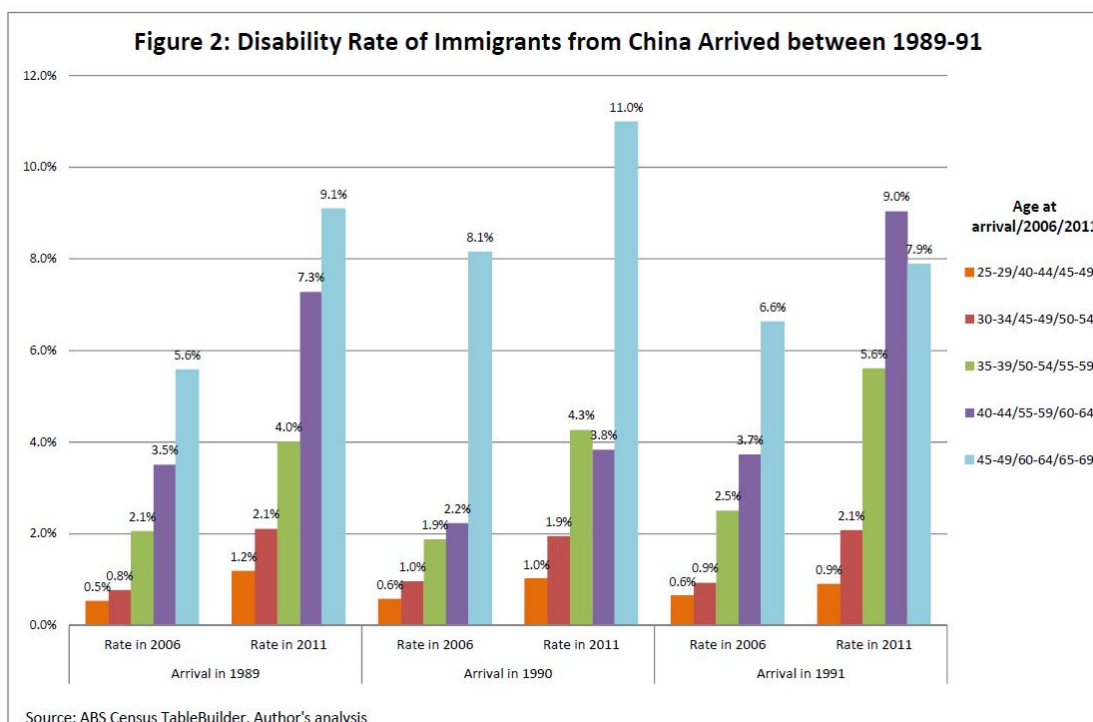
It is well documented that there were a number of “rushes” of Chinese immigrants to Australia with the most recent one occurring between 1989 and 1991 (Museum Victoria Australia, 2014). In Australia this group of Chinese immigrants is widely known as the Chinese students because the majority were student visa holders.³ According to ABS censuses, between 1986 and 1991 the China-born population in Australia more than doubled. Unlike earlier Chinese settlers these immigrants arrived in the late 1980s predominantly from families who could afford to pay college fees which were a substantial amount for a Chinese family at the time (Jupp, 2001).

After about twenty years living in Australia, they still report as a distinctive and stable population in the 2006 and 2011 censuses as seen in table 1 that compares the year of arrival of these Chinese students and their age ranges. For easy reading their age ranges are derived and presented both as in 1991 (showing they were mostly between 20 and 45 at the time of arrival) and at census times. The fact that the great majority of these people entered Australia under the student visa category means they had a healthy profile. Few, if any would have had a disability. These characteristics make it a good data set for this study to evaluate the relationship between duration of stay and disability.

Table 1: Immigrant age and year of arrival for those born in Mainland China

Arrival year	Age in 1991							All ages	% of aged 25-29 in 1991
	15-19	20-24	25-29	30-34	35-39	40-44	45-49		
	Age in 2006								
	30-34	35-39	40-44	45-49	50-54	55-59	60-64		
Arrival year	Age in 2011							All ages	% of aged 25-29 in 1991
	35-39	40-44	45-49	50-54	55-59	60-64	65-69		
<i>Census 2006 count of people</i>									
1987	85	307	1,144	1,104	773	462	231	4,860	62%
1988	100	744	2,001	1,659	1,206	714	308	7,621	64%
1989	133	1,165	4,067	3,405	2,117	721	274	12,857	75%
1990	128	1,039	3,018	2,324	1,186	316	174	9,202	71%
1991	268	381	1,110	1,309	1,052	543	168	7,614	46%
1992	352	410	773	679	498	358	214	5,261	37%
1993	119	309	528	383	252	137	86	2,938	40%
<i>Census 2011 count of people</i>									
1987	97	305	1,184	1,096	753	447	251	4,764	64%
1988	105	793	1,959	1,702	1,197	702	299	7,540	64%
1989	136	1,193	4,208	3,425	2,108	702	301	12,960	75%
1990	137	1,077	3,085	2,395	1,261	341	185	9,474	71%
1991	275	410	1,138	1,316	1,084	528	165	7,344	48%
1992	372	445	791	679	486	363	195	5,155	38%
1993	129	324	569	380	258	133	87	2,970	41%

Source: ABS Census TableBuilder, Author's analysis.



Alternative text description – The image above depicts a bar graph titled Figure 2: Disability Rate and Immigrants from China Arrived between 1989-91 and provides source ABS Census Tablebuilder, Author’s analysis. The y-axis ranges from 0.0% to 12.0% and the x-axis provides 3 categories: Arrival in 1989, Arrival in 1990, and Arrival in 1991. Each category provides 5 different measurements in 2006 and 2011 and the 5 different measurements are indicated by different colors, orange measures 25-29/40-44/45-49, red measures 30-34/45-49/50/54, green measures 35-39/50-54/55-59, purple measures

40-44/55-59/60-64, and blue measures 45-49/60-64/65/69.

Figure 2 plots the disability rates in 2006 and 2011 of the Chinese students who arrived at Australia for each of the three years between 1989 and 1991. Each colour represents a specific age cohort measured at the year of arrival. The cohorts are organised according to the age ranges which are presented as the time of arrival,⁴ Census 2006 and Census 2011 for easy reading.

Three observations can be drawn from Figure 2. The first is the different rate of disability among varied age cohorts in 2006 by which time the students would have lived in Australia for about 15 years. At the beginning of the 15 years, all cohorts were young and healthy students assumed to be without a disability. Some fifteen years later, older age cohorts have a much greater disability rate than younger age cohorts. For example, for those who arrived in 1989, only 0.5% of those aged 23-27 had acquired a disability by 2006, however 0.8% of the 28-32 had acquired it, and as high as 5.6% of these 20 years older had acquired it. In other words, if the assumption holds that few of these people had a disability when visas were granted, then age is clearly an accelerating factor in disability rates.

The second observation is that every age cohort experienced a deterioration of disability status within the 5 years without any exception. For example, as indicated by the orange bars, 0.5% of those who arrived in 1989 when aged 23-27 reported a disability in the 2006 Census. Five years later, in 2011, 1.2% reported having a disability. Similar increases are reported for those who arrived in the next two years. All other age cohorts show a similar upward direction of disability.

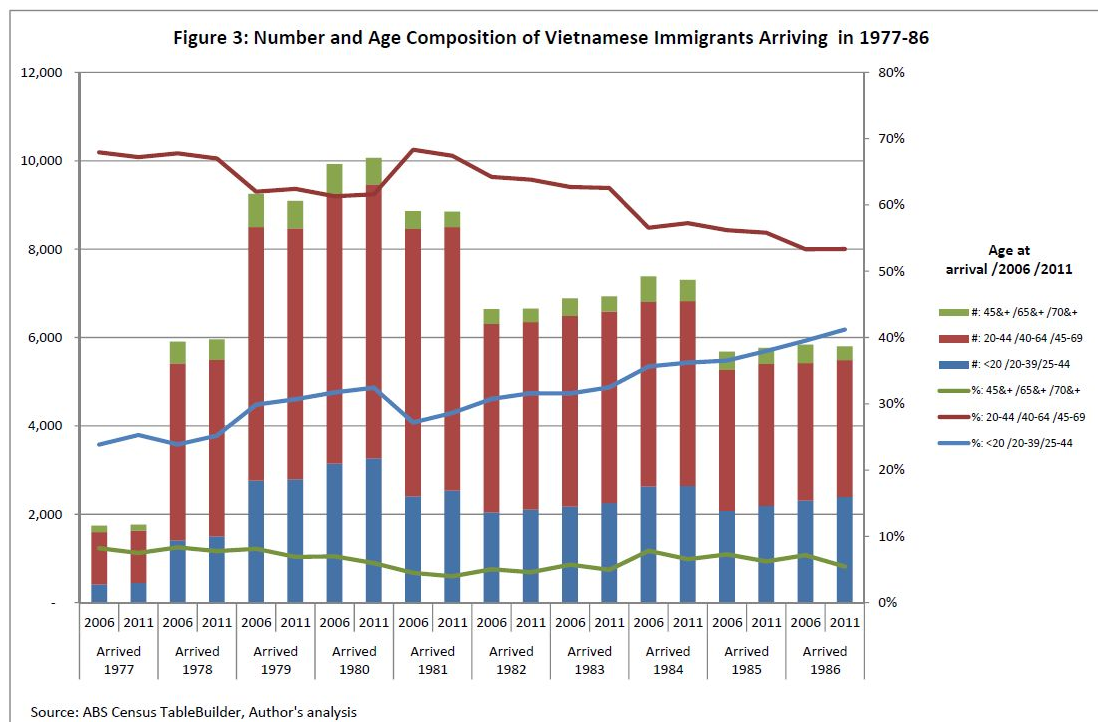
Thirdly, and perhaps most surprisingly, disability rates for those who were aged 45-49 at arrival (60-64 in 2006) reached 5.6%, 8.1% and 6.6% which is on par with the rest of Australians in that age range. Five years later in 2011, these rates become as high as 9.1%, 11.0% and 7.9%, which are around the overall rate of disability for all Australians in that age range (10.9%). In other words, living in Australia for 15-20 years has made the Chinese students the same as other Australians in terms of their disability profile.

Vietnamese Refugees - Case Three

The term 'boat people' entered the Australian vocabulary in the late 1970s with the arrival of the first wave of boats carrying Vietnamese people seeking asylum. Over half the population in Vietnam at the time was displaced in these years and, while most fled to neighbouring Asian countries, some embarked on the voyage by boat to Australia. Between 1976 and 1981 more than two thousand Vietnamese boats arrived at Australia (Phillips and Spinks, 2013) and a larger number of Vietnamese refugees came to Australia via air. The 1976 Census, in which the Vietnamese were recorded separately for the first time as a country of origin, reports less than 2,400 people born in Vietnamese in Australia. In the 1981 Census, the Vietnamese born population had bloomed to 41,000. By 1986 the number doubled to 83,000.

This research identifies those Vietnamese immigrants who arrived in Australia during

the period 1977 to 1986 as the third case group. Between 1975 and 1986, almost all of the Vietnamese arrivals were refugees, making this cohort of immigrants distinctive from later Vietnamese immigrants.⁵ According to an ABS analysis based on the 1986 Census, the Vietnamese immigrants were different from many other immigrant communities in their higher proportion of younger people, poorer ability to speak English, many not living as a family member but as a boarder in a family, lower levels of school education and employment (ABS, 1991). These characteristics indicate that Vietnamese refugees in Australia were a distinctive, disadvantaged socioeconomic community in the mid-1980s.



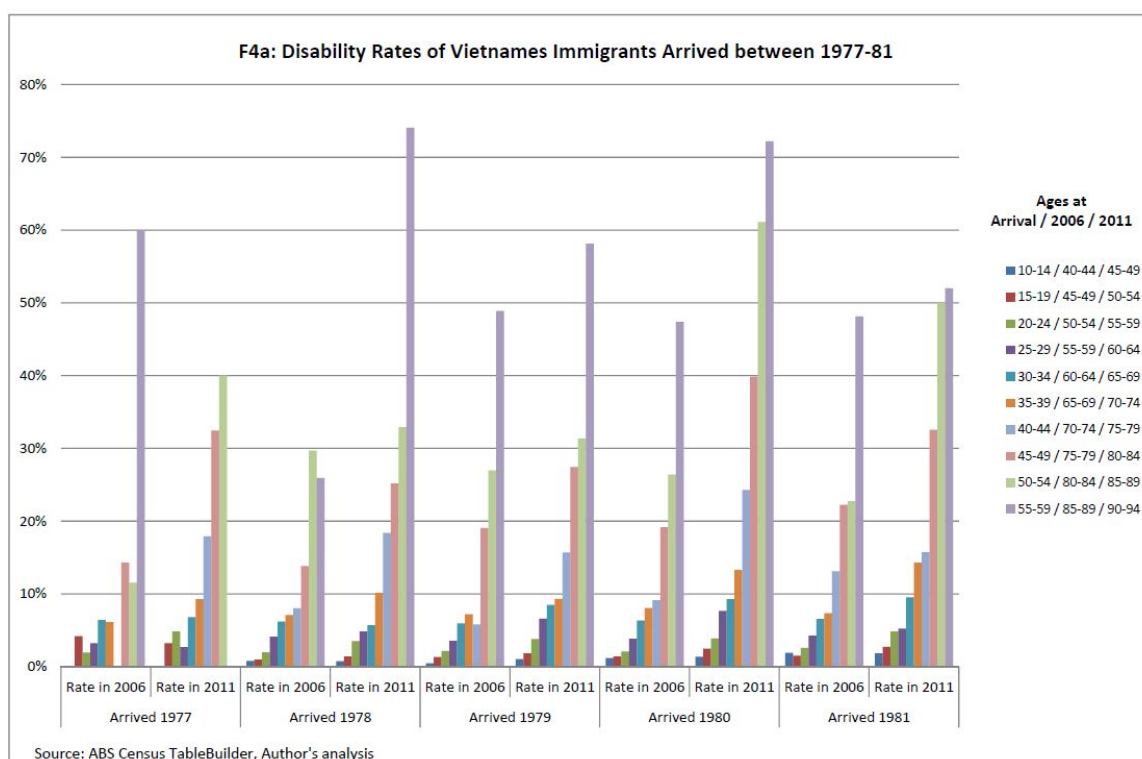
Alternative text description – The image above depicts a bar & line graph titled *Figure 3: Number and Age Composition of Vietnamese Immigrants Arriving in 1977-89* and provides source ABS Census TableBuilder, Author's analysis. The y-axis ranges from 2,000 to 12,000 and 0% to 80%. The x-axis provides 10 categories: *Arrived 1977, Arrived 1978, Arrived 1979, Arrived 1980, Arrived 1981, Arrived 1982, Arrived 1983, Arrived 1984, Arrived 1985, and Arrived 1986*. Each category provides 2 different bar measurements in 2006 and 2011 and in each bar there are multiple measurements *Age at arrival/2006/2011* with green measures 45&+/65&+/70&+, red measures 20-44/40-64/45-69 and blue measures <20/20-39/25-44. In addition, there are line graphs which intersects with the bar graphs *Age at arrival/2006/2011* with green measures 45&+/65&+/70&+, red measures 20-44/40-64/45-69 and blue measures <20/20-39/25-44.

Figure 3 shows the sudden increase and count of Vietnamese immigrants in these five years by year of arrival as reported in the two Censuses. It also shows that the age composition of the arrivals from Vietnam had shifted to having a higher proportion of young refugees in the second half of the ten year period. During the earlier years, about a quarter of

the Vietnamese refugees were under 20 years old but in the final years they were about 40%. This shift would have implications for the disability of Vietnamese immigrants as a whole some 20 to 30 years later.

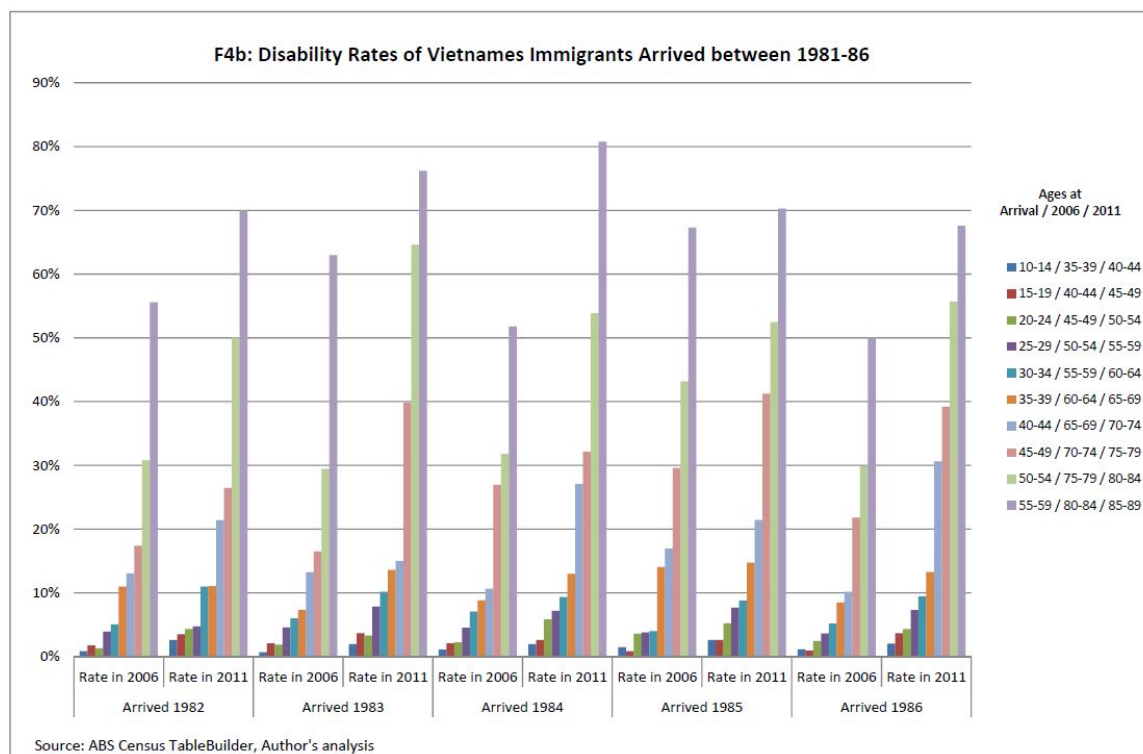
While it is clear that few Chinese students came to Australia with a disability; it is not necessarily the case for Vietnamese refugees at the time of arrival. Their specific characteristics means the understanding of changing status of disability over 2006 and 2011 will provide an interesting case study, in comparison to the previous two cases.

By the year 2006 when the Census, for the first time, started to collect information on disability, the refugees arriving in the 10 years to 2006 had lived in Australia 20-30 years. Figures 4a and 4b plot the disability rates reported in censuses 2006 and 2011 of Vietnamese refugees who arrived at Australia annually between 1977 and 1986 in the same manner as the earlier analysis of the Chinese immigrants. However, for presentation purposes we break the ten-year period into two sub-periods of five-years each (Figures 4a & 4b). While this is primarily because of presentation need the break point in 1981/82 is also consistent with a shift in the nature of these immigrants.⁶ These figures exclude the rates for age cohorts of the very young and very old, as these are based on small counts that have also been randomly adjusted by ABS for privacy reasons.



Alternative text description – The image above depicts a bar graph titled *F4a: Disability Rates of Vietnamese Immigrants Arrived between 1977-81* and provides source ABS Census TableBuilder, Author’s analysis. The y-axis ranges from 0% to 80% and the x-axis provides 5 categories: *Arrived 1977*, *Arrived 1978*, *Arrived 1979*, *Arrived 1980*, and *Arrived 1981*. Each category provides 2 different bar measurements in 2006 and 2011 and in each bar there are

multiple measurements *Age at arrival/2006/2011* with dark blue measures 10-14/40-44/45-49, red measures 15-19/45-49/50-54, dark green measures 20-24/50-54/55-59, dark purple measures 25-29/55-59/60-64, teal measures 30-34/60-64/65-69, orange measures 35-39/65-69/70-74, light purple measures 40-44/70-74/75-79, pink measures 45-49/75-79/80-84, light green measures 50-54/80-84/85-89 and light purple measures 55-59/85-89/90-94.

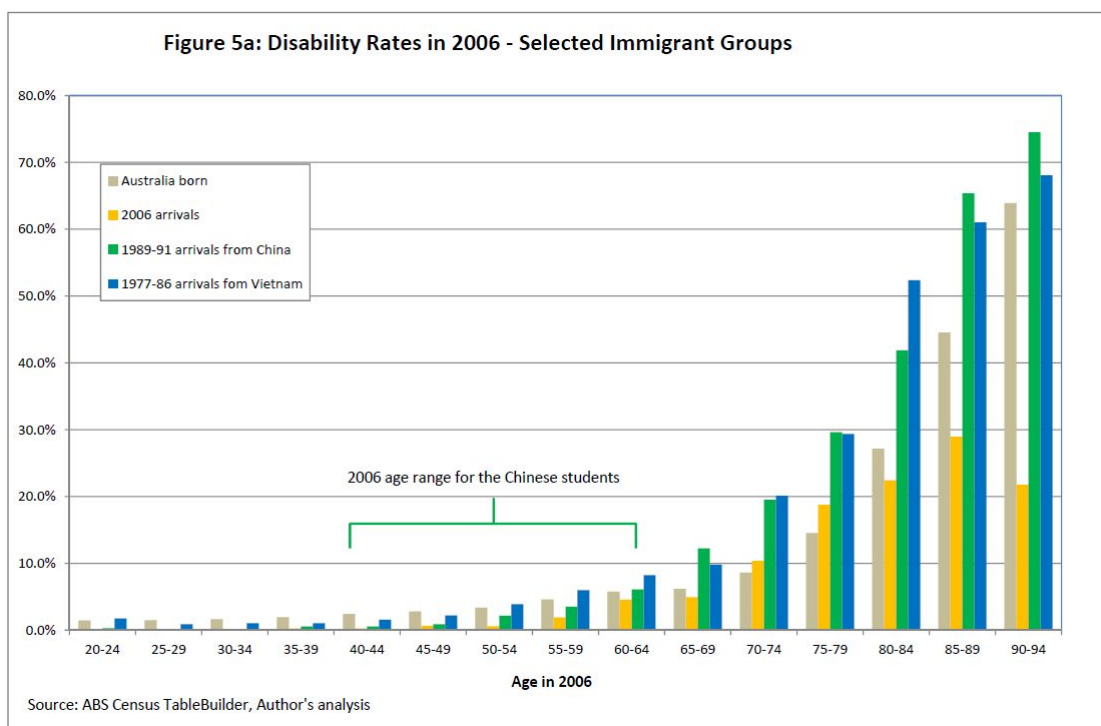


Alternative text description – The image above depicts a bar graph titled *F4b: Disability Rates of Vietnamese Immigrants Arrived between 1981-86* and provides source ABS Census TableBuilder, Author’s analysis. The y-axis ranges from 0% to 90% and the x-axis provides 5 categories: *Arrived 1982, Arrived 1983, Arrived 1984, Arrived 1985, and Arrived 1986*. Each category provides 2 different bar measurements in 2006 and 2011 and in each bar there are multiple measurements *Age at arrival/2006/2011* with dark blue measures 10-14/35-39/40-44, red measures 15-19/40-44/45-49, dark green measures 20-24/45-49/50-54, dark purple measures 25-29/50-54/55-59, teal measures 30-34/55-59/60-64, orange measures 35-39/60-64/65-69, light purple measures 40-44/65-69/70-74, pink measures 45-49/70-74/75-79, light green measures 50-54/75-79/80-84 and light purple measures 55-59/80-84/85-89.

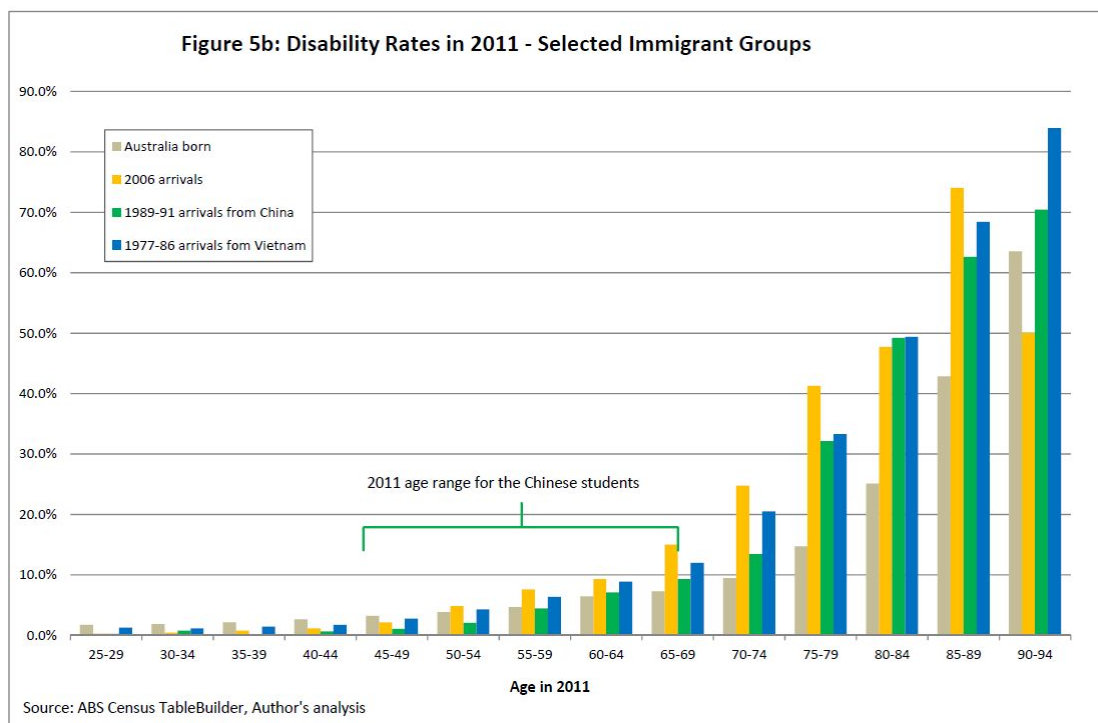
Figures 4a and 4b not only confirm two general patterns that were identified in the earlier Chinese case analysis but also reveal some unexpected trends. First of all, by 2006 when these refugees had lived in Australia for some 20-30 years, the disability rates for people of different ages settled into a pattern that is similar to those of the general population. Older Vietnamese refugees tend to have a higher rate of disability than younger refugees. Take, as an example, the refugees who arrived in 1980 (the year with the largest number of

arrivals); the disability rates increase progressively with the increase in age by 2006.

Second, between 2006 and 2011, almost every age cohort experienced a deterioration of disability rates. On average, 4.1% of all Vietnamese immigrants reported a disability in 2006. Five years later this rate increased to 5.9%. As the age spread of Vietnamese refugees is much wider than the Chinese students, the deterioration could be observed in both the younger and older age groups. At the youngest end, there are those as young as 10 years on arrival and about 40 years old in the census times; on the oldest end, there are those who were aged in their late 50s on arrival and in about their 90s at the census times. Of the 90 pairs of bars which compare the rates between 2011 and 2006 and are presented in Figure 5a and Figure 5b, 83 pairs show an increased rate.



Alternative text description – The image above depicts a bar graph titled *5a: Disability Rates in 2006 – Selected Immigrant Groups* and provides source ABS Census TableBuilder, Author’s analysis. The y-axis ranges from 0% to 80% and the x-axis titled *Age in 2006*: with ages 20-94 with 4 different categories *Australia born*, *2006 arrivals*, *1989-91 arrivals from China* and *1977-86 arrivals from Vietnam*.



Alternative text description – The image above depicts a bar graph titled *5b: Disability Rates in 2011 – Selected Immigrant Groups* and provides source ABS Census TableBuilder, Author’s analysis. The y-axis ranges from 0% to 80% and the x-axis titled *Age in 2011*: with ages 20-94 with 4 different categories *Australia born*, *2006 arrivals*, *1989-91 arrivals from China* and *1977-86 arrivals from Vietnam*.

Moreover, and not surprisingly, older age cohorts have much greater increases in disability rates than younger age cohorts over these five years. For example, more than 80% of those in the oldest group who arrived in Australia in 1984 reported having disability in the 2011 Census, compared to 52% five years previously in 2006.

Careful readers might observe missing bars in Figures 4a and 4b. These are missing due to either there being no count of particular age groups. Another unexpected finding is in the disability 2006 profile for the first year arrivals (1977) that is strikingly different from those of other later years in that the correlation between age and disability rate is not as smooth. Upon further investigation of the data it was apparent that this untypical distribution was primarily due to the small cell count. As Figure 4a shows, the number of Vietnamese refugees in the first year (1977) is relatively small (less than 2,000 are reported in the 2006 Census). When this small number is further broken down by age and disability status, the numbers become too small to be statistically reliable. In addition, random adjustments performed by the ABS to protect privacy might have further distorted the underlying distribution that may be expected, as for the arrivals in other years.

Discussion

This paper examined the disability rates of three distinct immigrant groups over varied residence periods. The first group included those born overseas, old and young, who came to

Australia up to five years prior to the 2006 Census. They came from all over the world for a variety of reasons. The short time between their arrival and the 2006 census means their reported disability status is treated as a proxy of the status at the time of entry. By the time of the 2011 Census, they had lived in Australia for at least five years. The second group, Chinese students, came to Australia in the late 1980s. They were predominantly student visa holders and few, if any, would have had a disability at the time of entry. By the 2006 Census, most of these people had been settled in Australia for more than 15 years. The final group, Vietnamese refugees, arrived in Australia in the late 1970s and first half of the 1980s. They were different from the first group in being from a single country of origin and being refugees. The Vietnamese were more diverse than the Chinese students in their age range, health and socioeconomic status and had lived in Australia for up to 30 years by the time of the 2006 census.

Analyses of these different immigrant groups suggests that age is one of the most important factors influencing the trajectories of disability status over the period 2006-2011. It has long been established that disability rate increases steadily with age (ABS, 2013). Disability prevalence tends to be much higher for older people regardless of the wealth of the country they live in (World Health Organization and the World Bank, 2011: Table 1 and Table 2). The data presented here make it evident that this is true for immigrant communities as well.

Recent immigrants to Australia present with considerably lower rate of disability than local communities of the same age who were Australia born or arrived earlier than them. To begin with, there exists considerable variation amongst these new arrivals in their level of disability. The older recent arrivals have higher rates of disability than the younger ones. One possible reason for this is that these older immigrants with a disability came to Australia primarily for family reunion. Even when Australian immigration regulation makes it unlikely that they came to Australia with a disability, which is reflected by a lower disability rate at the time of arrival (Figure 5a), they might have acquired a disability shortly after they landed in Australia. In a time-span of just five years, the rates of disability of young immigrants are in line with local people of the same age cohorts. For older cohorts (60 and over), the rates of change are much faster than that experienced by locals. After just five years, most of the older age cohorts of immigrants reported higher rates of disability than the local population (Figure 5b).

The Chinese student group presented similar trends over 15 to 20 years; although very few of them would have had any disability upon arrival. Some 15 years later, the rates of disability by age show a difference in age-related distribution that is similar to the local populations. More remarkable is the number of Chinese students in the older cohorts who had acquired a disability in the five years between 2006 and 2011; a much faster increase than that reported by the local born population in 2011 (Figure 5b). Interestingly, of those senior Chinese when arrived in the late 1980s their disability rates had reached the same level as the local population before 2006.

For Vietnamese refugees, disability rates surpassed those of the local population for all cohorts over 50 years old by the year 2006 by which time they had lived in the Australia for about three decades (Figure 5a). Five years later in 2011, the gaps had become even greater.

An intriguing question about the disability trajectory of immigrants in their host country is the amount of change since the time of entry. The present study had limited success in exploring this specific change as there are no comparable disability statistics at the time of entry. When examining the case of recent arrivals, we are able to take the 2006 statistics as a proxy of the disability profiles of these new arrivals because they have not lived in Australia long. In the case of Chinese students, it is assumed that few of these students had a disability at the time of entry. The study makes no assumption about the disability status of the Vietnamese boat people at the time of entering Australia. Instead it focuses the on changing status between 2006 and 2011.

This study makes no effort to untangle acculturation processes in which the changes in disability status of immigrants occur. Immigrant communities, by definition, originated from different cultures, and individuals within these communities may interact with the local communities differently. At the same time they also influence and contribute to the hosting cultures as well. In an Australian context, immigrants have become the mainstream as more than a quarter of Australians were born overseas and more than half have at least one parent who was born overseas. Acknowledging the process of acculturation and its impacts on the disability, this study focuses on the latter on these first generation immigrants.

Clearly older immigrants tend to acquire disability faster than their local counterparts. However, it is not clear why this trend exists and what factors contribute to this trend. New research is required to answer these questions in order to develop effective social policy responses. Any new research must be multidisciplinary in nature in order to adequately explore the complex relationship between disability, aging and cultural diversity. Only through a multidisciplinary approach will researchers be able to assist policy makers to identify ways to change the disability trajectory of people from CALD backgrounds, to slow down the rate of disability manifestation and acquisition, and to develop culturally appropriate services to an increasing number of people with disabilities from CALD backgrounds in both disability and aged care service settings.

Conclusion

Of the current Australian population, about a quarter are first generation immigrants. While immigrants might as a whole have a rate of disability that is lower than their hosting population at the time of their arrivals, they are not a homogenous group. Few of these immigrants had a disability when arriving, some others acquired disability or their disability conditions manifested after their arrival. As demonstrated in this paper, age is the most important factor influencing the trajectories of disability status of immigrants, just like their local counterparts. Not surprisingly older immigrants tend to have a higher rate of disability than younger cohorts upon arrival. Furthermore, the older the immigrants are the faster they acquire disability. In about a generation, immigrants tend to have an aged related disability

profile that is similar to the rest of the community. It is important to not underestimate this rate of the change when developing government policy and program design for specialist disability and aged care services.

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Endnote

¹ There are many ways to classify and count immigrants. This study adopts a simple and practical definition that an immigrant is a person who is born in a different country and comes to live for a considerable period of time in Australia, as self-reported in the Census of Population and Housing (ABS, 2006).

² The ABS (2015) generally recommends the uses of standard error (SE) and relative standard error (RSE) to indicate statistical reliability of any estimates based on the SDAC. Such indicators however are not necessary when the Census data are used as they cover the whole population and are therefore not subject to sampling error.

³ In the late 1980s, there was an increase in the number of people from China enrolling in post graduate studies in Australia universities. Meanwhile Australia came touting for Chinese students, offering visas and the chance to study English in private colleges for a fee. Consequently a large number of young Chinese rushed to Australia, not merely for the chance to study, but also the possibility of a new life. In 1989, the Australian government granted permanent visas to most Chinese students in the aftermath of the Tiananmen Square incident (Sydney Morning Herald, 2003 Dec 26). Several months later, a large number of Chinese citizens who had received a student visa prior to the Tiananmen incident also landed on Australia soil. Most of these people permanently settled in Australia.

⁴ For simplicity, arrival ages are based on 1991.

⁵ This decreased to around 45 per cent between 1986 and 1991 and only 22 per cent between 1991 and 1993 (NSW Department of Education, 2015).

⁶ In 1979, the Vietnamese government agreed to forcibly constrain unregulated departures, but to allow an Orderly Departure Program (ODP) in which Vietnamese were permitted to apply to migrate to specific countries. In 1982 the first Vietnamese immigrants under the ODP arrived in Australia. From the late 1980s this program was officially applied in Australia as the 'Vietnamese Family Migration Program' (VFMP). Under this program Vietnamese people with relatives in Australia were permitted to emigrate directly from Vietnam to Australia, subject to satisfying Australia's standard refugee requirements.

Research Article

Neighborhood Effects on Social Participation of Children With and Without Disabilities

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Abstract: Few studies have examined how neighborhood characteristics affect the social participation of children with and without disabilities. Analysis of survey data from 20 low-income U.S. neighborhoods confirmed that neighborhood safety and stability influence social participation. Furthermore, children with disabilities have lower odds of social participation, though disparities vary by location.

Keywords: disability studies, health, developmental studies

Disabled activists and disability studies scholars have long argued that disability is not an inherent trait within individuals, but, rather, is an experience that results from interaction between individuals and their environment. Thus various aspects of the environment, including built features, sociocultural norms, political context, and economic resources, can hinder or foster disabled individuals' participation in society (Field & Jette, 2007). Consequently, it is important to understand how different environments, such as residential, work, and community, affect the participation of people with disabilities. The current paper addresses this topic with a specific focus on neighborhood environments where families reside, and their influence on participation of children with and without disabilities.

There is growing interest in the effects of residence in poor urban neighborhoods on a variety of health and wellbeing outcomes (Browning & Cagney, 2002; Bernard et al., 2007; Mujahid & Diez Roux, 2010). Neighborhood influence is especially important in the developmental ages; children are less mobile than adults, and therefore local neighborhoods serve as their primary social context (Moren-Cross et al., 2006). Childhood exposure to neighborhood risk factors such as poverty and protective factors such as social capital can have effects that extend into adulthood (Danese & McEwen, 2011). Developmental specialists recognize that risk and protective factors accumulate at local levels of geography to influence child and family outcomes (Leventhal & Brooks-Gunn, 2011). Together, these developments have spurred studies of neighborhood effects on an array of children's outcomes.

Although a vast body of evidence links neighborhood disadvantage with negative effects on children's health, behavioral, and academic outcomes, little is known about how neighborhood conditions affect children's social participation (Coulton & Irwin, 2009). Lesser still is known about neighborhood-based differences in social participation of children with and without disabilities. For example, Coulton and Irwin (2009) found that neighborhood safety and parent involvement had positive effects on children's participation in out-of-school

activities. However this study did not assess disability-based differences in participation.

Several studies have demonstrated that children with disabilities participate less frequently in social activities compared with their non-disabled peers (Michelsen et al., 2009; Galvin et al., 2010; King et al., 2010; Solish et al., 2010; Bedell et al., 2013). Few studies have examined the role of neighborhood contextual factors in relation to social participation of children with disabilities. In a study of 427 children with physical disabilities living in Ontario, Canada, King and colleagues (2006) found that children's social participation was indirectly influenced by parental perceptions of physical inaccessibility of their community, unsupportive community attitudes, and inadequate institutional services and assistance. Forsyth and colleagues (2007) used similar measures of contextual factors with a sample of 600 severely disabled children and their families living in the United Kingdom. They found that children's social participation was influenced to a similar extent by their impairments and environmental factors such as physical accessibility, social supports, and transportation services. Conversely, Hammal and colleagues (2004) found that children's district of residence more than their impairments explained the social participation of 476 children with cerebral palsy from Northern England.

These studies provide evidence of neighborhood effects on social participation of children with disabilities. However, comparable studies in the United States are lacking. Moreover, the literature is beset by limitations such as lack of comparative analysis between children with and without disabilities, lack of samples drawn from neighborhood-based designs, and lack of both census-based measures of structural disadvantage and subjective measures of neighborhood conditions (Leventhal & Brooks-Gunn, 2000).

The World Health Organization (WHO) considers participation a chief indicator of child health and development regardless of impairment or functional ability (WHO, 2007). Thus social participation outcomes allow comparisons of neighborhood effects between children with and without disabilities. With child and family services increasingly offered at the local level (Leventhal & Brooks-Gunn, 2000), evaluating neighborhood-based differences in outcomes for children with and without disabilities is critical for promoting human rights and equity and for planning effective interventions (Michelsen et al., 2009).

Our study represents an attempt to address gaps in this area. Using secondary survey data from a neighborhood-based sample, we compared children with and without disabilities on social participation rates and barriers. We examined whether social participation differences between children with and without disabilities varied by neighborhood of residence. We also assessed the effect of neighborhood factors and child's disability on social participation accounting for other child and household-level variations.

Method

Data Sources

Our main data source was the Making Connections Cross-Site Survey, sponsored by the Annie E. Casey Foundation (AECF) and conducted by the Urban Institute and the National Opinion Research Center (NORC) at the University of Chicago. This survey was conducted between 2002 and 2011 in select low-income neighborhoods in 10 cities, nine of which were among the 50 largest U.S. metropolitan areas (Coulton, Chan & Mikelbank, 2010).

In each participating city, AECF and its local partners selected designated areas (survey sites) in which a large proportion of the population was socially and economically disadvantaged (Coulton & Irwin, 2009). Survey sites included declining neighborhoods in older industrial cities (Louisville, Milwaukee, Indianapolis), poor neighborhoods with growing immigrant populations (Des Moines, Hartford, Providence), predominantly Hispanic communities experiencing persistent poverty (San Antonio), and growing, diverse neighborhoods facing housing pressures (Denver, Oakland, Seattle) (Coulton et al., 2010). Comparisons with census data suggest that the Making Connections sample approximates nationally representative urban samples on several indicators (Rawlings et al., 2007).

List-assisted probability sampling was used to obtain a representative sample of households and children in each survey site. We refer to Coulton et al. (2010) for sampling frame details. Within each site, an equal probability sample of households was selected (Coulton et al., 2010). A roster of all children and adults was compiled for each household. One child per household was randomly selected as the focus child using Kish's method, and the adult who knew the child best completed the survey (NORC, 2010).

The survey was conducted in-person or via telephone in English or another language prevalent in the survey site (Coulton et al., 2010). Data were collected over three waves with a weighted response rate ranging from 69% to 79%. 'New households' were added to baseline samples at subsequent waves. These included new families that had moved into originally sampled addresses plus a subsample of newly constructed residential buildings (NORC, 2010).

We created a data set comprising data from all households that completed the survey in wave 1 and stayed in the same survey site at wave 2, plus baseline data from 'new households' sampled at wave 2. This yielded a cross-sectional sample representative of children (N = 2,295) living in survey sites at waves 1 and 2 from 2002 to 2007. We obtained data on neighborhood indicators by census tracts from the 2005-2009 American Community Survey (ACS). These data were linked with the survey data based on locations of households.

Dependent Variable Measure

Social participation. Respondents were asked if, in the last year, their child participated in organized out-of-school activities such as sports, music, dance, language classes, and youth clubs. Responses were dichotomized to indicate some participation versus none. For children with some participation, respondents reported frequency of participation as daily, 2-3 times a week, weekly, or less than weekly. For children with no participation, respondents reported reasons for non-participation.

Independent Variable Measures

Child characteristics. Sociodemographic variables included gender, age, and race/ethnicity. Child's *race/ethnicity* was determined based on the adult respondent's race/ethnicity. Child's *health status* was based on the adult respondent's rating of the child's general health on a five-point scale ranging from excellent to poor. *Disability status*, a dichotomous variable, was determined by a question that asked whether a health professional had ever told the respondent that their child had a physical, learning, mental, or chronic health condition that limits his/her participation in age-expected activities. Respondents were asked to report their child's primary health condition. Child's *health insurance coverage* was a dichotomous variable measuring whether the child was covered under any health insurance.

Household characteristics. We included a continuous measure of *household size*. We also included measures of household economic resources and household-neighborhood connectedness. *Household income* was defined as total annual income from any sources. *Household hardship* was derived from four questions which asked if, in the previous 12 months, the respondent and their family had experienced: difficulty filling a prescription for drugs, difficulty paying mortgage/rent/utility bills, repossession of belongings due to non-payment of bills, or insufficient money to buy food. A response of 'yes' to any question was classified as 'some hardship'; a response of 'no' to all questions was classified as 'no hardship'. *Home ownership* was dichotomized based on whether any household member owned or held a mortgage on the property where he/she lived. Similarly *vehicle ownership* was dichotomized based on whether any household member owned a dependable vehicle. *Household education* level was based on the highest level of education attained by the respondent.

Households' connectedness with their neighborhood was measured using two variables. First we used a continuous measure of the total number of years each respondent had lived in that neighborhood. Second, a measure of household neighborhood commitment was generated using three questions that asked if, in the previous 12 months, any household member had taken steps to address neighborhood problems or for neighborhood improvement. Examples included getting together with neighbors, talking to a religious leader, or speaking with a local political official. A response of 'yes' to any question classified the household as 'committed'; a response of 'no' to all questions classified the household as 'not committed'.

Neighborhood characteristics. Our data set included 20 project-designated sub-areas (henceforth referred to as neighborhoods) across the 10 survey sites (1 to 4 neighborhoods per site). The mean number of households per neighborhood was 114 (range 19-244). Previous analysis of Making Connections data has shown moderate reliability for neighborhood scales aggregated at this geographic level (Coulton et al., 2004). Following Coulton and Irwin's (2009) methods, we used two types of neighborhood measures: perceptions and structural variables.

Neighborhood perception variables. Multi-item scales measured perceptions of four neighborhood attributes: social cohesion and trust, shared expectations for informal social control, neighborhood safety, and disorder and incivility. The *social cohesion* scale comprised five items (e.g. "I live in a close-knit neighborhood", "People in my neighborhood can be trusted") with five response options ranging from 'strongly disagree' to 'strongly agree'. The *informal social control* scale included five items (e.g. "If a fight broke out in front of their house, how likely is it that your neighbors would do something about it?") with five response options ranging from 'very unlikely' to 'very likely'. The *safety* scale contained six items (e.g. "I feel safe at home at night", "On Halloween, most children go trick-or-treating") with seven response options ranging from 'very strongly disagree' to 'very strongly agree'. The *disorder and incivility* scale comprised seven items about gang activity, prostitution, graffiti, and related activities with seven response options ranging from 'does not occur' to 'very common'.

All scales demonstrated acceptable reliability at the individual level (Cronbach's $\alpha > .70$). The composite score for each scale was the average rating across all items. Individual responses were aggregated to obtain a neighborhood level rating for each perceived attribute.

Neighborhood structural variables. We included six variables associated with structural disadvantage and social disorganization (Browning & Cagney, 2002; Coulton & Irwin, 2009). Structural variable measures included: *percent families below poverty level*, *percent population (20-64 years) unemployed*, *percent owner-occupied housing units*, *percent single parent households*, *percent households that moved in last five years*, and *racial/ethnic mix* (percent population that is Non-Hispanic White, African American, and Hispanic).

Data for these variables were extracted at the census tract level from the 2005-2009 ACS estimates for small areas. These five-year estimates, known to be reliable for small geographic areas (U.S. Census Bureau, 2008), offer the closest overlap with survey period, which spanned 10 years from 2002 to 2011. Census tract data were summed within neighborhoods and weighted by census tract population size to obtain neighborhood level structural variables. The mean number of census tracts per neighborhood was seven (range 1-26).

Data Analysis

Cross tabulations and χ^2 tests were used to assess differences in rates of social participation and barriers to social participation between children with and without disabilities. To assess the effect of child, household, and neighborhood factors on social participation we estimated multivariate logistic regression models using the SAS surveylogistic procedure and the Taylor series linearization method for variance estimation. Survey site was specified as the stratum variable and neighborhood was specified as the primary sampling unit. This procedure is recommended to account for complex survey design and survey weighting for binary outcomes. In addition, finite population correction factor was specified since the sample fractions in some neighborhoods exceeded 5% of the neighborhood population.

Three models were estimated – the first included child level covariates, the second included child and household level covariates, and the third model included covariates at child, household, and neighborhood levels. All child level factors were conceptually important and therefore were included in multivariate analyses. All household characteristics except household income (omitted due to low response rate) were included in multivariate analyses. The household hardship variable served as a proxy measure of household financial status. Neighborhood characteristics were selected using the purposeful selection strategy (Hosmer & Lemeshow, 2000). We conducted bivariate logistic regressions between each neighborhood characteristic and social participation and selected covariates based on the Wald test and *p*-value cut-off point of 0.3. We also tested for interactions between disability status and each child, household, and neighborhood level variable. Interaction terms were selected for multivariate analyses based on the Breslow-Day test and *p*-value cut-off point of 0.05.

The Hosmer-Lemeshow Goodness-of-Fit test was used to assess the adequacy of each model. To test the sensitivity of the final model, which included covariates at all three levels, we estimated a logistic regression model with the dependent variable (child's social participation) specified as 'weekly' and 'less than weekly'.

Finally, to compare rates of social participation for children with and without disabilities by place of residence, we estimated a separate logistic regression model which included child and household level covariates along with interaction between child's disability status and survey site. Neighborhood level variables were excluded to avoid problems with multicollinearity.

Children with missing responses for any independent variable were excluded in multivariate analyses. All analyses were conducted using SAS 9.2 software. The Office for the Protection of Research Subjects at the University of Illinois at Chicago reviewed and approved this study under the expedited category.

Results

We analyzed data for 2,295 children aged 3 to 17 years. Data were provided by adult caregivers, who were mostly parents (87%), predominantly female (81.7%), and largely young adults (average age = 33.2, SE = 0.45).

Sample Description

Descriptive characteristics of the sample are summarized in Table 1. Of the 2,295 children, 15.6% (n = 341) were identified as having a disability. Specific diagnostic condition was available for only 66% (n = 226) of children with disabilities. The most prevalent conditions included chronic health conditions such as asthma, diabetes, and heart conditions (n = 81), ADD/ADHD or other behavior disorders (n = 69), learning disabilities (n = 32), speech impairments (n = 23), neurodevelopmental disabilities such as autism, cerebral palsy, and spina bifida (n = 8), sensory impairments (n = 8), and mental or emotional illness (n = 5). Sixty caregivers classified their child’s primary condition as ‘other’.

Table 1: Sample Characteristics (Weighted Analysis)

Characteristics	All ^a (n=2295)	Without Disability ^a (n=1939, 84.4%)	With Disability ^a (n=341, 15.6%)	Test statistic, p-value
	% (SE)	% (SE)	% (SE)	
Gender (n=94 missing)				
Male	48.4 (1.6)	46.5 (1.7)	57.2 (5.0)	$\chi^2 = 4.03$ $p = 0.04$
Female	51.6 (1.6)	53.5 (1.7)	42.8 (5.0)	
Child Age (n=23 missing)				
Preschool	25.9 (1.4)	27.6 (1.5)	17.4 (2.8)	$\chi^2 = 6.07$ $p = 0.11$
Elementary School	37.3 (1.5)	37.5 (1.6)	35.0 (4.1)	
Middle School	27.3 (1.5)	25.7 (1.6)	36.7 (4.5)	
High School	9.4 (1.1)	9.2 (1.0)	10.9 (4.3)	
Race (n=27 missing)				
Non-Hispanic White	14.3 (0.9)	13.5 (0.9)	18.8 (3.0)	$\chi^2 = 14.2$ $p = 0.007$
Non-Hispanic Black	26.4 (1.1)	26.7 (1.2)	24.8 (3.2)	
Hispanic	39.5 (1.5)	41.2 (1.6)	30.3 (3.9)	
Asian	4.6 (0.4)	5.2 (0.5)	1.6 (0.6)	
Other	15.1(1.4)	13.4 (1.3)	24.6 (5.4)	
Health Status (n=9 missing)				
Excellent	46.3 (1.5)	50.0 (1.7)	26.6 (4.1)	$\chi^2 = 22.57$ $p < 0.0001$
Good-Very Good	46.1 (1.5)	45.1 (1.7)	51.3 (4.6)	
Poor-Fair	7.6 (1.0)	4.9 (0.8)	22.1 (4.5)	
Child Insurance Coverage (n=28 missing)				
Yes	85.8 (1.3)	84.4 (1.5)	92.7 (1.9)	$\chi^2 = 9.7$ $p = 0.002$
No	14.2 (1.3)	15.6 (1.5)	7.3 (1.9)	
Household Hardship (n=29 missing)				
Some hardship	56.5 (1.6)	54.6 (1.7)	67.1 (3.9)	$\chi^2 = 6.81$ $p = 0.009$
No hardship	43.5 (1.6)	45.4 (1.7)	32.9 (3.9)	

Household Income (n=242 missing)				
\$0-\$9,999	28.1 (1.7)	25.8 (1.7)	40.7 (5.2)	$\chi^2 = 10.9$ $p = 0.01$
\$10,000-\$19,999	27.7 (1.5)	28.1 (1.7)	25.5 (3.8)	
\$20,000-\$29,999	20.5 (1.3)	21.2 (1.4)	17.2 (3.1)	
\$30,000 or more	23.7 (1.3)	24.9 (1.4)	16.6 (2.8)	
Home Ownership (n=12 missing)				
Yes	30.2 (1.4)	29.7 (1.5)	34.1 (4.1)	$\chi^2 = 0.93$ $p = 0.34$
No	69.8 (1.4)	70.3 (1.5)	65.9 (4.1)	
Car Ownership (n=32 missing)				
Yes	69.4 (1.5)	72.0 (1.5)	56.8 (4.8)	$\chi^2 = 6.97$ $p = 0.008$
No	30.6 (1.5)	28.0 (1.5)	43.2 (4.8)	
Highest level of educational attainment in household (n=36 missing)				
Less than high school	38.6 (1.6)	37.0 (1.7)	47.9 (4.7)	$\chi^2 = 5.79$ $p = 0.06$
High school/GED	34.9 (1.5)	36.2 (1.6)	27.4 (3.8)	
Greater than high school	26.5 (1.2)	26.7 (1.4)	24.7 (3.2)	
Neighborhood Commitment (n=32 missing)				
Committed	32.5 (1.4)	31.9 (1.5)	36.0 (4.1)	$\chi^2 = 0.83$ $p = 0.36$
Not committed	67.5 (1.4)	68.1 (1.5)	64.0 (4.1)	
Years in Neighborhood (n= 1 missing) ^b	8.95 (.38)	8.77 (0.36)	9.97 (1.44)	$F = 0.65$ $p = 0.42$
Household Size ^b	4.87(0.07)	4.83 (0.06)	5.04 (0.28)	$F = 0.52$ $p = 0.47$

a Frequencies in the 'All' column are not always the exact sum of frequencies in the 'With Disability' and 'Without Disability' columns due to missing data on disability status (n=15)

b Data reported as mean and standard error

Neighborhood Description

The average neighborhood safety rating (N = 20) was 4.34 (SD = 0.37) on a seven-point scale, with a higher score indicating greater perceived safety. The average disorder and incivility rating was 2.82 (SD = 0.43) on a six-point scale, with a higher score indicating greater disorder. The average ratings for informal social control and social cohesion were 3.24 (SD = 0.22) and 3.08 (SD = 0.20) respectively, both measured on a five-point scale with a higher score signifying better conditions.

Neighborhoods experienced poverty rates ranging from 11.4% to 83.4% (mean = 33.6%, SD = 15.6). The average unemployment rate ranged from 7.4% to 28.1% (mean = 14.9%, SD = 6.0). The proportion of single parent households ranged from 8.8% to 63.4% (mean = 22.9%, SD = 12.2). Residential stability varied across neighborhoods. On average, 36.4% (SD = 18.1) of housing units were owner-occupied (range 6.4%-62.7%) and 39.4% (SD = 6.4) of neighborhood residents had moved in the last five years (range 26.8%-50.3%). The average neighborhood was 26.7% Non-Hispanic White (SD = 21.4), 27.9% African American (SD = 25.7), and 36.1% Hispanic (SD = 26.2) with the remainder classified as 'Other' race.

Social Participation Rates

Half of all children in our sample (50.3%) reported some participation in organized out-of-school social activities. Site-specific participation rates varied from 43.9% in San Antonio to 62.8% in Denver. Participation rates (dichotomized as 'some' versus 'none') varied between children with and without disabilities. Fifty-two percent of children without disabilities reported some social participation compared with 42% of children with disabilities, $\chi^2 = 3.84$, $p = 0.05$. Among children with some participation, we compared children with and without disabilities in terms of frequency of social participation (daily, 2-3 times per week, weekly, less than weekly) and found no significant differences, $\chi^2 = 2.67$, $p = 0.45$.

Barriers to Social Participation

On average, children in both groups reported 1.2 barriers to social participation ($SD = 0.08$ for children with disabilities, $SD = 1.19$ for children without disabilities). The most common barriers (unweighted) included child being too young to participate in out-of-school activities ($n = 309$), lack of opportunities in the area ($n = 151$), transportation problems ($n = 148$), and inability to afford program fees ($n = 143$).

The proportion of respondents reporting age (child not old enough) as a barrier was higher for children without disabilities (33.8% compared to 12.9% of children with disabilities, $p < 0.0001$). Proportion of respondents reporting disability as a barrier was higher for children with disabilities (19.0% compared to 4.8% of children without disabilities, $p < 0.01$). Other barriers reported more frequently for children with disabilities included program unavailability, unaffordability, waiting lists, and safety concerns. These differences were not statistically significant.

Effect of Child, Household, and Neighborhood Factors on Social Participation

Model 1: Child level factors. Our first estimated model included child level characteristics (Table 2). In this model, gender and health status were not significantly associated with social participation. On the other hand, age, race, disability status, and health insurance coverage significantly predicted social participation.

Compared to middle school aged children, children in other age groups had significantly lower odds of social participation. Significant differences in social participation rates were associated with child's race and ethnicity. Compared to White children, social participation odds were 42% lower for Hispanic children and 48% lower for children of 'Other' race. Social participation odds were not significantly different for White and Black children or White and Asian children.

Having a disability was negatively associated with social participation. Social participation odds for children without disabilities were 1.85 times the odds for children with disabilities. Having health insurance coverage was positively associated with social participation. Social participation odds for insured children were 1.78 times the odds for

uninsured children with disabilities.

Model 2: Child plus household level factors. Household level variables were added to Model 1 (Table 2). In this combined model, four household characteristics had positive effects on social participation – home ownership, vehicle ownership, education level, and neighborhood commitment. Children living in families that owned their home had 42% higher social participation odds while children living in households that owned a dependable vehicle had 51% higher social participation odds. Similarly, participation odds for children from households with a greater than high school education were double the odds for children from households with a less than high school education. When household members demonstrated neighborhood commitment, children's social participation odds increased 85%. Other household level variables such as size, hardship, and length of time in the neighborhood did not significantly predict social participation.

The addition of household level variables did not change coefficients for child level variables except race/ethnicity. In the combined child and household model, the coefficient for Hispanic race/ethnicity (compared to White race/ethnicity) was no longer significant. The negative effect on social participation of belonging to this racial/ethnic group (seen in the Model 1) could be attributable to household level socio-economic characteristics correlated with race/ethnicity.

Model 3: Child, household, and neighborhood level factors. Neighborhood level variables were added to Model 2 (Table 2). Length of time in the neighborhood was dropped from this model as it was not statistically significant and impaired model fit. This combined model had the best fit among all three models as indicated by results of the Hosmer-Lemeshow Goodness-of-Fit test, supporting the combined effects of child, household, and neighborhood factors on social participation.

The neighborhood variables measuring disorder and incivility, poverty level, housing occupancy, and racial/ethnic mix were statistically insignificant in this model. Neighborhood safety had a significant positive effect on social participation. A unit increase in perceived safety was associated with three times higher social participation odds. Conversely, residential instability had a significant negative effect. Social participation was 93% less likely with every unit increase in the percentage of households that moved in the last five years.

The addition of neighborhood level variables did not cause notable changes in coefficients for child and household level variables except child gender. Being female was significantly associated with 34% higher odds of social participation. This suggests that gender-based participation differences might be attributable to neighborhood characteristics that hinder participation of boys more than girls.

Table 2: Logistic regression models showing the relationship between individual, household and neighborhood characteristics and the probability of social participation.

Characteristics	Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)
Child Level			
Gender: Females vs. Males	1.23 (0.93 - 1.62)	1.31 (0.99-1.74)	1.34 (1.01-1.78)*
Child Age:			
Preschool vs. Middle School	0.11 (0.07 - 0.17) ⁺	0.09 (0.06-0.14) ⁺	0.09 (0.05-0.13) ⁺
Elementary School vs. Middle School	0.46 (0.32 - 0.66) ⁺	0.41 (0.29-0.59) ⁺	0.41 (0.29-0.6) ⁺
High School vs. Middle School	0.55 (0.32 - 0.95) [*]	0.49 (0.29-0.82) ^{**}	0.48 (0.28-0.82) ^{**}
Race/Ethnicity:			
Black vs. White	1.08 (0.72 - 1.62)	1.15 (0.74-1.77)	1.31 (0.82-2.08)
Hispanic vs. White	0.58 (0.38 - 0.87) ^{**}	0.69 (0.44-1.08)	0.73 (0.43-1.25)
Asian vs. White	0.7 (0.4 - 1.21)	1.06 (0.57-1.97)	0.92 (0.48-1.76)
Other vs. White	0.52 (0.29 - 0.93) [*]	0.55 (0.31-0.99) [*]	0.6 (0.32-1.13)
Disability:			
Without Disability vs. With Disability	1.85 (1.17 - 2.93) ^{**}	1.68 (1.1-2.59) [*]	1.68 (1.08-2.6) [*]
Child Health:			
Excellent vs. Poor/Fair	1.73 (0.96 - 3.1)	1.69 (0.92-3.1)	1.68 (0.9-3.12)
Good/Very Good vs. Poor/Fair	1.52 (0.86 - 2.67)	1.53 (0.86-2.74)	1.55 (0.86-2.81)
Child Insurance Coverage:			
Insured vs. Uninsured	1.78 (1.15 - 2.76) ^{**}	1.73 (1.07-2.8) [*]	1.79 (1.09-2.94) [*]
Household Level			
Household hardship: None vs. Some		0.93 (0.69-1.25)	0.93 (0.68-1.26)
Home ownership: Yes vs. No		1.42 (1.01-1.98) [*]	1.47 (1.04-2.17) [*]
Vehicle ownership: Yes vs. No		1.51 (1.05-2.16) [*]	1.5 (1.03-2.17) [*]
Household education:			
>High School vs. <High School		1.97 (1.35-2.87) ^{***}	2.01 (1.38-2.95) ^{***}
High School/GED vs. <High School		1.41 (0.98-2.03)	1.43 (0.99-2.06)
Neighborhood Commitment:			
Committed vs. Not committed		1.85 (1.36-2.51) ⁺	1.88 (1.38-2.54) ⁺
Years in Neighborhood		1.01 (0.99-1.02)	
Household Size		0.95 (0.86-1.02)	0.94 (0.86-1.02)
Neighborhood Level			
Perceived safety rating			3.12 (1.24-7.75) [*]
Perceived disorder and incivility rating			2.02 (0.98-4.16)
% families below poverty			0.55 (0.14-2.19)
% owner-occupied housing units			0.36 (0.1-1.28)
% households that moved in last 5 years			0.07 (0.004-0.98) [*]
% Hispanic population			0.82 (0.46-1.87)
Hosmer Lemeshow Goodness-of-Fit Test	$\chi^2 = 19.83, p = 0.01$	$\chi^2 = 18.53, p = 0.02$	$\chi^2 = 14.37, p = 0.07$

*p<0.05 **p<0.01 ***p<0.001 +p<0.0001

Sensitivity analysis. All three models estimated the probability of ‘some participation’ versus ‘no participation’. To assess the robustness of Model 3, we re-estimated this model with social participation dichotomized as ‘weekly’ and ‘less than weekly’ (results not shown). Coefficients of independent variables were similar regardless of how social participation was

classified, but association strength for some variables changed.

Among child level variables, age and disability were significant predictors for both ways of categorizing social participation. Gender was not a significant predictor when social participation was defined as 'weekly' versus 'less than weekly'. Race/ethnicity significantly predicted social participation dichotomized as 'weekly' versus 'less than weekly'. Black children had higher odds of weekly participation compared to White children. Health status also emerged as a significant predictor. Being in poor or fair health predicted lower odds of weekly participation compared to being in excellent, good, or very good health.

Among household level variables, vehicle ownership, education level, and neighborhood commitment significantly predicted social participation regardless of whether it was dichotomized as 'some' versus 'none' or 'weekly' versus 'less than weekly'. Home ownership was not a significant predictor for the latter categorization of social participation. Among neighborhood level variables, safety was not a significant predictor when social participation was defined as 'weekly' versus 'less than weekly', while percent of households that moved in the last five years was a significant predictor for both ways of categorizing participation.

Social Participation of Children With and Without Disabilities by Place of Residence

In three of the ten sites – Des Moines, Hartford, and Oakland –social participation odds were lower for children without disabilities. This difference was significant only in the Hartford site where participation odds were 77% less likely for children without disabilities, OR = 0.23, 95% CI [0.07 – 0.77], $p < 0.05$. In the remaining seven sites – Denver, Indianapolis, Louisville, Milwaukee, Providence, San Antonio, and Seattle –social participation odds were higher for children without disabilities. This difference was significant in San Antonio and Milwaukee where the odds of social participation for children without disabilities were five times the odds for children with disabilities, San Antonio OR = 4.72, 95% CI [1.67 – 13.29], $p < 0.01$, Milwaukee OR = 5.21, 95% CI [1.41 – 19.28], $p < 0.05$.

We compared neighborhood characteristics (previously listed under 'Neighborhood Description') at these sites with the cross-site averages. There were no notable differences on any indicators except for racial/ethnic mix. The percent Hispanic population in the San Antonio site was 90.6% compared with the cross-site average of 36.1%. In the Milwaukee site the percent African American population was 74.3% compared with the cross-site average of 27.9%.

Discussion

Ours is one of the first studies to compare social participation rates of children with and without disabilities using a neighborhood-based sample of low-income children. We found near significant differences between the two groups across neighborhoods. However,

participation rates in both groups were markedly lower than what has been reported in the literature. Only 52% percent of children without disabilities and 42% of children with disabilities reported some social participation. In other words, half of all children without disabilities and 58% of children with disabilities were not participating in any organized social activities outside of their homes and schools. In contrast, previous studies have found that non-participation rates in a variety of social activities range from 6% to 44% for children with disabilities and from 0.5% to 20% for children without disabilities (Law et al., 2006; Imms et al., 2008; Michelsen et al., 2009; Bedell et al., 2013). The overall low participation rates in our study, across all sites and all children, highlight the distinctiveness of our data.

Previous studies have included children from middle and high income households and communities. Our findings indicate that household and neighborhood disadvantage hinder social participation of all children, although disparities persist for children with disabilities. Most notably, we found that a child's disability or health status was not the only significant predictor of social participation. Multiple indicators of neighborhood and household socioeconomic resources also contributed to odds of social participation. Thus our study supports the disability studies contention that environmental factors play an important role in influencing participation of individuals with disabilities.

Two neighborhood factors were significantly associated with children's social participation beyond the influence of household and child characteristics. The first was residential turnover. Social participation was negatively affected by the percentage of households that had moved in the previous five years. Previous research shows that the overall residential stability of a neighborhood, more than an individual family's residential tenure, influences parenting behaviors to promote youth participation in school and community activities (Cantillon, 2006). Stable neighborhoods foster social ties and friendship networks, which promote effective parental support and monitoring strategies (Cantillon, 2006). Parents who have a greater sense of comfort from knowing other children and adults around their children may be more willing to support their children's participation in social activities (Coulton & Irwin, 2009).

Perceived safety was the second significant neighborhood level predictor of social participation. Other studies have found that perceived neighborhood safety positively influences children's participation in recreational programs and out-of-school activities (Molnar et al., 2004; Coulton & Irwin, 2009). In our study, higher safety ratings were associated with higher social participation odds categorized as 'some' versus 'none'. However this association was insignificant when social participation was categorized as 'weekly' versus 'less than weekly', indicating that neighborhood safety may be a predictor of extreme social participation outcomes. Thus, safety concerns, where they exist, may exert a stark influence on children's social participation.

Parents might seek to enroll their children in programs outside their unsafe neighborhood (Jarret, 1999). However, this may require families to traverse unsafe

neighborhood streets, conferring an advantage to families with dependable means of transportation. This likely explains our finding that indicators of household socioeconomic resources, such as home and vehicle ownership, significantly predicted social participation even after introduction of neighborhood factors in the regression model. Furthermore, families reported transportation as a participation barrier for 15% of children with and without disabilities.

A related finding was that households raising children with disabilities, as compared to households raising children without disabilities, were significantly less likely to own a dependable vehicle and fared worse on most socioeconomic indicators. Therefore, it is likely that in unsafe neighborhoods, families of children with disabilities face greater barriers to accessing extralocal resources, further restricting their social participation. Consistent with this interpretation, we found that respondents representing children with disabilities more frequently reported safety concerns as a barrier to their child's participation.

A unique contribution of our study relates to effects of child's disability status on social participation, after taking into account household and neighborhood disadvantage. Having a disability was negatively associated with social participation across all models and specifications of social participation. This suggests that in similar situations of household and neighborhood disadvantage, children with disabilities fare poorly on social participation outcomes compared with children without disabilities. One possible explanation is that severity of a child's primary condition precludes participation in organized social activities. In our study, child's overall health rating served as a proxy indicator for severity of the underlying condition. Health status was a significant predictor only when social participation was categorized as 'weekly' versus 'less than weekly'. This suggests that severely disabled children might be precluded from participating more frequently in organized social activities; however severity of their condition does not explain why they would have lower odds for at least 'some' level of social participation.

The above finding points to the possibility of environmental barriers, such as lack of inclusive and accessible local resources, as another explanation for lower odds of participation among disabled children. Results of interaction analyses between child disability status and place of residence yielded interesting insights in this regard. Children without disabilities had higher adjusted odds of social participation in seven of ten survey sites. Participation odds were significantly higher for children without disabilities in two sites, San Antonio and Milwaukee. Conversely, participation odds were significantly lower for children without disabilities in one site, Hartford. These contrasting findings merit further discussion.

Neighborhood indicators for the San Antonio and Milwaukee sites did not differ from cross-site averages or from the Hartford site except for racial/ethnic mix. The San Antonio site represents one of the poorest neighborhoods in the country with a predominantly Hispanic population (Brischetto et al., 2000) while the Milwaukee site represents a classic white flight neighborhood with a predominantly African American population (Bartos et al., n.d.). In

contrast the Hartford site includes a more mixed racial/ethnic population. The Hartford site also represents multiple neighborhoods (Coulton, Chan, & Mikelbank, 2010) of which some have high risk scores on socioeconomic indicators, but others fare well on poverty, health, and education indicators (Colantonio & Martin, 2013). Previous analysis of second wave data from the Making Connections survey also shows lowest unmet need for welfare services in the Hartford site and highest demand in the San Antonio and Milwaukee sites (Price & Hayes, 2009). Therefore, these sites likely varied in degree of disadvantage with more detrimental effects for children with disabilities.

Previous research suggests that racial homogeneity is conducive to neighborhood collective efficacy (Lindblad et al., 2013), which positively influences child outcomes (Xue et al., 2005; Moren-Cross et al., 2006). The San Antonio and Milwaukee sites represent the most racially homogenous neighborhoods in this study, yet disparities in social participation between children with and without disabilities were greatest in these sites. It is likely that collective efficacy supports social participation for children without disabilities but does not facilitate participation of children with disabilities, thereby widening disparities. Participation of children with disabilities might be more contingent on availability, accessibility, affordability, and quality of social and recreational resources (Leventhal & Brooks-Gunn, 2000). Racially homogenous African American or Hispanic neighborhoods are often characterized by concentrated disadvantage (Sampson, Raudenbusch, & Earls, 1997) and poor availability of amenities such as public transit (McKenzie, 2013) and recreational facilities (Moore et al., 2008). Lack of such amenities and services at the neighborhood level have been shown to impede social participation of children with disabilities (Law et al., 2006; Law et al., 2007). Indeed, in our study, program unavailability and unaffordability were cited more frequently as participation barriers for children with disabilities.

Site-specific disparities in social participation of children with and without disabilities can also be traced to state-level disability-related policies and programs. For example, Michelsen and colleagues (2009) analyzed national disability policies to explain regional differences in participation of children with and without disabilities across seven European countries. In the United States, The Case for Inclusion is an annual ranking of how well state Medicaid programs serve American children and adults with intellectual and developmental disabilities. Between 2007 (the earliest year for which data are available) and 2012, Connecticut consistently ranked among the top ten states. On the other hand, Wisconsin and Texas ranked far lower, with Texas consistently being one of the worst performing states (United Cerebral Palsy, 2007; 2012). This suggests a lack of infrastructure to support people with disabilities in Wisconsin and Texas, with negative trickle-down effects for children with disabilities living in the Milwaukee and San Antonio survey sites.

Overall, our findings suggest the need for future research to illuminate the mechanisms responsible for social participation disparities between children with and without disabilities. One way to identify mechanisms would be to qualitatively examine participation profiles of a small sample of children with disabilities in 'best' and 'worst' performing sites

(Hammal et al., 2004). Backward mapping, which involves identifying local community barriers and assets and tracing them to state-level policies, could be another useful strategy (Law et al., 2007).

Limitations

Our study had a few limitations. First, not all neighborhoods in the metropolitan survey sites were represented. In addition, the study sample was not nationally representative, although it closely resembles the profile of urban poor communities in the United States. While we analyzed several relevant child, household, and neighborhood characteristics, it is possible that unmeasured neighborhood variables might account for some findings (Leventhal & Brook-Gunns, 2000). Also, social participation, a complex and varied phenomenon, was captured through a simple dichotomous measure of participation in organized out-of-school activities. This was a limitation in the survey questionnaire, although broadly applicable measures of children's social participation are lacking (King, 2013). Finally, no causal inferences can be drawn due to the cross-sectional nature of our analyses.

Conclusions

Our study makes an important contribution to the literature on neighborhood effects, disability status, and children's social participation. It is among the first studies to document neighborhood effects on social participation of children with and without disabilities and to examine interactions between child disability status and place of residence. Primarily, our study highlights the importance of understanding environmental factors at the neighborhood level that could hinder the participation of children with disabilities. We found low social participation rates for all children, with neighborhood safety, residential stability, and household socioeconomic indicators playing an important role. At the same time, adjusted participation odds were lower for children with disabilities overall and in most individual survey sites. These findings suggest that measures to strengthen neighborhood foundations, such as stability and safety, can facilitate the social participation of all children. At the same time, disadvantaged neighborhoods also need targeted after-school programs and social and recreational resources that are inclusive of and accessible to children with disabilities.

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Best Practices

Anxiety as a Tool for Critical Disability Studies Fieldwork

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Abstract: In this article, I consider the role of emotional response and anxiety in fieldwork by drawing on an incident where I was called a “fake deafie” by informants and a follow up interview transcript about this episode. I use emotions and particularly the tracking of anxiety as a tool to productively explore the subjective and intersubjective dynamics that give shape to encounters in fieldwork. This focus on affect in fieldwork allows me to productively attend to the ethical and methodological dilemmas that materialized as a bicultural, or an in-between, ethnographer (Valente, 2011, 2014a, in review). Importantly, attending to affect in fieldwork also allows me to draw attention to an integral component of conducting critical disability studies fieldwork, that is, the affective dimensions. I conclude by arguing for the need for researchers in critical disability studies to have a theory of anxiety. This theory of anxiety needs to be a part of the critical disability studies researcher’s reflexivity toolkit.

Keywords: fieldwork, anxiety, deaf culture, psychoanalytic ethnography

Introduction

While I was conducting fieldwork and interviews in France as part of the *Kindergartens for the Deaf in Three Countries: Japan, France, and the United States* study funded by The Spencer Foundation, I carried out the worst focus group interviewing work I have ever done in all my years of research. This disastrous interview, to no real credit of my own, somehow miraculously morphed into a really compelling discussion about the film we came to interview our deaf teacher informants about. I draw on the vignette that follows this introduction and a transcript of this event to address my so-called “fake deafie” anxiety and to consider the role of emotional response and anxiety in fieldwork, where emotions and particularly the tracking of anxiety is used as a signal and tool to productively explore and mediate between the intrapsychic and intersubjective dynamics that give shape to encounters in fieldwork. This focus on affect in fieldwork allows me to productively attend to the ethical and methodological dilemmas that materialized as a bicultural or as I prefer, an in-between, ethnographer (Valente, 2011, 2014a, 2015).

Importantly, attending to affect in fieldwork also allows me to draw attention to an integral component of conducting critical disability studies fieldwork, that is, the affective dimensions. Crapanzano (2003), a psychoanalytic anthropologist, argues that we have an ethical responsibility to present these messy events in our work as part of the reflexive ethnographic project to allow us to be more thoughtful and honest about how to deal with these issues in future projects. These messy events, such as the following “fake deafie” story, present to the audience the ethical issues that emerge in the course of conducting fieldwork

and allow us to think about how they might affect our findings and our writing.

A “Fake Deafie” in Southern France

When the school day ended on Wednesday, June 13, 2012, my host Agnès Campredon, the director of the preschool École Maternelle Gabriel Sajus, hurried our small research team—Patrick Graham, Adeline Lebeaux, and me—through rush hour traffic the six kilometers from Sajus to the public elementary school École Jean-Jaurès, located in Ramonville on the outskirts of the historic southern capitol Toulouse, France. We were set to meet with Marie-Paule Kellerhals, the coordinator for the preschool and primary grade class LSF, bilingual classes in French and French sign language (LSF - Langue des Signes Française) serving two- to five-year-old deaf children. Kellerhals would then bring us to the eleven classe LSF teachers she rounded up from the area preschool and elementary schools for a focus group interview. We were there to interview the teachers about a video we filmed during the previous summer of a typical day in a kindergarten class LSF. Subsequently we collaboratively edited and collapsed about twenty hours of film footage from two video-cameras into a 29-minute film, with the lead kindergarten teacher Vanessa Andrieu and her supervisor Marie-Paule.

When we arrived in the parking lot, Marie-Paule, who is deaf, greeted Agnès and our team in spoken French. Marie-Paule then switches to LSF and Adeline, who as our English to French translator and English/French to LSF interpreter, translates what Marie-Paule signs from LSF into French (for Agnès) and then LSF into English for Patrick and me. Because both Patrick and I are deaf, we read Adeline’s lips to understand. As Marie-Paule directs us through the school entrance, main lobby, and up a flight of stairs to the classroom where the focus group will be held, Adeline deftly positions herself next to Marie-Paule so she has everyone in eyesight so she can translate and interpret. As we make our way to the classroom, Marie-Paule continues to sign in LSF an update to our team on what is ahead and then a side discussion ensues in spoken French between Agnès and Marie-Paule, who reads her lips, about plans for dinner post-interview. Adeline translates this discussion from French into English for Patrick and me.

As we walked into the classroom, Patrick and I said quick “hellos” to the teachers, some of whom we know quite well from previous visits, and all of whom are sitting in chairs waiting for the interview to begin once a few more of their colleagues join us. We quickly set up the cameras to record the interviews and for later interpreting/translating into French and English. Adeline signs in LSF with some of the teachers as she also knows them, having interpreted for them in the past for school meetings.

Once Patrick and I finished setting up, Patrick, who is a fluent and regular user of American Sign Language and also had been studying LSF, signs with several of the waiting teachers. Patrick has a reputation for quickly picking up various sign languages, having traveled widely in deaf communities internationally. Nearby, I can make out Adeline talking

in French with Agnès.

I remember awkwardly standing next to the video camera, acting as if I was busily working to fine-tune the camera lens, and I watched as Patrick has an animated back-and-forth in LSF with the teachers, some of whom I occasionally notice were also trying out the ASL they knew from their own travels. I had only recently begun learning ASL, having been raised oral deaf (Valente, 2011a), and I was now overcome with anxiety that I could not adequately sign anything rudimentary in either LSF or ASL, nor could I speak French, so I stood by and watched. I realized everyone was engaged in conversation but me. I could feel the familiar shame of belonging nowhere—belonging “aneither” to the speaking or signing world (Wake, 1939; Valente, 2011a). I could also feel the enduring loneliness of being an in-betweener creep back into me. I’m not just deaf to the larger hearing world but I am sign-impaired in the deaf world (Valente, 2014a, 2014b).

At this point, I remember my mind shift to thinking about comments someone told me hushedly, that supposedly some in the group of teachers we were interviewing felt that I was a “fake deafie.” Mainly this was because I was mostly speaking English, rather than ASL, to conduct the interviews and socialize in general. I also, apparently, acted like a “hearing” person. These complaints hit a nerve because, in fact, if I did sign, it was to communicate only with Patrick, a graduate student at another university who was serving as a research assistant for me on the project and was also one of my closest friends. Patrick was one of the few people that I felt safe enough to sign with because he was so patient in his efforts to understand what I was trying to communicate. He knew that I was sensitive about the topic of coming late to learn ASL. Very rarely did I use ASL to communicate with Adeline, as it was easiest to communicate in English. Beyond a few words like “hello” and “thank you” and the like, I also did not know or use much LSF.

In short time, the teachers we had been waiting on finally joined us, and now I re-directed myself to thinking about a more pressing dilemma, that is, the reason why we are here now, which is because of the “failed” interview earlier on Monday due, in part, to having been postponed after several interruptions. To be precise, there was a surprise visit in the midst of the interview by an Inspector, a high-ranking education official from the Academy of Toulouse who oversaw the implementation of the French National Curriculum and administered the schools in the region.

Perhaps more scandalously, a confidante revealed to me there was another reason for the failed interview having to do with discussions amongst some teachers in the group that I—the “fake deafie”—was oppressing Patrick, because as the “real deafie” who signed fluently in ASL and was skilled in international sign languages, he ought to have been leading or co-leading the interviews. Plus, our original ASL interpreter backed out at the last minute and our backup ASL interpreters were unavailable on this day too. This had the unintended effect of making me—the project’s co-principal investigator—appear to the deaf teachers to be insensitive to Patrick’s communicative needs. To say that I was doing damage control

would have been an understatement.

The Reflexive Dilemmas of Critical Disability Studies Researchers

After engaging my informants about the “fake deafie” comment tangentially but with much emotion in the interview that followed this opening scene, I learned this all had little to do with deaf politics, as I believed going into the interview. That is, I believed after learning of the “fake deafie” criticism that I was dealing with the kind of insider/outsider politics related to skill with sign that can sometimes create hierarchies and positionings within deaf communities. However, it turns out that the struggles of that day actually had more to do with issues that are much more mundane in the daily life of teachers and parents. These reflexive dilemmas that materialized during and even more so after these interviews, resulted in compelling me to confront the dilemmas of what LeVine (1982) calls the bicultural researcher (p. x). By bicultural, LeVine is referring to the fact that the ethnographer – all ethnographers – are tasked with participating as quasi-community members as well as performing the role of an observer. LeVine is addressing more traditional fieldwork in which the researcher is not already a member of the community being researched. When he describes a quasi-community member, he is referring to the fact that insiders accommodate you in a way that allows you to take on a partial membership. The researcher struggles with the anxieties of “getting it right” as an emerging but inexperienced member in the community. For many researchers, this gives rise to anxiety and the desire to “get it right.”

These issues of the anxieties of being a clumsy initiate and wanting badly to get it right are present in heightened ways in my research. As a critical disability studies researcher, I am highly sensitive to the empowering and emancipatory projects of representing the insider perspective on disability. In addition, representing deaf ethnicity, as opposed to deaf disability, draws from a long anthropological and linguistic tradition that is largely underreported and often ignored by mainstream special education and deaf education researchers whose models are drawn from a cultural and linguistic deficit perspective (Valente, 2016). The stakes in demonstrating the cultural and linguistic strengths and competencies of my informants are high. Likewise, I am deeply committed to research as a means for improving the lives of deaf and “disabled” children. Finally, I am keenly aware of my personal investment, created through years of my own struggling as a mainstreamed deaf child denied access to sign language, in moving forward an understanding of deaf people as not disabled but a language minority. At the start of this study, my role as what I have described in my previous writings as an in-between (Valente, 2011a, 2014a, 2014b) – neither a full member of the sign or spoken language communities – was complicated by the fact that the image I had of myself as taking on a deaf identity was very clearly impacting the way I was interpreting what was happening during this fieldwork and interviews.

George Devereux and Emotional Responses to Fieldwork

This quintessential dilemma that all fieldworkers face – our emotional responses to

experiences of being insiders/outside, or in-between — has historically been addressed by psychoanalytic ethnography through examining transference and countertransference in fieldwork and attending to the intrapsychic and intersubjective dynamics that materialize (Devereux, 1967; LeVine, 1982; Heald and Deluz, 1994; Valente, 2015). As I have written about previously (e.g. Valente, 2014a, 2014b), before postmodernists concerned themselves with the pitfalls of representation and problems of reflexivity in research, anthropologist George Devereux borrowed from psychoanalytic techniques to analyze empirically emotional responses to fieldwork, particularly attending to feelings of anxiety. Devereux's 1967 classic, *From Anxiety to Method in the Behavioral Sciences*, addressed anxiety in fieldwork by borrowing from psychoanalytic techniques for systematically attending to transference and countertransference in therapy. An important feature of this strategy was to explore the consequences of emic and etic perspectives that materialized before, during, and after fieldwork. What made Devereux unusual was his emphasis on not only attending to the emotional and affective dimensions of fieldwork but also attending to these dynamics in the writing up of the such descriptions. At the time, Devereux called attention to the fact that it was an unquestionable norm in the social sciences to be “objective” and de-emotionalized observers and recorders of events. In simple terms, Devereux argued for the need for researchers to consider that emotions and “anxiety [were] not something to be avoided but is the driving force which propels our intellectual questings” (p. 12). Spiro (1969) writing of Devereux's book, says:

“Any investigation of other human beings is necessarily, Devereux argues, a self-investigation as well, because the beliefs and behavior of his subjects arouse in the investigator his own unconscious (and usually infantile) fears, wishes, and fantasies. This countertransference phenomenon—the term, of course, is borrowed from psychoanalytic therapy—evoking, as it does, much anxiety, is, extremely painful.”

Thinking about Devereux's axiom and back on what transpired that June day in 2012, I now know that though I experienced what I interpreted to be an attack on my “deaf credibility” as an individual, the more complicated story is that this is also about the collective anxiety of all researchers and especially important for those whom are researchers, participants, and/or collaborators in critical disability studies research, where the stakes are high because of our common commitment to empowering and emancipatory projects.

Critical Disability Studies: An Intersubjective Turn

My work has taken an intersubjective turn (Valente, 2014b), moving away from a focus on my anxieties as an individual symptom. Emotionally, I could not look at these interview transcripts until I got to a point where I came to understand the intersubjective dynamics that were at play that June day. This is how I came to find critical disability studies to be reparative and generative (Valente, 2015). Critical disability studies presupposes that differences, rather than being solely the property of the individual, emerges also in the group

and consequently requires a collective response. As Goodley (2013) writes, “Critical disability studies start with disability but never end with it; disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all” (p. 632). Through critical disability studies, I am able to decenter my own subjectivity to imagine I am a part of something bigger than me—a group subject—that is and is not personal, and is and is not structural, historic, regional, cultural and institutional (Valente, 2015; Boldt and Valente, 2016).

That is, even though I experienced this as an individual with my own complicated deaf identity still-becoming, this is all part and parcel of the dilemmas with identity theory and politics of identity that many are now writing about (e.g., Muñoz, 1999; Puar, 2005; Zingsheim, 2010, 2011). Roets and Braidotti argue against an individualistic and dualistic “us/them” or “insider/outsider” perspective. They reconceptualize impairment and disability not as an individual attribute but as a form of intersubjectivity, that is, as always emerging, taking shape and changing as something produced in the collective. To write about this, both emotionally and intellectually, I had to shift to an impersonal and intersubjective reading to grasp what lay beneath the surface of what transpired within me and the group that day. When I write about the impersonal, I am not suggesting that I do not experience these events in personal ways but that an individualistic and dualistic “us/them” or “insider/outsider” perspective has its limitations in terms of understanding and engaging with fieldwork phenomena (Roets and Braidotti, 2012; Valente, 2014a).

I now use critical disability studies to work with stories such as the “fake deafie” in a less personal way. Each story is a part of the material that makes up the fieldwork encounter. Such a perspective reminds me to think of how much I or my interlocutors can control or understand what we are ultimately responsible for—that is, our ways of relating to one another. Rather than reading this “fake deafie” narrative as merely oppression, I am able to imagine it instead to be as a creative force seeking to connect with multiple bodies (Valente, 2015).

Thinking about this now from an intersubjective point of view, I can understand my anxiety as signaling something that was important to attend to as a researcher. My beginner’s interpretation of experiences in American deaf politics led me to jump to conclusions about the possible meanings of our difficult prior interview. When it was suggested to me that the difficulties were a result of my inadequacies both with sign and with my sensitivities to Patrick’s language needs, I jumped on what I refer to as “deaf-on-deaf crime”—when deaf people oppress other deaf people for real and/or perceived differences to deaf cultural or signing norms—rather than using it as a signal that something intersubjectively interesting was happening. As I will describe in more detail below, from a psychoanalytic interviewing perspective, I missed an opportunity to use my anxiety as a signal and a tool.

Before visiting with the transcript, it is important to note that what follows is a block transcript that readers may find to be somewhat lengthy; however, I ask readers to read this in

its entirety because it demonstrates how the cascading of anxieties fed into one another and overwhelmed my capacity to think clearly. When I think back on this “fake deafie” episode now, I understand more clearly that I transferred my own anxieties about belonging to the deaf, signing community onto what it was that I thought was happening in this interview. These accounts of my worst interview are productive for forays into understanding how my anxieties about identity and my role as an in-between ethnographer became muddled. I should also add that this written account reflects my attempt to organize my anxieties about expected criticisms about my failures as a researcher.

An Excerpt from the Transcript of Focus Group Interviews

[VALENTE/INTERVIEWER]: [In English] I want to start by thanking everyone for coming today. I appreciate you taking the time out of your busy schedules. For starters, I want to talk with you about our [Monday] interview. I think there's a sense of frustration... maybe this is a very American way about being sort of blunt, very open about what I think. When we came here we were trying to have an American Sign Language interpreter for Patrick. I think I explained to you the day that we met that we were trying very hard to do that and that we do have [ASL] interpreters [going forward]... Unfortunately the three different interpreters that we tried to bring here could not come and one of them told me at the very last minute. So Patrick and I had to make a decision—Should he come to [Ramonville] without an interpreter?—Patrick wanted to come, obviously, because he wanted to see [all of] you so we had to make a choice so he decided to come here because he sees you as friends and it's not easy finding ASL interpreters here in France [with very little notice]... So we had to make choices and maybe it was a good choice, maybe it was a bad choice, I don't know. So that's the first thing I want to say, the second thing I want to say is that I made a really bad mistake in my attempt to try to give Patrick some ASL to interpret for him, it was not what I planned because as you know I'm not fluent in ASL yet. I've learned a lot of ASL but I'm not an interpreter too, so even if I was fluent I'm not an interpreter. I'm also deaf and I can't hear everything too. So I'm trying to read lips and while [English-LSF interpreter] Adeline speaks good English, she still has an accent so I have to try to read her lips with an accent, then try to speak in English [while at the same time interpreting for Patrick in ASL]... I am not as eloquent in ASL as I am in English and that wasn't my choice and the one thing I feel as someone who's a deaf person is very sensitive about that, I didn't make the choice to choose what language I was taught when I was a kid. What I really worry about [with] the deaf community is how deaf people can oppress other deaf people and my research is not just about deaf children. My research is also about the experiences of deaf people meeting other deaf people, both how that's good but how that can also be bad. And I would say that deaf people can also oppress other deaf people as much as hearing people can oppress deaf people. But to me it's more a problem if deaf people oppress other deaf people because many of you know and share the same story... If you know sign language better than I do, you shouldn't be feeling like you're better than me. You should be feeling that I'm still trying to make that journey to where you are today. You should be supportive. This is not just about me, it's

about everyone. The deaf community could do a better job of trying to support deaf people like me who are trying to learn sign and become members of the deaf community... If I wasn't trying and I came back here and I didn't know any sign language, I think, you would have every right to be upset with me, but I spent a lot of time studying sign language and trying my hardest to learn the language that I did not have a chance to learn [as a kid because hearing adults in my world did not think sign language was a real language].

That's the one piece. As far as the [Monday] interview went I was trying to be [an ASL interpreter for Patrick] and read Adeline's lips at the same time and speak English while also carrying out the interview. So I understand why Marie-Paule [the supervisor overseeing the deaf teachers] feels pressured but I feel pressured too. So I understand that some of you may have felt that the interview we had on Monday didn't go the way we wanted to, but for me, the language pieces was missing completely. I was doing for everyone else but I wasn't doing for me, what I was doing—I thought—was pretty selfless. I'm not trying to make you feel bad, I'm trying to make sure you understand because doing an interview means that I have to think about the questions that I have to ask you so I at the end of the project can write a really good book about this. I have a heavy burden to make this book represent what you want it to represent. I can't make a mistake—I feel a heavy responsibility because you have given me so much time and you have been so supportive with this project and to me I have another responsibility to deaf children—if I fail at what I do—deaf children will keep experiencing the kind of education that I experienced, which is no access to sign language, which is being alone all the time [in mainstream settings without deaf peers], so we all share this burden together. I think I was carrying this burden alone but now I'm telling you I can't [carry this burden alone... I want to make sure that communication [between us] is clear [because your perspectives are important and unique].

So today I'm going to speak in English. I want to sign with you but [that will impede our project] as Adeline is still learning ASL too and it's not fair to her to sacrifice her ability to communicate to you and it's not okay to do some [pidgin-like] LSF [mixed] with ASL [as suggested by some] because that means we'll miss things that are important. We can do [a mix of LSF and ASL] when we socialize and spend time together at night, that's fine but during this time, this is real work we have to make sure that everyone is clear because what if we interpret something you say that you did not want to say? That would be horrible and I would feel terrible, that would be a very big burden for me. So when we're in here [doing interviews], I have will have to use the language that I know best—English—is that okay? Does anyone have anything to say?

Jerome: It's better for everyone [if you use English].

Catherine: It's true that Monday night was a bad day for everyone, we had other meetings, and other obligations... It's not at all against you or anything, it's that we had many things to do at the same time. And, for me, I was there on Monday night, on Tuesday night I came [for the parent interviews] as a parent and I am here again this morning so the

involvement to come is there but we all had other constraints. It's not against you at all but it's just the way it is, personally I had no other choice [to come as many times to be a participant in interviews].

Jerome: ...I agree with you [Catherine]. I must say it's June, end of the year, you [VALENTE] come here and we're all tired, children are tired. At the end of the year there are always many things to do, reports to write, preparing and readying for next year, everything is happening at the same time.

The "Fake Deafie" Episode and the Interview Transcript

Researcher Anxieties

I now cringe when I read this. What I see now is how I experienced the previous failed interview through the later "fake deafie" comment as an attack on my status as a member of the deaf community and responded by becoming defensive, scolding my interviewees. The "fake deafie" comment struck at the heart of unlimited anxieties about my inadequacies as a signer and newcomer to the deaf community back home in the United States as well as in France.

The decision to either raise or not directly raise the "fake deafie" comment to the group was complicated. Ultimately, my conscious decision not to address it was based on my fear that pushing the point on this hurtful phrase might jeopardize the project or infringe on French customs having to deal with this kind of tension. I believed I had already offended them and worried about offending them further with my anger in ways that would be counterproductive.

Re-reading my "monologue" in this transcript, I can pick out the four major points I was trying to make, all strung together by intense feelings, particularly of anxiety and defensiveness. First, at the opening of the interview, I explained that under the circumstances, we had to make a choice as to whether Patrick would or would not come on this trip to Ramonville given that no interpreters were available. I explained Patrick decided "yes" and I agreed with him. Next, I apologized for attempting to simultaneously interpret for Patrick while I was conducting the interview in English, then shifted to explaining my own difficulties being without an ASL interpreter and reading Adeline's lips to understand. After that, much to my on-going embarrassment, I simultaneously scold and plead with those in the group who I imagine called me a "fake deafie" by launching into a rant about "deaf-on-deaf crime."

When laying side-by-side my vignette "fake deafie" and the transcript, I can clearly see how my anxieties about being a newcomer to the deaf community makes me over-read everything as having something to do with deaf politics. I can now clearly see that I was mapping my own newcomer deaf identity and desire onto the scene. I was a newcomer not only to the American deaf signing community but, in this instance, also the southern French deaf signing community I was studying in Ramonville. Looking back now, I can also see how

I was mapping my own anxieties about how I understood American deaf identity politics as already excluding me in important ways onto this scene. My anxiety has been fueled by my sense of the inadequacy of my membership in all of these worlds. I was more than just a random anthropologist coming to some new village but instead was someone who was trying to make my way into deaf cultural communities –and in a decidedly non-anthropological way, I overlaid politics onto the scene.

This situation was complicated in two ways: I was a novice to deaf politics but also to French deaf politics. And, having two assistants more versed in navigating the signing and French scene made me also feel inadequate. Then there is also the issue of Patrick being a strong signer who knew not only how to navigate with ASL but also knew how to communicate across various international sign languages. Patrick was gifted in his use of sign and my attempt to interpret was not only for the benefit of Patrick but also was a way to perform to my informants my own new deaf, signing identity.

In response to my scolding, the informants took two tacks. Jerome responded that it's best for everyone that I speak in English, in essence telling me that they don't have any problem with my using the language most familiar to me. The teachers respond by telling me that the issue most pressing for them is something much more mundane—that the interview didn't go well because of work and family obligations competing for their time and because of being tired because of the long school day and school year. When the focus group teachers did not take up the “fake deafie” issue or my discussion of oppression but instead raised new issues unrelated to what I thought it had to do with, I was relieved as it seemed if there was any issue - it was settled.

In the days afterward, I did not address the “fake deafie” comment with the person who told me about it because they did not themselves raise the issue again. Later I learned whatever had been told to me about the “fake deafie” comment was surely either misinterpreted by me or by the person who told me. Apparently, there was conversation in the group of teachers about worrying Patrick would feel excluded, even as they understood he came knowing we could not secure an ASL interpreter. A while later, I learned that there was also discussion in the group outside the interviews indicating that informants were worried about me too at the time. Some in the group expressed empathy to me being a newcomer to the deaf, signing community. Because I was willing to be mollified by the responses that they were just tired and busy, I will never know whether in fact my informants had feelings about issues that in fact are important for understanding the internal politics of deaf communication norms and deaf differences.

The Anxiety of Interlocutors

I have written about my own anxiety, but have said little about the possible anxiety of my informants. For the intersubjective fieldworker, to be methodologically reflexive means turning the gaze not only inward (as is exemplified by the “confessional turn” in ethnography) but also outward toward what Crapanzano (1992; 2010) calls “the Third” in the fieldwork. In

James Davies' introduction to the edited volume *Emotions in the Field* (2010), he describes Crapanzano's use of the Third:

“Whatever dominates, the Third will influence what and how things are experienced by all parties to the encounter. Emotions do not necessarily emerge only out of “self,” or even out of self in interaction with other (intersubjectivity); they may also emerge out of the structures that surreptitiously shape these intersubjective interactions” (p. 16).

Davies (2010) argues for the need to recover emotions from the margins of fieldwork methods. Davies explains that the primary task of the reflexive ethnographer is to ascertain how emotions that materialize in fieldwork can help us to meaningfully engage with interlocutors and the things that happen in or emerge from the field. A core historical critique of mainstream social science methodologies has been its lack of attention to emotions and sometimes outright rejection or devaluation of emotions. This traditional empiricist, rationalist stance “drew firm lines between the researching subject and the research subject” (Davies, 2010, p, 2).

Although I can't know, it is very possible that they were concerned about my capacity to do justice to something that was so critically important to them personally and politically. Most of the teachers themselves are deaf and some of them have children who are deaf. They all have a vested interest in deaf education. Those who are deaf were among the first deaf teachers to be certified by the French Ministry of Education. The *classe LSF* program was at that time an experimental bilingual education program under intense scrutiny by the Ministry and was just beginning to be held up as a national model for deaf bilingual education. At the same time, however, they were being asked to contribute time well beyond the parameters of the normal teaching day. Given that they were not able simply to use the French national curriculum but had to adapt it for their students, they were required to spend far more time than most teachers in preparation work. They also spent considerable time with the students' parents and families. The teachers understood the importance of the research that was being conducted, but felt stressed by the burdens of their responsibilities. The potential that I appeared in some ways to them as less than up to the task of representing their work may well have given rise to their own anxieties.

The response, “We were tired,” was doubtlessly true, but it might also be true that the informants had thoughts and feelings about the legitimacy of my deaf identity that could have added to the richness of the study's findings. At the same time, by exploring this in greater depth, I may have been able to get at some of the nuance of these kinds of responses. If there are in fact hierarchies in deaf belonging, what functions do those serve in the school and the community? Might they have anything to do with the kinds of pressures the teachers, parents and children experience? Given the commitment of all involved to improving the lives of deaf children, what kind of challenges do deaf communicative difference create and how might their responses to me have been reflective of legitimate frustrations. This takes me back to an

intersubjective approach to critical disability studies, wherein I can begin to imagine something at work that is bigger than me or my informants as individuals. In fact, when we shifted from my concerns into the actual interviewing material in that session, my informants were able to productively discuss our shared anxieties and burdens of doing and participating in this research project—both those anxieties and burdens as insiders to the deaf community tasked with giving rare, insider “voices” and those anxieties and burdens having to do with the mundane pressures of their daily lives.

Conclusion: Anxiety as a Tool for Critical Disability Studies Fieldworkers

The stakes are high in writing about disability or deaf cultural life and have great potential to provoke intersubjective dynamics that enunciate individual, collective, and cultural anxiety. Under- and mis-represented communities such as the disabled and deaf have for so long been marginalized in larger society and in research that so often makes them the subject of normative responses to difference. For everyone in Ramonville, as is often the case of those participating in insider research, it was so important to provide honest, affirmative, and sophisticated responses to deaf daily life.

Recognizing the anxiety of the community and of the researcher can give rise to opportunities for difficult discussions within the community, including discussions of how to represent the issues raised for the larger readership of the research. To raise the issue of the “fake deafie” or even experiences of “deaf-on-deaf crime” is sensitive, an airing of the dirty laundry, because it raises criticisms that the outside community can use against the deaf community. This legitimate concern makes it difficult for the deaf community to consider the ways that we fail to support one another, and especially those who are newcomers to the community and/or to sign language. In my research, exploring anxieties can also help to flush out important cultural differences in how different cultures respond to deaf children. This allows things that are seen as natural or inevitable in a given culture to come under question. I want to make these implicit assumptions explicit and therefore make it clear how they are political choices. My goal is to expand our understanding of what is possible for deaf children.

What is so remarkable about my account of anxiety in fieldwork is how such accounts are rarely reported yet are really unremarkable in fieldwork. Our emotional and affective responses to fieldwork—our anxieties, fantasies, boredoms, surprise, pain, loneliness, anger, fear, and so on—these experiences are common to all fieldworkers, though they are especially common to fieldworkers doing critical disability studies work. In this conclusion, I argue for the need for researchers in critical disability studies to have a theory of anxiety. I also want to argue that this theory of anxiety needs to be a part of the critical disability studies researcher’s reflexivity toolkit. In short, this is necessary because the stakes for those of us doing critical disability studies research are so high for everyone. So-called “disabled” or rather deaf researchers like Patrick and myself are good examples the complexities of reflexivity as

insiders to the deaf experience who are conducting research on deaf kindergartners. Subjective and intersubjective phenomena that emerged in my fieldwork are equally as worthy of intellectual scrutiny as so-called traditional fieldwork data. As is clear from this case in Ramonville, how fieldworkers perceive their own lifeworlds and the lifeworlds of their informants drives not only how we are affected by the fieldwork but also how the fieldwork and our interlocutors are affected by us (and, in turn, us by them).

An intersubjective lens on fieldwork counters traditionalist arguments that objectivity can and should be achieved and, by extension, the argument that subjectivity impedes the accumulation of productive knowledge and research. The marginalizing of emotion from research is evidenced by the fact that such a small number research taps into the potential of emotion in comparison to traditional social science research. Davies (2010) argues it is ironic that this empirical, rationalist agenda so actively conceals or under-reports emotions nor attends to the critical ways our emotional responses affect fieldworkers and, in turn, affect the fieldwork and our interlocutors. This is especially true since “true” empiricism is supposed to be based on facts. And, it is a fact that emotions, like they are in everyday life, will be present in and affect our fieldwork, whether or not we acknowledge them and use them as a tool. I too want to call for the need for attending to emotions in fieldwork.

However, I find that anxiety in particular is pertinent to any critical disability studies project. This has to do with the fact that as critical disability studies fieldworkers we are tasked with advancing the political project of critical disability studies that at its core is about naming and responding to ablesist ways of knowing and being which also gives rise to oppressive systems and the subjectification of individuals with disabilities and, in my case, deaf folks. Critical disability studies needs to have a theory of anxiety. This theory of anxiety could have methodological implications for reflexive critical disability studies fieldwork as it takes into account the intersubjective. Circling back to the opening of this article and Devereux’s (1967) assertion that, “anxiety was not something to be avoided but is the driving force which propels our intellectual questings,” through an intersubjective lens we can see this is about not only my anxiety but a collective anxiety made up of the teachers, parents, Inspector, principals, and researcher anxieties (p. 12). Rather than avoiding it, anxiety may turn out to be one of our most important tools for being in relationship with self, other, and our experience of self with other in fieldwork (Stern, 1985; Crapanzano, 2003; Valente, 2015).

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Multimedia

Picturing Scary Places: the Horror Genre and Mental Illness Review of Disability Studies Interview with Perry Blackshear

Raphael Raphael

RDS Associate Editor for Multimedia & Creative Works

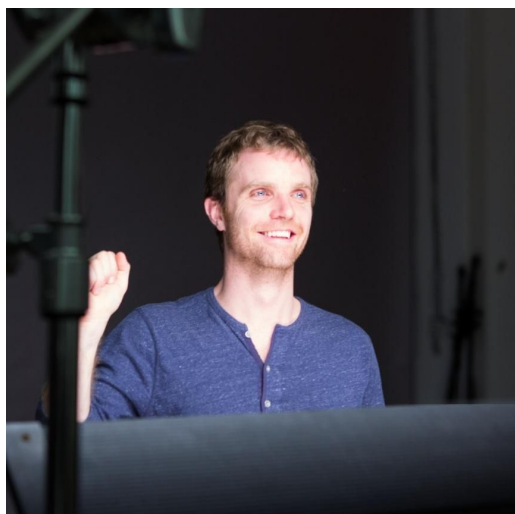


Photo 1: Picture of Perry Blackshear

At the time of this writing, the most popular film in the United States is a film about mental illness, a movie that makes its central character's disability a source of terror, M. Night Shalaman's *Split*. The film builds on a long lineage of films, (beginning at least with *Psycho* in 1960), that present those who suffer in their perceptions of experience as repellent villains that audiences are invited to fear and revile. Given the popularity of the genre and its intense visceral connection with audiences, horror may serve as an especially important space for cultural conversations about the nature of mental illness.

The following is an excerpt from a longer RDS interview with the filmmaker Perry Blackshear, director of the acclaimed independent horror film *They Look Like People*. The festival favorite about the experience of a sympathetic character enduring what appears to be a profound psychotic episode, is an unusual film. In addition to inviting audiences to identify with a character with mental illness, it is a horror film with few overt scares. It has also been considered the rare film that resists conventional genre boundaries, alternately considered drama and mystery, as well as horror. In this conversation, the director shares some of his intent with the film, the origins of his approach, and his feelings about the horror community's embracing the film as one of their own. He also shares some anecdotal experiences of the way those whose actual lives have been touched by mental illness have experienced the film. The interview was conducted by Raphael Raphael, RDS Associate Editor of Creative Works and Multimedia.

RDS: For those who haven't seen the film, can you give a quick overview?

PB: The movie's called *They Look Like People*. It's a story about love and nightmares. Quick plot is that a young man thinks the world is being taken over by evil creatures. He doesn't know whether to protect his best (and only) friend from what he thinks is a war that is going to happen or from himself because he's actually losing his mind and is going to start hurting people.

RDS: Some of the reviews of your film focus in on the strengths of the relationships you create along with the effective elements of horror. I have just written a book on so I've been viewing a lot of contemporary films in the genre. Your film is among the finest, most elegant of the contemporary pieces I've seen. And while your film is generally classified as horror, many of those who review your film frequently describe it as bending genre. With this in mind, how do you define it? Do you call it a horror film?

PB: This is a discussion we had a lot early on. Originally, we were very inspired by two films. One of them was Jeff Nichols' *Take Shelter*. It was clearly a drama with a little supernatural or thriller element. The other was *Absentia* by Mike Flannigan. It was very much set in the real world. I read an interview early on with him, and he was asked if it was a horror movie. He responded that it was a movie about people undergoing very scary things.

I thought that was very nice. [M. Night Shalman] talked about *Sixth Sense* in the same way. [*They Look Like People*] wasn't supposed to be scary originally; it was supposed to be more like *Take Shelter*. I'm not an expert [on mental illness] but I did a little bit of research, read a few textbooks, did some digging, looked at some people's stories. [Their experiences were] so scary that it ends up being much scarier than we thought it would be. We also didn't know how people would react until we saw it in a theatre for the first time with a crowd.

RDS: (Laughter). Is that right?

PB: We didn't plan it to be a horror film. We just planned it to be sort of more like a--I don't know -- like a romance, but a non-sexual romance between old friends, and a drama about struggling with failure, but it ended up being a lot scarier than we thought, I think. So the whole [horror] community kind of adopted it.

And it got into a lot of horror festivals. We're still try to list it on IMDB not as a horror film but as a drama, a thriller and a mystery. But it became adopted a little bit.

RDS: With the adoption, are you okay with it being called a horror film?

PB: There's been an interesting discussion online about the recent sort of indie horror [revival], with *It Follows*, *Babadook* and *The Witch*. There was a group of people saying that horror is like metal: you can't just be some [poser] and come in and pretend to do it...

Like the blues, it's something you have to earn, it's like blue-collar, a terrible life, blood...(Laughter). So I wonder if whether a movie is scary enough or not [is not a sufficient criteria]. There are some horror films that are not scary at all.

I had never heard that argument. I think it's actually kind of a compelling one. So we tried very hard when we to talked to people about it to let them know it wasn't a typical horror film because we didn't want people to be disappointed. So I'm conflicted about [the film's designation as horror film]. The best scary movies put you through a kind of frightening journey, and you feel you emerge from it kind of relieved, like from a nightmare where you wake up and you're like "oh gosh."

And I like that part of it, and I like the force of it. But I don't like some of the elements [of the

genre] that are very "gross." And what they say about people not caring about human life. I don't know, there's part of it that has sort of a dirty conscience that I don't like. So I'm conflicted about it.

RDS: Yours is really ultimately a life-affirming film.

PB: I hope so.

RDS: So basically it sounds like you reluctantly accept the way it has been adopted by the horror film community.

PB: Yea, the best compliment I've gotten is from folks that were ready to just see another horror film and then had a great experience. If you look at a lot of good drama, it's actually not that different from those but it's very different from a lot of the sort of run-of-the-mill horror films. So people find it a nice palate cleanser after watching a lot of other kinds of horror.

RDS: Yes.

PB: The best experience I've had has been at screenings in which people find stuff in the film [that has meaning for them]. There was a young man whose brother was in the army and had undergone something like [what's depicted in the film], and the young man was still struggling with it, with his brother. He came up to me in the Q & A and he was crying, then I started crying.

We didn't really even talk much, we just sort of sat there. That was pretty cool. I think there are a lot of great movies [addressing these issues] that are dramas but people don't see them. The film is based on a friend of mine who had a really bad string of luck. He lost his job and his girlfriend/fiancée. He had one week where, he told me afterwards, if he didn't have some good friends and a good family, he would probably be in jail, or dead. He's fine now, he's married and doing well. I wanted to make a movie about that week.

RDS: Yes.

PB: I think a lot of people when they're undergoing tough stuff go through a smaller version of what Wyatt [the central character] goes through.

RDS: Got you. I have read elsewhere you mentioned films that were inspirations; you just mentioned *Take Shelter* and *Absentia*, and I think elsewhere you talked about *Jacob's Ladder*. Where there any other films that inspired the work?

PB: *Jacob's Ladder* was actually never in my mind while making it. I can see when people talk about it--it makes a lot of sense--I had seen that movie many years ago so maybe it came through. But definitely the ones that I was watching or re-watching while I was making it--some of them are not actually even horror movies. *Babadook* came out while I was editing, and that was quite influential. *Let the Right One In* showed me that you could have a wonderful love story between kids and a scary vampire movie, and one made the other one more powerful. And also bizarrely there was a movie called *Fishtank*.

RDS: I haven't seen that one.

PB: It's a drama in England and the only thing that's remarkable about it--I mean it's a good movie -- but the third act jackknives into a totally different direction, and that was my inspiration for the last act of *They Look Like People*.

RDS: You mentioned a moment ago, and I've read elsewhere that you've talked about being approached by people who have seen the film and say it really resonates with their own personal experiences in either their own life or with a loved one. You mentioned the gentleman with whom you had a really intense moment together just being with the experience. I'm wondering what other kind of things have you heard about the way that it resonated with people's experience with mental illness?

PB: I think that when we were making it originally, we had ideas of it being a little bit more of an actual sci-fi type of movie. But when we decided to make the ending the way it was, I never wavered on [an approach emphasizing the experience of mental illness] for a minute. A lot of people were trying to get me to go the other way, and I held to that because that was my belief. When we decided we wanted to go that route, we really tried to do our research. The actor Macloud and I watched some documentaries; I read [books] on psychology, a few chapters on schizophrenia. We did what we could. There is also a video I think, it may have been through PBS, of sort of a VR experience of what it's like to be schizophrenic.

RDS: Yes.

PB: It was so frightening. We took a lot of inspiration from that. We knew we could not be experts. We wanted to have that moment in the movie when [the doctor] mentions schizophrenia and [the main character] sort of dismisses it, not to dismiss schizophrenia but to [show resistance to being labelled with the diagnosis].

From what I've read, mental illness is sort of stigmatized in a way that once you "have it," *you are* "mentally ill." And there's a hard line drawn there. From what I read, that's a bit of an archaic system; it stigmatizes [the experience] more than it should. Whether you have a history of depression, a mild bipolarism, or borderline, it's all a spectrum. I don't know whether this is valid, but the literature that I read points this way, that that's kind of where people want to try to push it.

It is sort of once you get the label that's sort of your life, like [the way the term 'cripple'] has been used. So we tried really hard not to make it [a totalizing definition of him], "oh, he schizophrenic," but rather let the film demonstrate how a series of factors: timing, brain chemistry circumstance, and upbringing helped this stuff "kind of explode."

And, moreover, to treat it as something very complicated.

RDS: Beautiful.

PB: The other thing we tried really hard to do was to show that always whenever we were

writing it-- and I told the guys to call me on this—was to make sure he was never “plain crazy.” So whatever was happening, all of his motivations needed to be that of a rational person trying to do the right thing with this awful stuff in his head.

RDS: Yes, that really comes through.

PB: So in the same way, I've never really experienced this, but when I'm very drunk (Laughter) or undergoing tremendous pressure from a break up or something, I think at the time [what you're thinking] makes sense but afterwards you like “that's crazy, that's awful.” But at the time when you're going through it, it totally makes sense. We knew we wanted to do our homework because we were really scared about [misrepresenting or minimizing the experience of] someone that had actually undergone this.

We get a lot of Q&As where people say “I work in the mental health field and we go”: [yikes!]. (Laughter). And so far in the Q&A's, we've always had positive responses and that's been really good. [This hasn't always been the case] for my other friends who have made movies [about other people and identified groups' real experiences]. So it's very scary when you're a filmmaker and you make a film about something that isn't yours; so many people have done it wrong. And you try to do it right.

RDS: That attention is really evident in the film. Coming from a disability studies perspective that considers the ways that disability might be constructed in the ways in which it may be represented in media, it's obvious that you've done your homework and really bring a thoughtful approach to your depiction of mental illness.

I know that you mention this VR experience was among your inspirations. (I think it was Janssen Pharmaceutical). And part of their purpose was to try to have people see what it's like to experience schizophrenia so that caretakers and families could better understand what it's like and not just pooh-pooh it and say “you would be better if you just tried harder.” A similar intent really seems to come through with your work. MacLeod's character (Wyatt) comes through as a sympathetic character, and as you described, a rational person doing the best with the sensory information he has.

A few other questions: a great deal of what makes your work so effective is kind of what is not seen. I have read elsewhere that you say that some other films kind of dampen their ‘fear factor’ by showing the object of fear directly, like Babadook and Conjuring do. I think you mentioned that there's a certain relief for the audience once they've seen it, and in yours we never fully have a reveal of what is in his mind's eye. And you mentioned that you scaled back a lot. Originally were some of his visions more visible?

PB: In an early draft of the script, we had kind of *Emily Rose*-style demon faces. We did a very long post-production process. What we discovered every time we showed [something

scary]—there's really only two 'scares' in the movie: one is the moment the jaw is sort of unlocking, and the face changing—we found whenever we did that, once that moment was done, it was sort of a weird thing; it was like blowing up a balloon and releasing it: you had to work harder to pump it up, everytime.

John Carpenter said something interesting which is you have to scare the be-Jesus out of them right away so they'll be freaked out for the next 80 minutes. [In the process of making this film], I went through a lot of the movies that scared me and tried to write down what I was thinking about as I was watching. *Paranormal activity* is a pretty good movie, but it's really masterful at how little shown can be so scary.

RDS: For sure.

PB: When there's a monster with a sword and a kind of corporeal danger [it's one thing], but when it's your *own brain* and you can't trust it at any given second that's much scarier. There were ready two sides: I did what ended up scaring me the most; and technically, in film, we found it was much scarier the less we showed. It's pretty simple. I would also say it changes for different people. Sort of like how some people think awkward humor is funny, and some people find it painful. People like the jolty kind of scares [or not], depending on personal taste.

RDS: Judging by a lot of the reception of your film, it seems people are hungry for that restraint that you've shown.

Blackshear, Perry (Director). Evan Dumouchel, MacLeod Andrews, and Margaret Ying Drake (Performers). (2015). *They Look Like People*. United States: Gravitas Ventures, 2015.

Submissions: We welcome submissions of interviews/ artist statements from working media professionals as well as film and media reviews, responses or creative works that dialog with concerns about ability.

Questions, see submission guidelines at:

<http://www.rds.hawaii.edu/ojs/index.php/journal/about/submissions> or contact Raphael Raphael, RDS Associate Editor, Creative Works and Multimedia: raphael@hawaii.edu.

Dissertation Abstracts

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