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**Small Bodies, Large Presence:**

An Exploration of People with Restricted Growth  
Experiences and Interactions in Social Spaces

Submitted for the Degree of Masters of Arts in  
Disability Studies

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For Mo

**Abstract**

People with restricted growth otherwise labeled as people with dwarfism or little people often encounter discrimination in their daily interactions with strangers in public spaces. Their small stature and bodily differences can produce strong reactions toward them from shock, pity, disgust and even hatefulness and violence. Staring, harassment, infantilization, teasing and unauthorized picture taking are some of the behaviours people with restricted growth encounter.

This project examines how interpersonal discrimination operates as a disabling external force for people with restricted growth. Qualitative in-depth interviews are utilized to explore these experiences and the meanings behind them. It is revealed that the social and cultural representations of people with restricted growth, both throughout history and today, have formed and continue to perpetuate prejudiced attitudes toward them. These attitudes often result in unique forms of discrimination.

This project analyzes the experiences of people with restricted growth, explores the possible origins of these experiences and reveals ways discriminatory attitudes and behaviours can be countered. The history of the social and cultural roles that people with restricted growth have occupied is reviewed, providing an understanding of how their cultural representations have been formed. Theories of stigma, normality and liminality are examined to explain the interpersonal discrimination they encounter.

The perspectives of people with restricted growth are valuable to incorporate into the dialogue of how disability operates through social and cultural realms, and this perspective is largely missing from research in disability studies. It is the aim of this project to examine how their unique experiences and perspectives can aid in understanding how external forces operate and oppress disabled people.

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## **Chapter One**

### **Background and Project Goals**

*One's dignity may be assaulted, vandalized, cruelly mocked, but it can never be taken away unless it is surrendered*

-Martin Luther King Jr.

#### **I. Background**

Every day, people with restricted growth (RG), also labeled as people with dwarfism or little people (LP), must navigate public spaces while dealing with a myriad of reactions to their short stature and physical differences (Shakespeare et al. 2007; Adelson 2005a; Adelson 2005b; Ablon 1984). Social interactions and encounters with strangers illustrate a range of attitudes toward them from curiosity, pity, kindness, harassment, disgust and even hatefulness and violence (Shakespeare et al. 2007; Kruse 2002; Kruse 2003; Adelson 2005a; Ablon 1984). Previous research has identified that interpersonal discrimination is a barrier to full social and economic inclusion for people with RG (Shakespeare et al. 2007; Adelson 2005a; Adelson 2005b; Kruse 2001; Kruse 2003; Ablon 1984).

Theories of stigma, “normality”, cultural anthropology and social psychology have been used to explain this discrimination (Garland-Thomson 2009; Davis 2006; Adelson 2005a; Marks 1999; Shakespeare 1997; Goffman 1966). However there has been a lack of research that explores what people with RG believe to be the social and cultural meanings behind these encounters and what their understandings reveal about the nature of public attitudes toward them (Shakespeare et al. 2007; Adelson 2005a; Kruse 2001; Kruse 2003).

The day to day experiences and insights of people with RG provides an understanding of social reactions to physical “abnormality” and the influence of culture and ideologies on social attitudes and behaviours (Shakespeare et al. 2007; Kruse 2001, Kruse 2003). The perspectives of people who encounter

these attitudes and behaviours directly are essential to understanding these experiences and situating them into broader sociological theories and contexts. By examining how people with RG navigate these interactions, we are able to identify the origins of these attitudes and how they can be challenged (Kruse 2001; Kruse 2003).

This research project explores the experiences of people with RG from firsthand accounts of interactions with strangers in public spaces and the meanings these individuals attribute to their experiences. This project will contribute to a dialogue on how people with RG provide a unique and valuable perspective in the study of disability, which has, thus far, been largely ignored (Shakespeare et al. 2007; Adelson 2005a; Ablon 1984).

The first chapter will describe the aims of the research project, discuss the definitions and terminology for people with RG and provide an overview of how the research was conducted and how this, ultimately influences the structure of the dissertation.

## **II. Project Aims and Structure**

The primary aims of this project can be divided into three parts: to record the experiences of people with RG in social spaces, to listen to what they understand to be the reasons for these experiences, and to compare and contrast these meanings with previous theories on the discrimination and oppression of disabled people in social interactions. The goal is to identify the unique experiences and perspectives of people with RG and examine how these can add value to the discussion of disability. Through in-depth interviews the perspectives of people with RG were gathered, generating complex qualitative data that represents the diversity and nuances of people with RG experiences, as well as their commonality (Silverman 2011).

This dissertation is divided into seven chapters. Chapter one introduces the main objectives of the research project and outlines how the dissertation is structured. Chapter two reviews literature that addresses the specific



interpretation of the social model of disability and culture that will be applied in this dissertation, as well as an overview of the concepts of normality and stigma (Davis 2006; Snyder and Mitchell 2006; Priestley 1998; Oliver 1990; Goffman 1966; Williams 1961). Chapter three will highlight the accounts pertaining to the lives and experiences of people with RG, both historically and today, and the themes illuminated through literature (Shakespeare et al. 2007; Adelson 2005a; Adelson 2005b; Adelson 2005c; Kennedy 2003; Kruse 2001; Kruse 2003; Ablon 1984). The issue of a disabled identity or label for people with RG will also be reviewed.

Chapter four will breakdown the methodology the research project took, including the role of the researcher and the strengths and challenges of the chosen methods. It will also outline how the data was analyzed. In chapters five and six the findings of the research data will be presented. These chapters will identify the recurrent themes revealed through the research generation pertaining to both the participants' experiences in social spaces and the meanings they attribute to these experiences. Previous discussions and theories surrounding interpersonal discrimination toward disabled people and the issues of culture, normality, liminality and disability will be integrated into these final two chapters; analyzing how the participants' views reflect or diverge from these theories.

In the concluding chapter the main findings of the data will be summarized, reflecting on the insights and knowledge gained from this research project. The final chapter will also illuminate what issues would benefit from further exploration.

### **III. What's in a Name: Terminology for People with RG**

To contextualize the issues that this project seeks to examine it is valuable to first define restricted growth (RG) and discuss the terminology used to label people who fall under this term. RG is defined as a person with an adult height of 4'10" or below (or a child who will not grow above this height) who also has a physical impairment that causes their height to be restricted (Shakespeare et

al. 2008; Ablon 1984). There are over 200 impairments which can cause restricted growth (Shakespeare et al. 2008; Ablon 1984). The majority of these impairments also produce bodily differences in proportions and bone and muscle structure (Shakespeare et al. 2008; Adelson 2005c). While each impairment has a specific name, restricted growth (RG) is an umbrella term that is often used to encompass all people who fall within this category (Adelson 2005c). Similar to movements by other groups of disabled people, there has been a fight to establish terminology for people with RG that is empowering and part of a positive individual and social identity (Kennedy 2003; Ablon 1984). Punch (Punch 2005 p. 177) reasons that “the meaning of words derives largely from their use”. This has been especially true of the terminology or labels assigned to people with RG (Ablon 1984).

The word “dwarf” is derived from the old English term “dweorg” meaning “very small human being” and has been used commonly in the English language to refer to a person with RG in both medical and social contexts (Online Etymology Dictionary 2013; Adelson 2005a; Ablon 1984). “Dwarf” has also been used to label a non-human mythical being similar to a troll or gnome in fairy tales and children’s literature (Adelson 2005a; Ablon 1984). The term “dwarfism” is commonly used to describe all impairments that cause RG in both social and medical contexts (Adelson 2005c).

The term “midget”, generally considered the most derogatory and offensive term, was first used in reference to people with RG by businessman, P.T Barnum, in the mid 18th century (Garland-Thomson 1997). Mr. Barnum had an empire of circuses and exhibits in the US, a number of which promoted “midgets” as entertainers and celebrities (Garland-Thomson 1997; Gerber 1992; Howells and Chemers 1992). The etymology of the term “midge” or “small fly” was utilized to apply the term midget to people with RG who were proportionate, contrasting them against “dwarfs” who were people with RG that had different bodily proportions (Adelson 2005a; Gerber 1992; Howells and Chemers 1992).

The term little person (LP) which was coined by an organization in the US called Little People of America (LPA) is used most often in the US and Canada to describe people with dwarfism (Adelson 2005a; Ablon 1984). In the UK restricted growth (RG) is a commonly used term (Adelson 2005b; Ablon 1984). There are a number of debates surrounding the use of all the terms outlined above, with people both advocating and objecting to each term for different reasons (Kennedy 2003; Ablon 1984). This reveals a challenge in reconciling past labels that were used to categorize people with RG in accordance with their cultural representations and social roles (Adelson 2005a; Gerber 1992).

This paper will use the term people with RG with the awareness that this may not be a label that all people who have an impairment causing a height of below 4'10 identify with. The debates surrounding the terminology were a factor during the research process and will be further discussed in chapter three.

## **Chapter Two:** **What Has Gone Before: Literature on the Social Model, Normality and Culture**

### **Introduction**

This chapter will begin with an overview of the social model interpretation of disability that will be used in the research project. Following this a definition of culture and the ideal of normality will be examined. It will also address how the concept of stigma has become a central explanation of discrimination towards people with RG in social spaces.

### **I. The Social Model and Defining Disability**

The social model attributes the socio-economic, cultural, political and environmental barriers disabled people face as a direct result of society's exclusionary policies, structures of inequality and disablist attitudes (Barnes and Mercer 2003; Oliver 1990; UPIAS 1976). The Union of Physically Impaired Against Segregation (UPIAS 1976) provided the first definition of "disability"

that utilized the concepts central to the model stating, “disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society” (UPIAS 1976 p. 14). The social model separates disability from impairment, which is defined as an individual’s physical, psychological, intellectual or sensory diagnosis or condition (Barnes, Oliver and Barton 2002; Oliver 1990). The social model was developed in opposition to the individual model of disability, which assumes that an individual’s impairment is the root cause of all social, economic, cultural and environmental barriers they encounter (Barnes and Mercer 2003; Oliver 1990). The individual model maintains that disability is a “personal tragedy manifested in the material condition of the individual” (Priestley 1998 p. 79). The social model counters this perspective by claiming that:

Disability has some real collective existence in the social world beyond the existence or experience of individual disabled people (Priestley 1998 p. 83).

The social model provides a conceptualization of disability that allows disabled people to politicize the social, cultural and economic oppression they experience, this forms:

(...) a direct attack on the disablist notion that [they are] nothing more than victims of defective bodies (Hughes and Paterson 1997 p. 31).

The social model will be used as the basis for defining disability for this research project (Priestley 1998; Oliver 1990; UPIAS 1976). There are a number of debates surrounding how the social model should be interpreted and which sociological paradigms and theories are most relevant to explain the model (Shakespeare 2006; Armer 2004; Bailey 2004; Priestley 1998; Crow 1996; Shakespeare 1996; Oliver 1990). Priestley (1998) succinctly forwards the two divergent interpretations of the model that have been debated. First is the view of disability as a:

(...) material product of socio-economic relations developing within a specific historical context (Priestley 1998 p. 78).

This view links the creation of disability to materialist or Marxist theories of power and oppression (Barnes and Mercer 2003; Priestley 1998; Oliver 1990). Specifically that industrialization led to the institutionalization, isolation and denigration of disabled people in social and cultural spaces as they were deemed detrimental to the development of a capitalist economy (Oliver 1990).

An alternate conception of the social model switches focus from socio-economic relations to culture and values, defining disability as:

(...) a social construct – the idealist product of a society developing within a specific cultural context (Priestley 1998 p. 81).

This interpretation contends that cultural forces, including norms, values and representations, construct and perpetuate disability (Snyder and Mitchell 2006; Armer 2004; Priestley 1998). While these values and norms can be influenced by material structures of power, one “specific historical context” is not required in the creation of disability (Priestley 1998). The constructionist or idealist interpretation of the social model will be used in this research project (Priestley 1998). Ideology can be understood as “a system of theoretical domination which justifies oppressive social relations” (Shakespeare 1997 p. 289). Priestley (1998 p. 89) finds that “values play a central role in oppression when they function ideologically”. How cultural values and beliefs are linked to and become part of the dominant ideologies is debated and will be discussed in the next section several sections of this chapter (Snyder and Mitchell 2006; Priestley 1998).

## **II. Defining Culture**

Defining culture is no simple task. Smith (2003 p. 4) contends culture is “a slippery, even a chaotic concept”. While many associate culture with art, literature and music it can also represent the entirety of “ideas, customs, and

social behaviour of a particular people or society” (Oxford Dictionary 2013).

This project will use two central explanations of what culture is as forwarded by Williams (1961).

Culture can be defined as:

(...) the body of intellectual and imaginative work, in which, in a detailed way human thought and experience are variously recorded (Williams 1961 p. 41).

These recordings are “described and valued” according to either their quality or resonance within a particular culture at a particular time (Williams 1961 p. 41). Culture can also be understood as:

(...) a description of a certain way of life, which expresses certain meanings and values not only in art and learning but also in institutions and ordinary behaviour (Williams 1961 p. 41).

How cultures create and express the meanings and values assigned to disabled people as well as how they have been represented in cultural recordings is important to understanding their oppression (Snyder and Mitchell 2006; Barnes 1997; Shakespeare 1997; Williams 1961).

Snyder and Mitchell (2006) focus exclusively on culture in their understanding of disability as well as impairment. That cultures:

(...) classify and pathologize human difference (known today as disabilities) and manage them through various institutional locations (Snyder and Mitchell 2006 pp. 4-5).

Barnes (1997) uses a materialist perspective and forwards that the denigration of disabled people in cultural recordings and representations is related to their exclusion from the modes of production and the ideology of capitalist individualism that pervades all aspects of social life (Barnes 1997). He argues that literature and cultural imagery work to reinforce the beliefs that people with impairments are socially undesirable, dependant and a drain on economic

resources (Barnes 1997). Shakespeare (1997 p. 225) contends that, while examining socio-economic influences is vital, “the role of culture and meaning is crucial, autonomous and inescapable” in understanding disabled people’s oppression. He examines the concepts of “otherness”, borrowing from feminist theory and philosophy to explain how disabled people are categorized as lesser in relation to the dominate groups identity, which is primarily male and non-disabled (Shakespeare 1997).

The “slippery” and “chaotic” (Smith 2000 p. 1) concept of culture makes it difficult to pin down all the direct and subtle ways that cultural values, meanings and representations oppress disabled people (Snyder and Mitchell 2006). This research project will demonstrate, through the participants’ perspectives in chapters four and five, how both the recordings throughout history on people with RG as well as the meanings and values assigned to their cultural representations are oppressive (Adelson 2005a; Ablon 1984). One of the most dominant cultural values that has proliferated the individual model of disability is the value or idea of normality, which will now be outlined (Davis 2006; Abberley 1997; Hughes and Paterson 1997; Shakespeare 1996).

### **III. What is Normal**

Disabled people have been and are still labelled abnormal for their physical, sensory, intellectual and psychological differences (Davis 2006; Armer 2004). It has been argued that social and cultural conceptions of normal and abnormal reduces the social status of disabled people and perpetuates their oppression (Davis 2006; Armer 2004; Paterson and Hughes 1997; Hunt 1966; Goffman 1966).

How the concept of normal developed, and its relationship to social structures and culture, is complex and multilayered (Davis 2006; Snyder and Mitchell 2006; Armer 2004; Barnes 1997; Shakespeare 1997). Davis (2006) traces the historical origins of the term “normal” in the English language. He suggests that it was created at the beginning of the 19th century through scientific

discoveries using statistical measurements (Davis 2006). Behind these developments were eugenic beliefs of racial inferiority and the linking of social deviance to genetic abnormalities (Davis 2006). Abberley (1997) and Oliver (1990) locate the propagation of the normal/abnormal divide as a result of materialist ideology. This view forwards that the individual model of disability is proliferated through a belief in capitalist individualism that:

(...) is made possible by the somatic dichotomy that distinguishes between normal and abnormal bodies (Hughes and Paterson 1997 p. 39).

Armer (2004) contends that while initially the ideology of materialism constructed the concept of normal:

(...) the abnormality of disabled people has progressed from an edifice constructed on material foundations to a societal concept that now has a very large cultural component (Armer 2004 p. 19).

Garland-Thomson (2009) also examines how normality developed as a product of industrialization. She incorporates the concept of rationalization to forward how “things and people must fit into pre-existing patterns and templates for modern information systems to process them” (Garland-Thompson 2009 p. 30). This rationalization leads to a prescription for normal and the categorization and devaluation of those who are abnormal, as explained:

(...) *abnormal* reduces people’s economic and social status and relegates them to the outer edges of the human community (Garland-Thomson 2009 p. 31, italics in original).

Marks (1999 p. 51) identifies how western medicine has focused on eradicating abnormality, classified as “pathological and dysfunctional,” by making specific judgements on what is functional and normal for a human body.

While “abnormality” can be understood as a modern concept, the roots can be traced back centuries in Western culture to Greek and Roman beliefs



surrounding deformity (Davis 2006; Sullivan 2001). It has been contended that:

Our attitudes toward deformity are a product of a particular value system inherited from Classical Greece (Sullivan 2001 p. 262).

The Greeks believed “in the perfection of the human form and the concomitant rejection of deformity and disfigurement” (Sullivan 2001 P. 262) and practiced infanticide for deformed infants (Adelson 2005a; Sullivan 2001). Since the Classical Greek era, Western cultures have continued to revile physical deformity, associating it with sin, evil and corruption (Sullivan 2001). This view has been proliferated through religion, art, law and literature (Davis 2006; Sullivan 2001; Barnes 1997).

#### **IV. Stigma: Abnormality Experienced**

Goffman (1966 p. 5) sought to explain how a person’s “undesired differentness” including physical abnormality, separated them from the rest of society with his concept of stigma. Borrowing the term “stigma” from the Greeks who used the term to apply to those they had physically branded to identify their lesser social status as “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman 1966 p. 1). Goffman forwarded that stigma was used in modern society to assign a “discounted trait” to those who were “socially abnormal”:

The dwarf the disfigured the blind man the homosexual [...] they are all socially abnormal and therefore in danger of being considered less than human. (Goffman 1966 unpagged)

Under Goffman’s view social interactions are influenced by the presence of stigma, relegating the stigmatized to a lesser social status (Garland-Thomson 1997; Goffman 1966). Stigma has been both incredibly influential and highly criticized (Abberley 1997; Finkelstein 1980). Many have dismissed it as an

outdated theory that perpetuates the individual model of disability (Abberley 1997; Finkelstein 1980).

Abberley (1997) takes issues with Goffman's stigma believing that it reduces the discrimination of disabled people in public to inevitable psychological reactions to 'abnormality'. He forwards that Goffman (1966) does not examine how inequalities between disabled and non-disabled people are the result of larger power structures and beliefs that disabled people are inferior (Abberley 1997 p. 5). Finkelstein also rejects stigma contending that it "serves to shift the attention from those who create the problem on to those who begin to appear as the ones who signify it" (Finkelstein 1980 p. 20).

While Goffman's (1966) theory may not be sufficient to explain why stigma occurs, it can assist in identifying how it becomes socially acceptable to treat stigmatized individuals certain ways. Garland-Thomson (1997) explains:

The process of stigmatization thus legitimates the status quo, naturalizes attributions of inherent inferiority and superiority, and obscures the socially constructed quality of both categories (Garland-Thomson 1997 p. 31)

Stigma is often cited in documents that explore discrimination against people with RG and is commonly used to explain why they, as well as other disabled people, are treated negatively in public spaces (Adelson 2005a; Kruse 2003; Ablon 1984). What is behind the assignment of stigma is often left unexamined and we are forced to take a closer look at what constitutes a stigmatized trait to understand the origin of its devaluation (Adelson 2005b; Ablon 1984).

The next chapter will review literature that has identified the treatment that people with RG encounter (which many people attribute to stigma) in public spaces. It will also provide accounts of the cultural categories and roles that have been assigned to them throughout history.

### **Chapter Three:**

#### **Hidden in Plain View: People with RG in History and Culture**

##### **Introduction**

The differences and rarity of the impairments that cause RG make it challenging to find literature that reflects the diversity of the experiences of all people with RG (Adelson 2005a). There is a dominance of representations of people with RG who have Achondroplasia, both in historical literature and literature of today (Adelson 2005a). The distinct physical characteristics of Achondroplasia, the most common form of dwarfism, are often represented as the typical person with RG, despite the hundreds of other impairments that cause RG (Shakespeare et al. 2008; Adelson 2005a).

Disability activist and PhD candidate Joseph Stramondo participated in an interview for this research project (Stramondo 2013). His research focuses on how attitudes and meanings assigned to disability and impairment influences bio-medicine in the US (Stramondo 2010; Stramondo 2011). Stramondo has RG and is an active volunteer for Little People of America (LPA). Stramondo (2013) cautions:

When you talk about the experience of dwarfism you don't want to treat it as a unity, as some kind of monolith, because it can be really complicated and diverse even within the community itself (Stramondo, 2013 personal correspondence).

However the accounts that are available of people with RG lives and experiences do provide insight into how they have been perceived in social and cultural realms with the caution that these accounts cannot be applied to all people with RG throughout history (Adelson 2005a; Howells and Chemers 2005).

Adelson (2005a) contends that “the history of dwarfs is embedded in the history of civilization in general” (Adelson 2005a p. 3). There are a large number of documents that contain reports of people with RG; most often found

in medical journals and anthropological research and they have been represented in paintings, sculptures, cultural artifacts and fictional literature (Adelson 2005a). However few of these accounts and representations offer a well-rounded, real depiction of the diversity of their lives and experiences. We are left to piece together an understanding of their lives from fractured, biased and second-hand accounts (Shakespeare et al. 2007; Adelson 2005a). The work of Adelson in *The Lives of Dwarfs: Their Journey from Public Curiosity to Social Liberation* (2005a) counters this. Adelson's work (2005a, 2005b, 2005c) seeks to identify the relevant issues pertaining to the social and cultural meanings assigned to people with RG by utilizing their own perspectives in her investigations.

### **I. Gods, Animals and Circus Freaks**

While "every society has treated dwarfs differently" (Adelson 2005a p. 3) and forms of this differential treatment range considerably, common themes on the beliefs and perceptions of people with RG can be found. Throughout history there has been an overarching belief that people with RG are separate from the rest of humanity; a different species or "race" closer to gods, mythical beings or animals than humans (Adelson 2005a; Gerber 1992). The belief that people with RG were non-human or were in possession of non-human qualities was propagated from ancient Egypt to the early 20th century (Adelson 2005a; Gerber 1992). Ancient myths and religions supported this view, depicting people with RG as symbols of fertility, evil, mischief, and goodness and linking them to magic and godly powers (Adelson 2005a; Barnes 1997; Gerber 1992; Ablon 1984). It has been contended that in ancient Egypt people with RG were revered and attributed with high intelligence (Adelson 2005a; Ablon 1984). The Egyptian god of childbirth and midwifery, Bess, was depicted as a dwarf (Adelson 2005a). Garland-Thomson (2002) explains how this perception of impairment:

(...) springs from a premodern interpretation of disability as either augury or marks of distinction, whether representing good or evil (Garland-Thomson 2002 p. 59).

Historical accounts of individuals with RG mostly document those who lived higher profile or more public lives (Adelson 2005a). For centuries, a number of people with RG lived as a court dwarf or “pet”, who were owned by royalty and nobility and kept for their entertainment and comfort (Adelson 2005a; Gerber 1992). While court dwarfs often lived in luxury and could be perceived to have a higher quality of life than most people in their time, they were denied free will and autonomy. They were treated as incapable of achieving or desiring the same life goals, and having the same feelings and emotions as “normal” people (Adelson 2005a). They were infantilized and their inclusion in the court circle was to satisfy the whims of those who owned them (Gerber 1992).

In the early 19<sup>th</sup> century until as late as the 1960’s, people with RG were often on display in freak shows or performed as circus dwarfs in travelling roadshows (Gerber 1992). Howells and Chemers (2005) chronicle the rise of “midget cities” or amusement parks at the turn of the century which were communities of people with RG visited by the public for a fee. Living in midget cities or working as a circus dwarf allowed many people with RG to earn a living and provide for their families in the absence of other opportunities (Howells and Chemers 2005; Gerber 1992).

In more recent times, people with RG have been represented in popular culture through fairy tales and popular children’s stories and films such as *Snow White and the Seven Dwarfs* (1938), *The Wizard of Oz* (1939) and *Willy Wonka and the Chocolate Factory* (1971). In all of these cases people with RG are portrayed as separate from humans and either possessing or representative of non-human qualities. In recent years there has been popularity in reality television programming following the lives of people with RG in the US and UK - such as *Little People, Big World* (TLC 2014), *The Tiniest Boy in Britain* (Channel 5 2010) and *The Little Couple* (TLC 2014). The majority of people

featured on these programs are depicted as accomplished individuals going about their daily lives as any other person. Additionally these programs often feature a running dialogue on the issues of being a person with RG. However there has been debate over whether these shows promote a new kind of voyeurism and play into the concept of “freak shows” of the past (Backstrom 2012; Kennedy 2003).

People with RG, particularly in the western hemisphere, now live largely autonomous lives (Adelson 2005a; Ablon 1984). They are represented in most professions, are equal and valued members of their families, and are respected and acknowledged as individuals in their social and professional circles (Kruse 2003; Kruse 2002; Kruse 2001; Ablon 1984). There are many examples of people with RG who have been honoured and renowned for their artistic, academic, or social achievements (Adelson 2005a; Koren and Negev 2004; Ablon 1984). However the stereotypical cultural imagery of people with RG continues to be perpetuated and some people with RG still work in avenues that have been described as degrading and dehumanizing (Adelson 2005b; Gerber 1992). In 2009 a “dwarf empire” or midget city amusement park was built in China employing only people with RG and attracting visitors to gawk at the size of the inhabitants (LaFraniere 2010). There are also companies that employ people with RG to attend parties (Dwarf My Party 2013). There are dwarf-themed bars, midget wrestling, and several countries offer the controversial activities of dwarf bowling or dwarf tossing (Adelson 2005b; Gerber 1992). While associations such as the LPA condemn many of these forms of entertainment, people with RG are still offered, and accept the role-play of “freak” to be laughed at, patronized and mocked (Adelson 2005b; Kennedy 2003; Ablon 1984). People with RG have defended their right to participate in these roles, as one individual declares:

I had always been looked at and watched. If everyone is going to stare at me and make fun of me, I'd rather be in control than a passive participant (Adelson 2005b p. 9).

This perspective illustrates while there have been positives moves forward in the inclusion of people with RG in social and cultural realms they still often experience staring, teasing and harassment from the general public (Shakespeare et al. 2007, Kruse 2003; Kruse 2002; Kruse 2001).

The next section of this chapter will explore this treatment as recorded in previous research and literature.

## **II. Public Gaze: Staring, Teasing and Harassment of People with RG**

Shakespeare et al. (2007) forward that:

Research showed that the rarity and novelty value of people with RG meant that it was impossible to escape the curiosity, and occasionally the hostility, of non-disabled people (Shakespeare et al. 2007 p. 29).

People with RG describe daily staring, teasing, laughing, rude comments and occasional direct hostility toward them (Kruse 2001, 2002). They have reported a myriad of social behaviours that they feel signify their treatment as a dwarf and not a human being (Kruse 2001; Kruse 2002; Kruse 2003; Ablon 1984). As Ablon (1984) explains:

All dwarfs must live with the constant stares, curiosity, and often gross or rude comments and questions of the average-sized populations around them as the explicit reminders of their difference (Ablon 1984 p. 81).

In research conducted by Kruse (2003, 2002, 2001) and Shakespeare et al. (2010, 2007) participants expressed that when they are viewed in public they feel they are perceived and judged based on old cultural beliefs and stereotypes and that they are ostracized for their differences (Shakespeare et al. 2007; Adelson 2005a; Kruse 2001). They claim that certain stereotypes of people with RG, such as the circus dwarf, have become woven into the social and cultural milieu (Shakespeare et al. 2010; Kennedy 2003; Kruse 2001). As Ablon (1990)

explains, people with RG must contend with their representations in history and “carry the cultural baggage of special and even magical status much more than persons with other physical differences” (Ablon 1990 p. 80).

Occasionally, people with restricted growth encounter serious abuse from strangers including violent attacks of stoning, being chased with threats of violence, and being picked up against their will (Henderson 2012; Kennedy 2003; Kruse 2003). These extreme incidences reflect the existing notion that a person with RG is lesser because of their RG. “They are relegated to a strange kind of category without detail of face, body or personality” (Ablon 1984 p. 82). Kruse’s (2001, 2002, 2003) research finds that both social and physical barriers affect how they navigate public spaces (Kruse 2001). The combination of these barriers represents the inability of the social and material environment to accept the existence of people with RG as cohabitants (Kruse 2001). Disabled people with other physical, sensory and intellectual impairment have also identified this experience (Keith 1996; Morris 1996; Hunt 1966).

### **III. Disabled or Dwarf? The Private Perception**

Some people with RG have questioned the assigned label of disabled or disabled person (Shakespeare et al. 2007; Kennedy 2003; Ablon 1984). Objections to this label have mostly been in response to the individual model’s definition of disability as outlined in the previous chapter (Shakespeare et al. 2007; Kennedy 2003; Ablon 1984). People with RG have argued they are limited by cultural, social and environmental barriers rather than individual physical limitations, essentially reiterating the social model’s conception of disability and the belief that disability is socially caused (Shakespeare et al. 2007; Kennedy 2003; Ablon 1984). “There is nothing really ‘wrong’ or dysfunctional about any one part of them” suggests Ablon (1984 p. 29). This perspective has been used to separate people with RG from people with other physical, sensory or intellectual impairments (including some people with RG) (Shakespeare et al. 2007; Kennedy 2003; Ablon 1984). It has also been argued



that people with RG have been socially and culturally classified separately from other disabled people, as Kennedy (2003) explains:

(...) dwarfs are seen as wonders of nature, aberrations, freaks. Dwarfs are simultaneously part of and apart from disability culture, a duality that continues to this day (Kennedy 2003 P. 97).

The social model has given people with impairments, including those with RG, a new way of identifying as disabled that reflects their lived experiences, shifting disability from the individual to the social and cultural (Oliver 1990; UPIAS 1976). Stramondo (2013) reflects on how the social model resonates for people with RG:

I do think a lot of people with dwarfism intuitively get it [the social model] thinking 'I might need to use a certain kind of equipment and I might get a certain kind of sickness once in a while, but most of my problems are either how people treat me in individual interactions or systematic discrimination in how the world is not set-up so that I can access it' (Stramondo, 2013 Personal Correspondence)

However dominant cultural values and definitions still perpetuate the individual model. This links the label of disabled with individual deficiency, making it a less than desirable label or identity for many people with RG (Shakespeare et al. 2007; Ablon 1984).

## **Conclusion**

This literature review has examined the social and cultural roles people with RG have occupied throughout history and the implication this has on the lives of people with RG today. In the next chapter the methodology and methods of generating the research data will be discussed as well as the challenges and ethical issues of this project.

**Chapter Four:**  
**Connections across the Globe: The Methodology and Methods of Research  
with People of RG**

This chapter will first forward the methodology utilized in this project and the role of the researcher. Second, the methods used to locate participants, conduct interviews and generate data including the strengths and weaknesses of these methods, will be outlined. Third, the ethical issues surrounding the generation and presentation of the data will be addressed.

**I. Interpreting the Social World**

The methodology or “worldview” that this project utilizes directly influenced the generation of data and research findings (Creswell 2009; Brown 2003; Hakim 1987). My position as a researcher, my own personal beliefs surrounding disability and my life experiences also guided this research project (Vernon 1997).

A methodology is the combination of an ontology or belief about “the nature of social reality” [and an epistemology or understanding of], and “the kinds of knowledge that are possible” (Punch 2005 p. 92). This research project uses an interpretivist view of the social world and the knowledge we can extract from it (Blaikie 2009; Creswell 2009; Owens 2007). Blaikie (2009) explains the basis of an interpretivist perspective:

(...) social reality is regarded as the product of its inhabitants; it is a world that is interpreted by the meaning of the participants produced and reproduced as a necessary part of activities together (Blaikie 2010 p.99).

Each person with RG has experiences in social spaces that are not easily described or understood by those outside of the experience (Shakespeare et al. 2007, 2010; Kruse 2001, 2002, 2003). The interpretivist view posits that these experiences are a valid part of the creation of the social world (Prus 1990).

Epistemology is the belief about “the kinds of knowledge that are possible” (Punch 2005 p. 92). The interpretive paradigm argues that knowledge that can be gained about the social world through the interpretations of social actors and the meanings behind them (Prus 1990). As Prus (1990) argues:

The interpretivists envision people’s depictions of their situations as the (imperfect but essential) foundation upon which to build an “empirical” social science (Prus 1990 p. 357).

These meanings are only known through the individuals perspectives described in their own words (Blaikie 2009; Prus 1990). The aim is to:

(...) redescribe these motives and meanings, and the situations in which they occur, in the technical language of social scientific discourse (Blaikie 2009 p. 19).

This research project is seeking to acknowledge the experiences of people and sees these experiences as social truths for these individuals, however as Bailey (2004) explains:

Recognising and valuing subjectivity does not preclude talking about shared experience or social process or structure (Bailey 2004 p. 6).

## **II. Working through the concept “The Inside”**

Emancipatory research is an increasingly popular approach to conducting social research (Barnes and Mercer 2004). It looks to counter the oppressive practices of traditional research (Barnes 2008; Barnes and Mercer 2004). Barnes (2008) outlines the main concept behind this approach:

Emancipatory disability research requires researchers to fully involve disabled people and their representative organisations in all aspects of the research process (Barnes 2008 p 5).

This project was viewed as a collaboration with the research participants. It was illustrated to them that their beliefs and insights were the essential guide

for the outcomes of the project (Bailey 2004; Barnes and Mercer 2003). However this research cannot be labelled emancipatory as the time and resources were not available to allow for the participants to be involved to the extent required to be considered emancipatory (Barnes and Mercer 2003).

The researcher's own perspective directly influences all aspects of a research project (Vernon 1997). My personal reasons for an interest in this issue relates to being a disabled person with RG. Vernon (1997) points out that:

(...) the closer our subject matter to our own life and experience the more we can expect our own beliefs about the world to enter into and shape our work, to influence the very questions we pose and the interpretations we generate from our findings (Vernon 1997 p. 1).

As a person with RG this project can be considered as research from "the inside" (Vernon 1997). My perspective has been shaped by my own personal experiences and has directly influenced this research project's purpose and aims. This was approached as a positive aspect of the project (Vernon 1997). As will be provided in detail when the methods are discussed, being a person with RG allowed a level of access to participants that may not have been granted otherwise and provided a measure of insight when conducting the interviews.

My view of disability also frames how this project was approached. I believe strongly that disability is created by the social, economic and cultural barriers that people with impairments encounter (Oliver 1990; Priestley 1998; UPIAS 1976). Social conceptions of abnormality have become woven into political and cultural power structures and our everyday belief systems causing disabled people to be discriminated isolated and excluded (Davis 2006; Armer 2004; Priestley 1998).

### **III. Across the Globe: Locating Participants**

The rarity of impairments that cause profound short stature make people with RG a “geographically dispersed population” (Kruse 2001). This presented an initial challenge when trying to locate participants to interview. However for over fifty years, people with RG have been joining together to form groups and associations (Ablon 1984). These associations like Little People of America (LPA), Little People of Canada (LPC) and the Restricted Growth Association (RGA) promote equal rights for people with RG, provide support for members and advocate for education and awareness (Adelson 2005a; Ablon 1984). The first phase of obtaining participants for this research project was to contact these organizations via email, post and phone to see if I could make connections that would link me to potential participants (Appendix A). A representative from one of these organizations suggested I use a Facebook group for people with RG to advertise my project online. After my initial posting a “snowball” effect took place with group members connecting me to other groups to post my request. Some groups were affiliated with particular associations while others were independent groups run by people with RG (Brickman-Bhutta 2012). This project did not work in collaboration with, nor was it endorsed by any association of people with RG. Each participant represented themselves only in their interview.

The second phase of obtaining research participants was to post to the University of Leeds Disability List email server, which allows you to send an email to all individuals that are part of the list. I received a number of responses to my email through this as well, and a “chain referral” (Brickman-Bhutta 2012 p. 79) took place with individuals forwarding my inquiry to colleagues or friends they knew with RG. Through both my Facebook groups’ postings and my email through the University of Leeds a number of people contacted me directly, inquiring into my research and offering to participate. I was also able to connect with and interview Joseph Stramondo (introduced

previously) whose own research on disability and involvement with the community of people with RG in the US provide insight into the issues in this research project.

The challenges of locating participants through social networking sites (SNSs) such as Facebook are unique (Brickman-Bhutta 2012; Meho 2006). The sites that I used to locate participants are online communities where members are encouraged to share, network, pose questions or discussion topics, and connect with each other. All of the groups I joined were closed groups, which mean you have to be added to them by the moderators in order to view the group or post messages. To be accepted into these closed groups you must either have RG or a family member with RG and some groups only allow people with RG to join. Brickman-Bhutta (2012) points out:

Thanks to widespread use and niche groups, Facebook offers researchers a way to easily reach many otherwise hidden populations (Brickman-Bhutta 2012 p. 79).

The SNSs memberships ranged from 60 to 1,500 members. I posted my request for participants and contact information on each groups feed page, which can be seen by any member that logs in and allowed those interested to contact me.

Being a person with RG was essential to gaining access to these groups and recruiting participants (Brickman-Bhutta 2012; Vernon 1997). However once I was added to these groups I did not use any information or data that was presented through the groups' postings. This would have violated the terms of the group and could also be considered an unethical violation of privacy (British Sociological Association 2002).

All of the responses to my posting on SNSs were from individuals outside of my geographical area. I was able to offer three options for participating: an interview via phone call, video call or email. I conducted eleven qualitative interviews for this project. Four of the participants were phone call interviews,

five email correspondences and two video call interviews (Appendix B, chart 3). I will now review how these interviews were conducted and approached as well as the ethics and challenges involved.

#### **IV. Interviews and Profiles**

An interview guide was prepared in advance of the interviews containing general questions and themes that I had identified through my literature review as well as through my personal experiences (Appendix C) (Blaikie 2009). This guide and the themes and questions within it, was aimed to generate data through the phone and video interviews that would pertain to all three of the research project's aims as outlined in the introductory chapter. Most often, however, the in-depth interview style allowed the conversation to flow and the participant to decide what direction they wanted to take the conversation. This resulted in generating data that encompassed a larger range of experiences and opinions, and stayed true to the research aims (Opdenakker 2006; Cachia and Millward 2011).

A series of open-ended questions was drafted for the email interviews that could embed in the email for easy answering (Appendix D). These questions were designed to allow the participants to explore what they felt was relevant to their experiences and beliefs, while using the themes identified through previous research (See Appendix A). The participants were then asked if a response email could be sent to ask for expansion on what they had shared and the majority were receptive to this process (Meho 2006). My phone and video interviews ranged from 30 to 120 minutes and my email interviews produced answers totalling between 500 to 9000 words.

Ten out of my 11 participants were female. One of the reasons for this skewed ratio could be that women have been shown to respond more frequently to other studies using SNSs (Brickman-Bhutta 2012). I was not able to obtain information on the gender ratio of the members of the groups I posted on, but the response indicates a higher proportion of women belong to these groups.

The participants ranged in ages from 20 to 63 and lived in Canada, South Africa, the US, England, Scotland and Wales. (Appendix B, chart 1). They have a variety of impairments that cause their RG; although a high percentage - five participants - have Achondroplasia (Appendix B, chart 2).

## **V. Challenges and Ethics**

This research project used qualitative in-depth interviews to obtain the participants' views. Creswell (2009) states that, "qualitative research is a means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem (Creswell 2009 p.4).

Gathering views through in depth conversations allowed the participants to share the subtleness and complexity of their interactions (Blaikie 2009; Gerson and Horowitz 2002; Mason 2002; Maykut and Moreh 1994).

Several challenges were faced during the interview process. As outlined in chapter one, the issue of terminology to describe people with RG is a sensitive and debated subject (Kennedy 2003). Initially the term little people (LP) was used to refer to people with RG; this is a commonly used term in North America where I reside (Adelson 2005b). Despite the debates surround the terminology, little people has been used over the past 50 years by many people with RG as a positive self-identity (Ablon 1984).

When the participant request was sent to the University of Leeds Disability list server a number of responses was received from individuals who were offended by the use of the term little people (LP). They explained that they associated the term with children and found it infantilizing (Kennedy 2003). The decision was made to use restricted growth (RG) instead of LP in any future correspondence and in the writing of the dissertation. I felt that as a University of Leeds student it was valuable to ensure that it would not be deemed offensive or denigrating by individuals in the UK. There was no feedback that RG was a negative term and it appears to be more neutral; however it should be



mentioned that this term is unknown to some people in North America (Adelson 2005b).

The issue of anonymity is especially challenging when social research is focused on people who have rare impairments. It was explained to the participants that a pseudonym would be used in the presentation of the data and their identity would not be revealed in accordance with ethical guidelines on anonymity and confidentiality (Punch 2005; British Sociological Association 2002). A confidentiality form was created outlining the ethical guidelines of the research and contact information for my supervisor so that they could confirm the project was legitimate if they wished (Appendix E). The participant profiles are presented in a way that does not make it easy to identify them and in accordance with ethical guidelines (British Sociological Association 2002).

The issues discussed with my participants were personal and potentially emotionally charged. From my own personal experiences I understood that it may be difficult for the participants to be able to share with me some of their experiences without causing emotional distress to them (Vernon 1997). This was addressed by being cognizant of the sensitivity of these issues during the interviews and allowing the participants to share as much or as little as they wished. My personal experiences played an essential role in allowing me to interview the participants with an increased level of sensitivity. I shared my experiences with them, usually at the beginning of the interview to make them feel comfortable. I was also open with them when they asked me questions about my experiences in public spaces. Upon completion of the interviews the task was to then organize and code the data.

## **VI. Data Analysis**

Once the data was generated it was then organized and coded. In order to honour the complexity of interpersonal interactions in public spaces the data was categorized into “broadly framed sorting files” (Anzul et al. p.143) sectioning the data according to the three primary research aims: to record

direct accounts of the participants' experiences, the meanings they ascribe to these experiences and to link these meanings to previous theories of interpersonal discrimination such as stigma, culture and normality. It was important to analyze both the language used by the participants as well as the contexts of the meanings they shared in order to identify the central themes (Blaikie 2009).

Once the themes were identified the data was coded again to identify any sub-themes that were generated. Utilizing memoing to broaden the information shared (Punch 2005) the researcher incorporates ideas about the codes being prescribed, what they mean, their relationship with each other and how they are relevant to existing sociological theories or concepts (Punch 2005). This linked what the participants' shared with the issues that were previously outlined in chapter one and two.

Reliability, validity and generalizability are concepts used to qualify research which examines the consistency and authenticity, as well as to determine if the research findings can be generalized to a larger group or population (Silverman 2011). Reliability relates to how the researcher can justify the particular meanings and classifications they assign to the data (Silverman 2011 p. 19). Qualitative studies are particularly vulnerable to reliability issues as the interpretations of the data are done at the researcher's discretion (Silverman 2011). They determine what descriptions are included in the final report and how these descriptions are imbedded into larger theoretical discussions (Silverman 2011).

As was explained previously in this chapter the ontological position of interpretivism is being utilized in this project (Blaikie 2010). This position challenges the idea that there are concrete knowable truths in the social world (Blaikie 2010). Instead it is how social actors experience and interpret the social world that creates it (Blaikie 2010). Within this position it is still possible to offer methods to ensure data is reliable, valid and representative of the group being studied (Silverman 2011). As will be seen in chapters five and six

long extracts of the participants' interviews are utilized. The central reason for this is that picking apart their descriptions reduces the context of what they are sharing and can distort their meanings.

As will be outlined in the next few chapters, the participants revealed the complexity of their social interactions. Any one experience can't be taken to represent how they are perceived or treated in public spaces all of the time. Not every participant experienced every interaction that will be discussed either; however the idea that each and every participant experienced varying levels of differential treatment because of their RG allows for these experiences to be generalized to the larger population of people with RG (Silverman 2011).

## **Conclusion**

This chapter has outlined the methodology and epistemological perspective of the research project. It also provided an illustration of how the interview participants were selected, interviewed and how the data was analyzed, including reviewing the reliability and generalizability of the data. The ethical issues and challenges that arose during the data generation and analysis phase were also presented. This chapter provides a comprehensive understanding of the decisions made during this research project that assists in contextualizing the research data which will now be presented.

## **Chapter Five: Staring, Harassment & Cultural Shadows**

### **Introduction**

The participants shared a wide range of experiences in public spaces to illustrate how having RG influenced those interactions in public spaces. They also provided their beliefs and insights into why they had these experiences. These beliefs can be linked to theories on how they, and other disabled people, have been systematically discriminated against (Snyder and Mitchell 2006; Barnes 1997; Shakespeare 1997). Participants identified that they often felt there was a unique form of discrimination toward people with RG that can be

related to their current and past cultural representations, as was identified in chapter three [Adelson 2005a; Ablon 1984). The participants also shared how they resisted or countered discriminatory behaviour towards them, demonstrating their power in challenging the prejudice they experience. The next two chapters will explore both the participants' experiences and their perspectives on these interactions.

While each of the participants shared unique, multi-layered and complex experiences and insights, a number of themes emerged. In this chapter the experiences of staring, harassment and unauthorized picture taking will be discussed. It will also examine the participants' views on how cultural representations of people with RG influence these interactions.

### **I. Upon First Glance: Staring**

Staring proved to be the most pervasive and common experience of all the participants. For many, the staring was a constant reminder that they are seen as abnormal or different from other people. When asked if she experiences staring, Anne shared:

I experience this every day. Sometimes I don't mind it at all, and I think, "If you find me interesting then [keep looking]", whereas other times I just want people to go away.

Other participants were able to distinguish between the different types of staring they encountered. Marjorie outlines some of these:

From long drawn out following with the eyes with mouth open, to serendipitous sideways glances almost peek-a-boo style [edit].  
Anyone with a significant visible disability has experienced this, we are not alone. It is never pleasant.

Stephanie, who has two daughters that have RG, finds her whole family is stared at for their differences:

I have experienced a tonne of staring. And now that I usually have my two achon [Achondroplasia] daughters and a rather large AH [Average Height] husband with me. People really stare. And you can see them trying to figure out, if the girls are ours. How can that possibly medically/physically work?

She found one reaction of a parent with their child particularity unsettling:

An adult parent was literally nudging their child in the arm over and over. The adult parent was trying to get their child to notice and stare at me. I can't remember the child's reaction. But to have an adult parent point me out - was really hard on me that day.

Hughes (1999 p. 161) forwards that “To be subjected to the gaze of another is to have ones objectivity disclosed to oneself”. The participants expressed that being stared at reminded them that they were perceived as abnormal, an unexpected curiosity (Reeve 2002; Hughes 1999; Morris 1991). Staring reflects specific social and cultural beliefs on what is strange or different and socially acceptable to stare at; as Reeve (2002 p. 499) claims “the power of the gaze is intimately linked and nourished by knowledge from within the social domain”. Staring can be used as a social power tool to emphasize the inferior social status of those under the gaze (Garland-Thompson 2009; Reeve 2002). Reeve (2002) contends:

(...) having an impairment that is immediately visible presents the observer with privileged information and therefore power over that body (Reeve 2002 p. 499)

Shakespeare (1997) also identifies that power is held over the person being stared at, finding that it objectifies the body as “passive and available” (Shakespeare 1997 p. 288). He makes a connection between the gaze that disabled people experience with the male gaze that women experience when they are being sexually objectified (Shakespeare 1997).

Garland-Thomson (2009) forwards that staring is a complex and dynamic social interaction that can take many forms and meanings. Disabled people with a visible physical impairment are stared at because:

The sight of an unexpected body – that is to say, a body that does not conform to our expectations for an ordinary body – is compelling because it disorders expectations (Garland-Thomson 2009 p. 37).

This relates back to the discussion of normality in chapter one. The concept of normal, through science and cultural imagery, has prescribed a set of characteristics that the human body should conform to (Davis 2006). When confronted with a body that defies these specific characteristics we are forced to re-evaluate these concepts (Garland-Thomson 2009; Marks 1999). Hughes (1999) forwards that:

Normative order (convention!) is treated uncritically as an empirical given - constituted by the vigilance and lucidity of the gaze - and deviance derived from it. (Hughes 1999 p. 158)

Garland-Thomson (2009) sees power in those whose bodies are stared at for their abnormality. That while the stare may feel intrusive and oppressive:

(...) these encounters work to broaden collective expectations of who can and should be in the public sphere and help create a richer and more diverse human community (Garland-Thomson 2009 p. 9).

However dealing with staring on a daily basis can be psychologically exhausting and oppressive (Marks 1999). Some of the participants identified behaviour in public spaces beyond staring, such as teasing, harassment and name calling, which will be examined in the next section.

## **II. The “M” Word: The Teasing and Harassment of People with RG in Public Spaces**

A number of the participants experienced derogatory name calling, laughter or teasing in public. For some, this happened more frequently than others. They indicated that the public setting and demographic of the people present influenced these encounters.

Kate had experienced numerous incidents of name calling and even some threatening behaviour towards her:

It is rarely to your face, you are walking, you know you will be by a shop and then you walk a bit further and then somebody starts singing the Umpa Lumpa song at you or Snow White's Hi Ho song, they wait until you get that little bit further away from them but you know it's at you because you are the only dwarf wherever you are, or the person has to shout midget across the street, and you think "You know I haven't forgotten that I am small" they have to shout it especially if they are drunk and men can be very dirty and they can be perverted, you know, and they have to shout something sexual at you because you are the same height [as their genitals] and so they always feel they have the right to shout at you or laugh.

People with RG have been fetishized in pornographic imagery and their bodies seen as sources of sexual objectification (Kennedy 2003). Kate's experiences may be understood as a reflection of this objectification (Kennedy 2003).

Nicole who has a daughter with RG has also experienced name calling:

Oh yeah, we get called midget actually there is a funny story when I first started at [Workplace], we were working one day and this lady came in and she said to someone else "There is a leprechaun working here."

When asked if she experienced teasing Anne shared that she has developed the skills to resist and counter these sorts of behaviours towards her:

I have experienced teasing my whole life, but people tend to only do it the once, because I am very good at flipping it around, shaming people, and then educating them. In terms of teasing in the street however, this happens less than it did when I was at school for example, and in these instances I make a decision at the time as to whether to challenge the person or to let it slide.

Patricia indicated that young adults were more likely to name-call or tease:

I live in an area where there are a lot of students and on a Saturday night if I walk through the area, where they are standing outside the pub having a cigarette, and I walk past [is when name calling occurs]. It is very much a showing off thing, they want to look big by laughing at me and look big in front of their friends.

A number of the participants expressed that they avoid certain public spaces as a result of behaviours or treatment they had received in these settings or with an instinctual feeling that they would be met with discrimination in these spaces. Patricia reflected:

I know not to put myself in certain situations where it is likely to happen. [Edit] I volunteer for a charity and we do fundraising and I won't sign up to stand outside of a football match because I know that would be asking for trouble.

The representations of people with RG in the entertainment industry are pointed to as one of the reasons people with RG encounter staring, teasing and harassment (Adelson 2005b; Kennedy 2003; Gerber 1992). As outlined in chapter two people with RG are most often given roles where their stature or bodily difference is their primary attribute, with a number of these roles for non-human beings such as leprechauns or elves (Adelson 2005b). The next section will explore the participants' views on how these cultural representations affect their interpersonal interactions.



### III. Cultural Shadows

Kruse (2001 p. 8) contends that “rather than relating to dwarfs as individuals, people of average height often relate through social constructs they have of dwarfs”. These constructs, outlined in chapter two, associate people with RG as non-human entities and portray their bodies as objects to be ridiculed or used as a source of entertainment. Gabriella shares:

In South Africa people with RG often played clowns in circuses up until very recently and perhaps even still. In South Africa today, People of RG still play roles of entertainers at sports matches and in adverts.

The participants in this research project expressed that they sometimes feel associated with these social constructs and it influences their everyday interactions. They not only attribute their experiences to the influence of the social and cultural category of a dwarf but also with other disabled people who were and sometimes still are considered “freaks” for their “abnormalities” (Davis 2006; Gerber 1992). Adelson (2005b) contends that:

(...) the forces that caused [people with RG] to be mocked and exploited as they struggled to cope are still very much in evidence (Adelson 2005b p. 1).

Kate communicated that because people with RG are still used as objects of entertainment, people feel free to view all people with RG they encounter this way. She states:

I think we are treated sub-human because of the way we have been treated throughout history, the cultural representations that we are there for people’s entertainment for other people’s pleasure.

She feels that there are strong repercussions of these roles that need to be countered with positive images, and that people with RG should fight against these forms of entertainment:

In a dwarf throwing competition, if that only effected that one dwarf then you could say fine let him do it it's his life. But because it has an effect on say 20 other dwarfs, ones that just go to the bar for a drink and somebody picks that person up for fun, it has an effect on us. So I think it's our duty to say you know what no, it's affecting the rest of us, and we have a right to say you can't do it. [Edit] You know if I could walk down the street and not get called an Umpa Lumpa then I wouldn't care. [Edit] but we have to get together and say no this is not happening anymore we are not going to be your sidekicks we are not going to be your freak shows. [Edit] I think we can make it political. A lot of people with RG are now saying [edit] "I am not doing the stereotypical role and I am not being in a circus and I am not here for you to laugh at."

Marjorie also feels that people with RG take on roles that do not help in changing how they are perceived culturally:

There are some LP's [little people] who chose professions or modes of income that perpetuate negative stereotypes. I have been approached to appear in a traveling "Freak show" and repulsively declined.

Anne also feels people with RG are treated poorly because of their past cultural roles:

Unfortunately a lot of little people are still seen as a big joke... I think that people are changing though, very slowly, but surely. I think the freak-show thing has stuck to an extent.

She also shares that until people make an effort to communicate with her she feels treated as less than fully human:

I feel that before certain people take the time to get to know me or have a conversation with me, they see me as an object rather than a human being. I am a THING. And that is still so reminiscent of the freaks and midgets of the circus. (Capitalization in original correspondence)

Alex believes that while some people perceive people with RG as less than human this is not always the case:

I think the way people perceive LP's [little people] varies dramatically. I'm sure, to some, we are nothing more than an odd, almost sub-human-like object, fit to be ridiculed. To others we are a completely normal genetic variation that is part of the human race.

Marjorie believes that the way people with RG have been portrayed in children's literature blurs the line between reality and fantasy and can create false ideas in children:

When children first learn of little people, giant people, people of differences in size and shape, the topic is often broached in a 'fun' way. The stories are fanciful, often inaccurate, and difficult for a child who knows nothing of the subject to get a clear feeling of what is real and what is fantasy.

Patricia expressed that she feels those with less education are more likely to base their views of people with RG on cultural images:

I think those that are less educated or worldly have a specific view of people with dwarfism, the type of media portrayals, Snow White, circus you know, freaky all that kind of thing. That is the only kind of knowledge they have of it.

Stramondo (2013) suggests that it is easy for the media to continue to portray people with RG in stereotypical ways:

That is what is comfortable for the world to think of LP so that's what is portrayed in the movies, in the news. There is no counter narrative. It is a confirmation about what people already believe and that why it gets picked up in the media, it doesn't challenge anyone. (Stramondo 2013 personal correspondence)

The beliefs of many of the participants reiterate the constructionist conception of the social model of disability as discussed in chapter two. That cultural values and representations result in the denigration of people with RG and the view that they are less than human (Snyder and Mitchell 2006; Shakespeare 1997; Priestley 1998).

#### **IV. The Acceptance of Rarity**

The rarity of RG can be used to explain why their cultural representations have such resonance, as Adelson (2005b) points out “most members of the general public do not know any dwarves personally, their impressions are formed by what they see in popular culture” (Adelson 2005b p. 11).

Kate believes that it has been harder to tackle the cultural prejudice that people with RG face because of its rarity:

I definitely think because of the rarity of dwarfism it is harder to tackle than say racism. I mean if you look back a few hundred years ago they put black people in freak shows because they were like, “Oh my god, look at this person with different coloured skin” [edit] and obviously people still get racism. But with dwarfs because we are not on TV or in magazines and not in the social norm, there is that rarity there. If you see a dwarf on the street you are going to take a second look, I don't mind, but I think we

can fight the cultural representations; we can fight how we are treated to some degree.

The participants pointed out that while people with RG have historically been exploited, denigrated and excluded this has been fought over the past 50 years through political and social activism (Ablon 1984). Cultural values and beliefs have changed toward not only disabled people, but towards other groups that have been systematically discriminated against. As Emily states:

A lot has happened to advance the treatment of people who are perceived as different, for example people have been fighting for the rights of the LGBTQ [Lesbian, Gay, Bisexual, Queer and Transgendered] community, people are fighting against bullying, the world is slowly attacking and breaking down certain differences and welcoming them and I think that is fantastic. Dwarfism or those who are different by dwarfism we have not hit our stride yet [edit].

This supports the view that “cultures are not independent or static formations” (Charlton 1998 p. 105) but malleable with ever changing belief systems. In Emily and Kate’s view the cultural representation of people with RG could be altered through social awareness and political activism. However shifting cultural beliefs and meanings is a gradual process (Gill 2011; Snyder and Mitchell 2006). While these changes can be intrinsically connected to alterations in social, political and economic structures one does not necessarily preclude the other. Stramondo (2013) explains:

In terms of the disability community in general you have this idea that if you change the built environment and you deinstitutionalize people and get people out into the world that you know culture will sort of catch up. [Edit] When it comes to LP [little people] we can lower the gas pumps, that is important, but there is still going to be this catch up that might never get there if

we don't address these cultural issues. You can't assume the work is going to happen magically.

Stramondo (2013) compared this issue to challenges in the feminist movement in regards to using structural and legal changes to alter the cultural oppression of women. Kate summarizes how shifting cultural changes can support environmental and structural changes:

I think we can change representations. We can change how we are treated and perceived through changing attitudes, changing cultural representations. [Edit] I might always get stared at for the rest of my life, but because of people like [the actor] Peter Dinklage we can alter the representations of people with RG and get treated a lot better. So as the social barriers decrease the spacial barriers decrease, I am not saying it is ever going to happen but it is nice to think that it might.

Another important experience some of the participants felt are influenced by the cultural representation of people with RG was the unauthorized picture taking of them in public. This experience and the implications it has on the identity of people with RG will be addressed in the next section.

## **V. Through a Lens: Picture Taking in Public**

A number of the participants experienced strangers taking their picture in public spaces without their consent. This behaviour was done with the implication that the picture taker was recording the person with RG's "abnormality" for their own interest or amusement.

Kate explained one of these incidents that escalated into harassment:

There was this group of teenagers that were trying to take a picture of me, my friend stopped them she put her hand in front of their mobile and because one of the girls was embarrassed they started calling, "Midget, midget come here midget, come suck my

cock midget” and they were demanding “Come here now midget” and I just kept walking because I thought, “oh my God it is a big group of teenagers I got to keep walking.”

Patricia also describes how picture taking was used as a part of a harassing incident:

A few years ago I was walking down the street and someone drove past in a white van and somebody lent out of the window and yelled “midget” and took a picture of me. And I found that really disconcerting.

Marjorie shared that she “dreaded taking a picture with their camera phone” as it felt like the ultimate invasion of her autonomy as a person. Kate again links this back to the cultural representation of people with RG.

I think subconsciously they think, “Oh it’s fine, they don’t mind, they are not going to fight back if you take a photo and we can just treat people with restricted growth in what we feel is right.”

This behaviour appears uniquely targeted to people with RG, however as Garland-Thomson (2002) explores photography has been frequently used to objectify disabled people, especially those with visible physical impairments (Garland-Thomson 2002). She argues that as the freak show of the early 20<sup>th</sup> century became socially unacceptable, photos of disabled people became a new way to perpetuate the idea that an impaired body is abnormal and for the curious to gawk at (Garland-Thomson 2002). She forwards that:

Photos absolve viewers of responsibility to the objects of their stares at the same time that they permit a more intense form of staring that an actual social interchange may support (Garland-Thomson 2002 p. 58).

In these cases she is referring to viewing photos rather than the act of taking them; however the same concept can be applied to those who take pictures of

people with RG in public. While the initial act may require some exchange between the picture taker and object, the idea is that their photo will allow them to stare at leisure at the abnormality of the person they have captured (Garland-Thomson 2002). This relates directly back to the use of people with RG in freak shows and how their bodies have been put on display throughout history (Adelson 2005a; Howells and Chemers 2005; Gerber 1992).

## **Conclusion**

This chapter has explored the experiences of staring, teasing and harassment of people with RG. It has also discussed, using the participants perspectives, how the cultural representations of people with RG influences how they are treated in social spaces. In the next chapter the interview data will continue to be analyzed, focusing on infantilization, ignorance toward people with RG and the use of mobility aids.

## **Chapter Six: Infantilization, Ignorance and Mobility Aids**

This chapter will focus on experiences of infantilization and the differences in social interactions when the participants used a mobility aid. It will also discuss how ignorance and lack of education surrounding people with RG is one of the primary reasons the participants felt they experienced discrimination from strangers.

### **I. Infantilizing**

Some of the participants shared experiences of being infantilized in public spaces. Infantilization is treating an adult like a child because of an assumed incapacity or helplessness on the part of the infantilized person (Kennedy 2003; Keith 1996; Morris 1991). It has been illustrated that many disabled people experience this treatment (Keith 1996; Cahill and Eggleston 1994; Morris 1991). Kate had interactions where she was assumed to be a child, despite obvious clues that she is an adult:



I was in a pub and I was drinking a pint of beer, and so that automatically tells you I am over the age of 18, and this woman [edit] she goes to me, “Oh so what did Father Christmas get you?” and I was drinking a beer and it was confusing because I am an adult but because I am small you still think I believe in Father Christmas, [edit], but because you have restricted growth and you are similar height to a child you must be like a child.

Nicole shared experiences of being infantilized:

People come over and say, “Aren’t you cute?” and pat you on the shoulder or the head and say, “can I give you a hug” and I say like hello, I am human being I am not a dog, or a doll.

Marjorie stated:

When going to restaurants and movies in the past as a younger adult I was often automatically placed in the child category.

Anne shared that she is often both infantilized and treated like she has an intellectual impairment:

Probably the biggest reaction I get is the patronising, being spoken to as if a child, often coupled with nervous laughter. Occasionally people will mistake me for someone with a mental impairment and speak to me very slowly and carefully. I wouldn't dream of speaking to someone with a mental impairment in this way in the first place, but I always take pleasure in correcting people.

The infantilizing of people with RG can be examined on a number of levels. It has been linked to beliefs that disabled people are incapacitated because of their impairments, which renders them dependant and helpless like children (Keith 1996; Morris 1991). However for people with RG there is often an added element of being equal in size to a child. The concept of liminality was

developed by social anthropologists to explain people that exist in ambiguous social or cultural positions; persons that “elude or slip through the network of classifications that normally locate states and positions in cultural space” (Turner 1969).

This concept can be applied to how people with RG have been perceived throughout history and even today as neither human nor non-human; as neither adults nor children; as neither disabled nor non-disabled (Ablon 1984; Adelson 2005a). The participants felt that they had to negotiate or establish their presence in public spaces to allow others to interact with them. They had to deal with other’s uncertainty of how to perceive and “classify” them (Turner 1969).

## **II. Ignorance: Fear of the Unknown and Prejudice**

The participants expressed that they felt ignorance about people with RG was a contributing factor in their social interactions where they were treated differently. They often found that people were uneducated about the numerous impairments that cause RG and the reality of their lives as people living with these impairments.

When asked why, Anne thought people with RG were treated differently she relayed a story of asking her friends their thoughts:

I think people are afraid of what they don't understand. I find this question very difficult to answer because it boggles my mind as to how people can be so ignorant of this issue, and yet in many cases very clued up on other issues and other types of discrimination. [Edit] I remember talking to a few of my friends about my condition back in high school, and a couple of the guys said that when they first saw me around, they were scared of me. They found my presence uncomfortable because they had never been faced with anything like me before, and said that until they got to know me, never once thought of me as an equal.

Patricia feels that while those that know her are able to accept her impairment, she does not expect this of people who see her for the first time:

But I think that kind of ability to suspend awareness [of my RG] is not going to happen to people who haven't come across dwarfism before, they can't pretend that it is not something unusual and therefore react differently.

Judy also feels that many people have not been exposed to people with RG or other differences and so they react to it:

I think whatever disability you have whether you are tall or short, it is because we are different that people can't really accept it. I don't think they mean it in a nasty way, the majority of people, they are just not used to it, and they have not been brought up with it.

Stephanie feels that people are afraid and don't know how people with RG want to be treated:

Society just still does not know how or what to say to us. Still can be a bit scared of us. Or they are over nice to us. [Edit] They are worried that they are going to say the wrong thing - that would offend me. They don't know how I want to be treated. Not sure if they can ask me, if I need or want help.

Anne finds that people are especially ignorant about people with RG:

People should not have such twisted views of disability in the first place, and little people are at the height of that ignorance and prejudice as far as I am concerned.

Emily finds that she has to read people's reactions and make them feel comfortable with her, that she is the one who has to take control of the interaction:

Someone coming down the aisle [of a grocery store], are they going to say something? Ask something? Offer something? Are we just going to pass and nothing will happen at all? Another thing I was just sort of thinking, I think how we are received in public spaces, I think it also changes a drastic amount, like you can almost like see a shift in people, right, if you talk, if you express and show part of yourself. [Edit] When people see that it instantly melts something away for them, “this is a real person I can talk to them” I don’t know why this is, why it is for certain people outward difference is like “I don’t know how to approach this situation”

Goffman (1966) applies a social interactionists perspective attributing negative reactions to people with an “undesired differentness” as natural and inevitable (Abberley 1997; Finkelstein 1980). Others look to larger social influences, structures and ideologies that condition people to react to abnormality or rarity in certain ways and have examined how these belief systems can change and modify social behaviours (Snyder and Mitchell 2006; Abberley 1997; Charlton 1998; Finkelstein 1980).

Snyder and Mitchell (2006) claim that:

(...) our understanding of human variation has been filtered through the perspectives and research of those who locate disability [impairment] on the outer margins of human value (Snyder and Mitchell 2006 p. 21).

People with RG are considered abnormal because it has been socially and culturally determined that their impaired bodies are unacceptable (Abberley 1997; Finkelstein 1980). However the reality of the variation of what constitutes a human body contradicts this (Davis 2006). In fact a large majority of people are exposed or aware of this reality in human variation, as Emily finds:

There are some people you meet and you can already see they are at peace with difference, and I find when you start talking to them it is because they have someone of difference in their life already.

The concept of liminality, as discussed previously in chapter five, is helpful for explaining how these definitions of normal vs. abnormal can change in a cultural sphere (Gill 2001). Liminality

(...) allows for the processional shifting nature of socially constructed meanings affecting particular social groups (Gill 2001 p. 358).

In this sense a group that has existed in a liminal state can experience changing perceptions or classifications of them in relation to how cultural values shift and alter (Gill 2001). This demonstrates how categories of normal and abnormal are malleable and socially and culturally determined (Davis 2006). The participants identified that one of the ways that their specific classifications became blurred in social spaces was when they used a mobility aid in public. These experiences will be discussed in relation to the concepts of impairment and disability and how they have been applied to people with RG.

### **III. Disabled or Dwarf? The Public Perception**

The participants identified that they had different experiences in public spaces when they used a mobility aid such as a wheelchair or scooter. This issue has not been fully explored in previous literature on people with RG (Shakespeare et al. 2007; Kruse 2003; Kruse 2002; Kruse 2001). Over half of the participants use mobility aids to navigate public spaces. Some use them intermittently while others permanently or every time they leave their home. These participants have experienced different treatment in public when using their aids and shared these experiences.

Anne summarized her experiences in both these situations:

I have had name-calling, laughter and teasing, people completely ignoring me and of course a lot of staring, which I barely notice anymore! I should stress that this is almost always when I am out of my wheelchair. [Edit] In the most extreme cases, for the most part, when I am in my wheelchair I am invisible, and when I am out of my wheelchair it's a freak show.

Judy uses a wheelchair permanently and feels she is more accepted in public spaces compared to when she walked:

I am in a wheelchair permanently. [Edit] I thought it was better [using a wheelchair] actually I know that sounds silly I can get about a lot better. I think I looked ridiculous walking to be honest. I did not have very much confidence when I was out walking, people used to stare and things like that. You know you go shopping and you could not reach anything you would always need somebody with you and stuff, so I hated that side of it. And going for jobs as well that was not very pleasant. Now I think people accept me more.

Marjorie has found that using her scooter allows people to know she is an adult:

The wheelchair/scooter alerts people to a disability. It is an easier leap for the AH [average height] mind to jump from disability to person grown, but small, than from small person to mature person.

Emily has experienced different treatment when out in public depending on if she is using her scooter or not, she has tried to understand the reasons behind this change in how she is received:

If I go somewhere, not home, somewhere unfamiliar and I am either walking free, using a cane or using my scooter I feel like I

am received differently. And it is amazing, sometimes it is a real drastic difference other times it is just minimal stuff. And it is funny too how people will connect with you more [when using a scooter], and that is fantastic. [Edit] I am still trying to pin down what it is that makes the difference, either the adaptive products are making me more different in outward appearance. It is almost like you don't have a buffer [If you are not using an aid].

The participants that used aids found that they were treated more in accordance with social and cultural definitions of a disabled person who does not have RG (Keith 1996; Morris 1991). However this difference or alteration in their interactions was often complex and blurry. Stramondo (2013) explains how people with RG have to navigate these different experiences across their lifetime:

Many folks [with RG] when they become older and older can mean 35 they need to use a scooter, they need to use crutches and that can change the experience too as far as what the stigma looks and feels like. There is diversity within the community and there is diversity across someone's life span. That is not to dismantle or discredit the idea that people with dwarfism experience a different sort of ableism than other disabled people, because I do think that is true. I just think that the thing they experience can be a lot messier. (Stramondo 2013 personal correspondence)

In contrast to the experiences of the participants who used mobility aids some of the participants who did not use aids were sometimes denied disabled status in public. As Kate recounts:

There are times when [her status as a person with an impairment] is contested. I find when I am in a queue and you have one low counter it's like people don't realize that that

counter is better for me to use than the very high counter because they think it is for a wheelchair user and so people question you if you go and use it and you are like you have to explain to them they can't obviously see that you are small and need a low counter.

These experiences reflect that some people with RG can be perceived as separate from other disabled people, making the category of dwarf separate from disabled (Kennedy 2003; Ablon 1984). As Patricia shared:

It's kind of, it goes beyond seeing someone as disabled, you know somebody who is in a wheelchair is looked on differently but the condition that puts them in the wheelchair is [made anonymous] by the wheelchair, but because dwarfism is so different, so unusual and in the past the difference has been emphasized in the ways dwarfs are portrayed.

The concept has often been argued that a mobility aid is the central marker of disability (Morris 1991; Keith 1996). The differences in the experiences of the participants who used a mobility aid show how these aids complicate the distinct cultural and social categories of people with RG (Shakespeare et al. 2007; Adelson 2005a; Ablon 1984).

## **Chapter 7: Conclusion**

The final section of this research project will summarize the preceding chapters. Areas revealed through this research project that would benefit from further exploration will be discussed as well.

This research project has explored the experiences of people with RG in their interactions with strangers in public spaces and the meanings they attribute to these experiences. It has been identified that:



(...) each day all dwarfs confront a range of peculiar complexities in what would often be otherwise ordinary existences (Ablon1984 p. 9).

The constructionist interpretation of the social model of disability was the lens used to analyze the experiences of the participants (Priestley 1998). This interpretation of the social model suggests that cultural values or ideals construct and perpetuate disability (Snyder and Mitchell 2006; Priestley 1998; Shakespeare 1997). Literature that outlined the issues relevant to this research project, such as stigma, normality and liminality was explored and an account of previous literature that examined the accounts and experiences of people with RG was provided.

Qualitative interviews were conducted to generate the data. The central guide of the project was the experiences and perspectives of the participants, all of whom have restricted growth. The participants shared complex and diverse experiences and insights that provided valuable data that addressed the research aims. An interpretivist ontology, or world view, was applied to this data contending that each participant's experiences and views are a valid part of the creation of the social world.

The participants' interviews revealed common themes in their interactions. Staring, harassment, infantilization and unauthorized picture taking were identified as some of the experiences the participants had when they ventured into public spaces. The participants pointed to the influence of cultural representations and roles assigned to people with RG throughout history as one of the primary causes of these behaviours. In conjunction they posited that there is a general lack of education and awareness of people with RG and that this exacerbated prejudiced attitudes toward them. The participants that used mobility aids cited drastic differences in their social interactions when they used these aids. This revealed a complexity in how impairment and disability is defined in social spaces and the affects these complexities have on the daily lives of people with RG.

The participants identified that their physicality, or bodily differences, are a dominant factor in their interactions in public spaces (Adelson 2005a; Shakespeare et al. 2008). Normality or the rejection of physical “deformity” was identified as a pervasive cultural value that causes people to treat them differently (Davis 2006; Garland-Thomson 1997). Theories of stigma, normality and liminality were examined to explain the social and cultural origins of why the participants’ bodies elicit different or discriminatory behaviour toward them (Garland-Thomson 2009; Davis 2006; Goffman 1966). What this reveals is that the historical rejection or devaluation of bodies that do not confirm to an accepted ideal of “normal” has relegated people with RG to the margins of social and cultural acceptability (Davis 2006; Adelson 2005a). The way that people with RG have been mythologized throughout history has also contributed to their bodies being singled out as ‘abnormal’ and even subhuman (Adelson 2005a). This has cumulated in people with RG often experiencing a specific form of prejudice unlike many other disabled people (Adelson 2005a; Shakespeare et al. 2007; Kruse 2001; Kruse 2002; Kruse 2003).

This project revealed a number of issues surrounding people with RG that would benefit further exploration. Although this project touched on how people with RG are treated in public spaces when they used a mobility aid it was not originally considered when recruiting participants. A project that separates those who use aids from those that do not, and examines the underlying reasons for this alteration in treatment would provide further insight into how disability and impairment are perceived and understood in social spaces. It would also provide insight into how a mobility aid interferes with the stereotypical cultural representations of people with RG.

Another area that should be examined further is the issue of terminology for people with RG and how the terms used have impacted the social and cultural perceptions and representations of people with RG. The limitation in length and scope of this project prevented in depth exploration into this issue.

Analyzing these terms and how they have been used both in the past and currently in medical, social and cultural realms would uncover some of the ways that people with RG have been excluded and discriminated against throughout history.

People with RG experience the social world from a unique perspective that has been largely ignored in disability studies (Shakespeare et al. 2008; Shakespeare et al. 2007 Adelson 2005a). It is imperative that their perspectives are incorporated into the dialogue on disability to provide insight into how cultural values and norms perpetuate discriminatory attitudes and behaviours and oppress disabled people.

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## **Appendix A – Participant Request Letter**

The University of Leeds, UK: Social Research Project

**Small Bodies, Large Presence:** Exploring the Experiences of People with Restricted Growth in their Interactions with Strangers in Public Spaces

**Researcher:** Lesley Ellis



My name is Lesley Ellis and I live in Vancouver, BC. I am a social researcher currently pursuing a Masters of Arts in Disability Studies through distance education at the University of Leeds, United Kingdom. I am also a person with restricted growth. My research focuses on the experiences of people with restricted growth in their interactions with strangers in public spaces. I am interested to learn what they experience in their daily lives in social spaces and the meanings they give to these experiences. In my studies I have found a lack of research that explores this issue from the perspectives of people with restricted growth. Our interactions with people and what we understand from these experiences provides distinct viewpoints. Giving us a voice to share our experiences is vital to understanding how people view difference, and how they react and negotiate these perceived differences in social spaces. I feel this subject is valuable to both people with restricted growth and society as a whole.

I am writing to your organization in the hopes of finding some participants that would be interested in talking to me about this project and if they are willing, participate in an informal interview with me. This research project is for my dissertation that I will be submitting to the University of Leeds for the completion of my degree.

If you would like to verify my research project please contact Dr. Alison Sheldon, Disability Studies Department, University of Leeds, UK Tel: 0113 343 4715 Email: [a.sheldon@leeds.ac.uk](mailto:a.sheldon@leeds.ac.uk).

Thank you in advance for any assistance you may be able to offer.

Sincerely,

Lesley Ellis

**Appendix B – Participant Information****Chart #1**

<b>Age</b>	<b>Living in</b>
20	US
21	England
26	US
27	England
27	Scotland
33	South Africa
44	Canada
44	Canada
48	US
46	Wales
63	England

**Chart #3**

<b>Interview Types</b>	
5	E-mail Interviews
4	Phone Interviews
2	Video Interviews

**Chart #2**

<b>Impairments of Participants</b>
Achondroplasia (5)
Osteogenesis Imperfecta (Brittle Bone Disease) (1)
Bilateral Proximal Femoral Focal Deficiency (1)
Spondyloepiphyseal dysplasia congenital (SEDc) (3)
Undiagnosed (1)

**Appendix C – Interview Guide****Interview Guide****➤ Social reactions that may be brought up:**

Staring	Teasing	Harassment
Violence	Infantilizing	Pity
Kindness	Helpfulness	Personal Questions
Ignoring	Invading personal space	

**➤ Social interactions to ask about:**

Meeting new people	Customer service	Every day errands (Groceries, banking etc.)
Walking/Wheeling on street	Traveling	Public transportation

**Experiences:**

- Do you feel you are treated differently or the same as people who do not have RG in public spaces? If yes, can you expand on some of these differences?
- Do you find there is a difference on how you are viewed/treated according to what type of public space you are in?
- Are there public spaces you avoid because of people’s potentially negative or intrusive responses to you as a person with RG?
  - Why do you think this public space causes these types of reactions to you?
- What would you say is the most common reaction to you when you are in public?
  - What do you think people are thinking when they are reacting this way?
- There are many different terms to refer to people with short stature, which one do you use or identify with?
  - Is there a reason you use this term over others?
  - How do you feel about the term midget?

- Have you ever been in a social encounter that made you feel unsafe?
  - What do you think were the motivations/justifications to treat you this way?

**Meanings behind experiences:**

- If you have felt treated differently (*either sometimes, often or all the time*), what do you feel are the central reasons for this differential treatment?
- How do you think people who do not have RG view us?
- Do you think there has been a change over time/history as to how people with RG are perceived?
- Do you think there has been a change over time/history as to how people with RG are treated?
- When you begin interacting with people do you find there is change in how people perceive you?
  - Why do you think people alter their perceptions of you when interacting?
- If you have experienced discriminatory treatment in public, what do you think are the ways we can combat/fight/change these experiences?



## **Appendix D – E-mail Interview Questions**

### **Interview Questions for E-mail Correspondence**

Age:

Sex:

Living in (City, town or country):

Diagnosis or condition that causes your restricted growth (Short Stature):

Personal Information (Optional, anything you wish to add):

About the researcher:

*My name is Lesley. I have Morquio syndrome (Type A) a very rare genetic disease that has caused my bones to form differently. I have restricted growth (short statured) and have a different body shape from the 'average' person. My experiences with strangers in public as a person with restricted growth have been varied but I feel that I affects my personal interactions with strangers in social spaces. I often experience staring by both children and adults. I have experienced direct prejudice against me in the form of name calling or teasing and laughing. I have also had people treat me as if I was a lot younger than I am. I have sometimes been ignored while waiting in line and often have my personal space violated. I also find that people can be especially kind to me. These are just some of the things I have experienced; you may have similar or very different experiences. The research project is looking to explore the experiences of people with restricted growth/little people in public spaces and what we feel are the meanings behind them.*

*Here are the questions I would appreciate you answering as a participant in this research project. Feel free to add anything that is not asked about. Please elaborate as little or as much as you want in your answers. Thank you!*

1. In your interactions with strangers in public spaces do you think you are treated differently that people who do not have restricted growth? If yes, do you find this frequent or infrequent?
2. If you have experienced different treatment, why do you think this is?

3. What do you think people are thinking about you when they treat you differently?
  
4. Have you experienced the following, and if so would you like to elaborate on these experiences? Why do you think you have or have not experienced these things?
  - 4a. Staring:
  - 4b. Teasing:
  - 4c. Name calling:
  - 4d. People ignoring you:
  - 4e. Other experiences:
  
5. How do you think people in general perceive people with restricted growth?
  
6. Why do you think people perceive people with restricted growth this way?
  
7. Do you find there is a difference on how you are viewed/treated according to what type of public space you are in?
  
8. When you begin interacting with people do you find there is change in how people perceive you?
  
9. If so, why do you think this perception changes?
  
10. What is the term that you use to identify yourself (if any), person with restricted growth (RG), little person (LP), Dwarf, person with Dwarfism?
  
11. Why do you identify with this particular term?
  
12. What does the term you identify with mean to you?
  
13. Do you identify as a disabled person or person with a disability?

End

## **Appendix E – Consent Form**

### **Informed Consent Form for Social Science Research**

The University of Leeds, UK

**Title of Project:** Small Body, Large Presence: Exploring the Experiences of People with Restricted Growth in their interactions with Strangers in Public Spaces

**Principal Investigator:** Lesley Ellis, Graduate Student

**Supervisor:** Dr. Alison Sheldon  
University of Leeds  
School of Sociology and Social Policy  
University of Leeds  
LS2 9JT  
England

- 1. Purpose of the Study:** The purpose of this research study is to explore the social interactions of people with restricted growth in public spaces. A further exploration of how these experiences can be encompassed within the social model of disability will be addressed.
- 2. Procedures to be followed:** You will be asked to participate in an informal in-depth interview either in person, or via e-mail or telephone.
- 3. Discomforts and Risks:** There are no risks in participating in this research beyond those experienced in everyday life. Some of the questions are personal and might cause discomfort, you do not have to answer any questions you do not want to.
- 4. Benefits:** You might gain insight into how people with restricted growth are perceived and treated in public spaces and the reasons behind this. You might also have an opportunity to connect with other people with restricted growth.

- 5. Duration:** The interview will be approximately one hour, but can be concluded at any time if you wish.
- 6. Statement of Confidentiality and Anonymity:** Your participation in this research is confidential. The data will be stored and secured by the principle researcher. Pseudonyms will be used and no real names will be included in the drafting or dissemination of the research.
- 7. Right to Ask Questions:** Please contact Alison Sheldon at UK Tel: 0113 343 4715 Email: a.sheldon@leeds.ac.uk with questions, complaints or concerns about this research.
- 8. Voluntary Participation:** Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 18 years of age or older to take part in this research study. If you agree to take part in this research study and the information outlined above, please sign your name and indicate the date below.

You will be given a copy of this consent form for your records.

\_\_\_\_\_

Participant Signature Date

\_\_\_\_\_

Person Obtaining Consent Date