

**FACING STIGMA, NEGOTIATING EXPECTATIONS, AND EXPLORING
IDENTITIES IN A SPECIAL OLYMPICS GROUP TRANSITIONING INTO
ADULTHOOD**

By

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ABSTRACT

Special Olympics continues to be controversial to those who criticize any segregated activity that is not inclusive for people with disabilities. Rather than dismissing the Special Olympics outright as an outdated organization that has not kept pace with the push towards inclusion, I engage these controversies from the perspectives of the disciplines of folklore and disability studies. I demonstrate that close attention to the actual practices and lived experiences of a Special Olympics group provides important insights about the challenges and goals of inclusive versus exclusive practices.

I examine the athletes' conceptions of identity, disability, and kinship to better understand how stigma affects people with intellectual and developmental disabilities (IDD) and the opportunities for full the participation in public life. Based on extensive ethnographic research, participant observation, and open-ended interviews with adult athletes, their families, coaches, and support professionals, I describe a Midwestern team's activities, including athletic practices, games, home life, and social events. To what extent people with IDD are aware of stigma and its effects emerges as one of the underlying questions from this research. In addressing this, I encounter methodological challenges that require an appreciation for different communication styles, including deceptive practices, moments of resistance, and exercises of agency.

I begin by looking at the history of the Special Olympics, how it is structured, and where it provides (or inhibits) possibilities for full participation. As part of that

discussion, I describe the roles of safety, sportsmanship, and self-esteem. To further develop the issues that arise in discussing Special Olympics and inclusion from a disability studies perspective, I turn to the subjects of pity and its corollary, the celebration of individuals with IDD as mascots who are awarded symbolic, rather than actual, roles in sports, school, or community events. As mascots, individuals with IDD are hypervisible, but this does not necessarily counter the stigma they experience that prevents them from being fully included in other domains. In particular, obtaining and maintaining competitive employment are often the central measures of inclusion, so my concluding chapter considers the challenges faced by Special Olympics athletes in the workplace.

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Chapter One

Introduction

This thesis demonstrates how an in-depth exploration of a Special Olympics team, the athletes' understandings of identity, disability, and kinship is useful for understanding the questions of stigma and full participation in public life for people with intellectual and developmental disabilities (IDD). My work is motivated by a concern that people often sell individuals with IDD short. Having spent over thirteen years either working with, volunteering, or socializing with individuals with IDD, I have seen numerous situations where contact between those with and without disabilities occur and how the potential for inclusion deteriorates. Oftentimes well-meaning people, partly out of a concern for politeness towards people with disabilities as stigmatized individuals, behave in ways that ultimately defeat the possibilities of engagement and inclusion that are most likely their true objective. Is the goal of inclusion for individuals with disabilities to experience kindness as a sign of acceptance or is the interest in inclusion strictly for its own sake as an opportunity to participate, to identify just two of many options? For some parents, inclusion for their children means equal access to participate in activities with their mainstream peers. For other parents, inclusion offers the promise of something more—not just momentary interaction, but sustainable friendships, acceptance, and/or ongoing participation in ordinary life.

The chapters that follow address how a comprehensive exploration of a Special Olympics group that offers some opportunities for inclusion and serves primarily as a kinship group can be useful for understanding how athletes with IDD and their families counter stigma and what they hope for in terms of participation in public life. I am driven

by how people behave in the contact zones that Special Olympics affords, how social rules are performed, and what is at stake when inclusion is the goal. To examine these issues, I consider first the contemporary climate in which the public and scholarly debates about inclusion and segregation move beyond the education system into the fields of sports and recreational activities and employment. Inclusion and segregation are really about the quantity and quality of interaction time between people with and without disabilities. Ethnographic studies (see Frake 1964; Briggs 1970; Cashman 2008) describing how people manage interaction have the potential to offer significant insights into the complexity of inclusion and exclusion.

The Individuals with Disabilities Education Act (IDEA) was passed in 1975 to afford every child with a disability the legal right to have a free and appropriate education. The practical applications of this law vary immensely, and it is not my goal to offer a detailed analysis of the inclusion debate in education; instead, my study contributes to the greater understanding of inclusion by considering how interaction time among peers with and without disabilities shapes developing minds and perceptions. After high school, this interaction time changes as some people go to college, seek employment, move out of their parents' homes, and establish social groups and communities of their own. For young adults with IDD, those hours that might have been spent with mainstream peers at school are no longer inevitable but instead require intentional planning. A fundamental premise of thinking about inclusion, and how people spend the majority of their day, is the goal of people with disabilities being as visible and integrated as possible in the community, not hidden away in homes, institutions, sheltered

workshops, or developmental center day programs. Because there is such a vast and complex range of intellectual and developmental disabilities, not to mention geographical, cultural, and social factors influencing their options, it is no simple matter to ask what choices are available to help someone be a member of the community. Further complicating this question is to ask: whose interests are served by inclusion?

I begin by looking at the history of the Special Olympics, how it is structured, and where it provides or inhibits possibilities for full participation. As part of that discussion, I describe the roles of safety, sportsmanship, and self-esteem. To build upon the issues that arise in discussing Special Olympics and inclusion, I turn to the subjects of pity and its corollary, the celebration of individuals with IDD as mascots. One of the underlying questions that emerges from this research concerns whether and to what extent people with intellectual disabilities are aware of stigma. To pursue this, I examine data I collected on their deceptive practices, moments of resistance, and the exercise of agency. Finally, the consequences of stigma and inclusion and/or exclusion culminate as the Special Olympics athletes attempt to find competitive employment. Two of the remedies to stigma and exclusion are proposals for the equitable treatment of all and equal access to resources.

Equity and equality are never the same, but they are often in relation to each other and can get easily confused, particularly when people believe that making things equal translates into making things equitable. In the case of disability, as many have noted (Oliver 1998; Erevelles 2000; Kittay and Carlson 2010), equality is often not possible. It is not the same to have or not have a disability, nor are different disabilities experienced

equally. Beginning with the inclusion debate in education, there are parents who argue forcefully for inclusion in education because their children will be treated equally. Those types of inclusive classroom may, to some extent (with limitation), provide equal opportunities or equal treatment, but they are rarely equitable. In other words, even if everyone is treated equally, they do not have equal access to the resources provided. The Special Olympics takes us a step further into the complex relationship between equity and equality. For example, we could consider situations in which every athlete who participates in a Special Olympics event is given a ribbon as a ritual gesture intended to promote equality. It does not, however, actually achieve equity and this is part of the complaint lodged by critics of the Special Olympics who argue that if everyone gets a ribbon, those individuals who achieved more are not properly recognized and rewarded as exceptional. They see this practice as not equitable. If the goals of the Special Olympics are to allow people with disabilities to participate in events and activities in which they would otherwise be excluded, to promote being a good sport, being a part of a team, and achieving one's personal best, then (according to promoters of Special Olympics), it is not incongruent to give everyone a ribbon regardless of their performance. The detractors point out, however, that this practice can be construed as infantilizing and not setting high enough expectations and rewards for those who do perform better than others do. Special Olympics as an entity provides opportunities for athletics that are not available for people with physical or cognitive issues that compromise their athletic prowess. It is equitable in that it provides an opportunity for them to be competitive in an arena with similarly skilled athletes (an opportunity similar

to that available to people without disabilities). As I will discuss, the critics of Special Olympics (Orellove, Wehman, and Wood 1982; Hourcade 1989; Bersani 1990; Storey 2008; Gard and Fitzgerald 2008; Counsell and Agran 2012) argue that Special Olympics is flawed for its failure to be inclusive, its promotion of stigmatization based on paternalistic and demeaning portrayals of those with disabilities as requiring help, pity, and charity, and that it cannot count as competitive because it is already a restricted group. Although there are divisions and opportunities to compete in increasingly more competitive levels, it is still not like the Paralympics, which has much different standards and requirements for elite athleticism. However, it is a mistake to assume that all Special Olympics sports have such lax standards that they do not belong to the same genre of competitive sports. All sports competition involves a kind of restriction that categorizes people according to their abilities. Underlying these arguments about authenticity and the integrity of competition is the assumption that competition and the desire to win has more value than alternative approaches, or other types of recreational activities, where the goal of winning is replaced by performing one's personal best, being a good sport, and learning how to be a part of a team. Cultural norms idealizing individualism and competition, almost without thought to the possibility of other options, form the foundation for this taken for granted assumption, whereas other cultures do not value these goals as ideal. I am concerned that if we measure people's value by their ability to compete, then we risk excluding a large number of people with IDD who might never reach a level playing field with those without IDD, and thus deny full personhood to those with differing abilities.

This is precisely where the notion of capabilities is useful to further analyze the issues at hand. In Amartya Sen's terms, "The idea of 'capability' (that is, the opportunity to achieve valuable contributions of human functioning: what a person is able to do or be)" is a concept he finds useful for distinguishing between the things people value and the resources that are available to them (2004, 332). Oftentimes, equity is understood in terms of resources, especially material resources, but it needs to be expanded to encompass social resources and the different attitudes towards Special Olympics. Some parents I interviewed chose not to have their children participate in Special Olympics at all because it is not inclusive. They reject any activities that are restricted to individuals with disabilities on the grounds that those activities cannot be "equal." Parents who do value the opportunities provided by the Special Olympics more often make an argument for equity and see the Special Olympics as a point of access for their child to play team sports. The debate about equality and equity, although rarely discussed in these terms, is frequently a topic of conversation among Special Olympics coaches, parents, and participants. Many discussions revolve around what is equitable in terms of what is "fair." Should everyone get equal playing time or should the best players be allotted more time than others should? Should the coaches take into account the fact that the players want to win and might be more interested in winning than in equal playing time? Flexible definitions of sportsmanship and chivalry complicate this further, as in the act of giving the ball to a weaker player to allow them a chance they might not otherwise have. One parent said that the Special Olympics is all about learning what is fair. It is not fair if someone unnecessarily pushes another person down, but if it is accidental because the

athlete lost his or her balance, then it might be unfair to penalize him or her. However, in a competitive game, most athletes would be penalized regardless of intention, and this is still considered fair. This same parent summarized the complexity of these rules and lessons by saying, “Special Olympics is one of the few places where my son gets to understand such complicated relationships” (P5:9/13).¹

A folklorist’s approach is particularly useful because these rules and social norms involve adherence to rituals and learning by imitation. It is precisely this type of learning that is possible through Special Olympics that can be seen as critical to helping teach the rules and rituals necessary to participate in fully inclusive settings.

The requirement for participation in Special Olympics is having an Individual Education Plan (IEP) in school. Many participants, but not all, have developmental disabilities. All but one of the athletes on the team I studied have developmental disabilities. Developmental disabilities are disabilities that are considered to be severe, chronic, appear before an individual reaches the age of 22, and can impair physical and/or cognitive abilities. Intellectual disabilities are a subset of developmental disabilities that must be diagnosed before the age of 18 and are characterized by significant limitations in intellectual functioning and adaptive behavior (American Association on Intellectual and Developmental Disabilities 2013). For the purpose of this thesis, I use IDD to signify the categorical marker of those who have been diagnosed with having an intellectual and developmental disability.

¹ See the Methodology section and the appendix for an explanation of the coding system used for identification.

Current debates about inclusion serve as the larger historical social political contexts of my research. In Ohio, there has been an ongoing controversy about the role and value of programs designed exclusively for those with developmental disabilities; for example, the state government's adoption of the Employment First initiative has called for more attention and resources to be directed towards providing employment opportunities in the community for people with developmental disabilities. Some individuals and families object to this redirection of funds away from more exclusive, supported environments.

Ohio is part of a growing nationwide movement towards greater inclusion of people with IDD into the general community. Part of this inclusive movement is the belief that funneling people from high school into sheltered workshops is unacceptable, so funding is being redistributed in order to ensure more people with IDD have the opportunities to try employment in the community. The sheltered workshops have been criticized as unnecessarily segregated and as relying on false assumptions that individuals with IDD are "unemployable" and therefore only capable of being placed in sheltered workshops. Sheltered workshops, or places where people with developmental disabilities are placed in a location separate from the non-disabled community and surrounded by other people with disabilities, can vary in terms of wage-earning possibilities and production goals and materials, but they are generally geared towards repetitive piecework production; payment is often based on production amount and can be sub-minimum wage; and the only people who do not have disabilities are the staff members. It has been estimated that there are 450,000 people with developmental disabilities across

the nation who spend the majority of their days in sheltered workshops and segregated settings (Heasley 2014), which has caused concern that states are overly relying on sheltered workshops as placement for people with developmental disabilities rather than exploring other options, including employment in the community, and that this is a violation of the Americans with Disabilities Act (United States Department of Justice Civil Rights Division 2014).

Emerging out of the Civil Rights movement, the Americans with Disabilities Act (1990) and the Olmstead Decision (1999) have highlighted the importance of accessibility and community integration and participation for individuals with disabilities. This is particularly relevant and often problematic when young adults with IDD leave the school system and face significant obstacles when trying to achieve the ideal of community integration. The transition out of high school into adulthood for people with intellectual and developmental disabilities is a critical time in their lives that can be identified as both an institutional and cultural category. Service professionals and educational practitioners define this stage in terms of age and changing institutional responsibilities, but it is also a liminal category defined by what opportunities are and are not accessible based on cultural standards of normalcy and competency. Concerns about employment opportunities, inclusion, segregation, what it means to live a full life, and in whose best interest people are serving, resonate deeply with the group of people that I have known for over twelve years. Although their stories and perspectives represent only some of the issues faced by individuals with IDD and their families, they complicate the

more visible and easily summarized snapshots highlighted in newspapers and media accounts surrounding the funding cuts to sheltered workshops.

For example, in a newspaper article covering the unclear fate of a local sheltered workshop for individuals with IDD, one employee is portrayed as reminiscent about how she had once found her dream job of working at a cash register, only to be crushed when her employers changed their minds and said she wasn't fast enough. Now working as an assistant helping others with developmental disabilities at the sheltered workshop, where "bosses remain patient and no one gets fired," she argues that workshops like hers are hugely important. However, declining enrollment, shifting policy trends, and a push for competitive employment are contributing to a decrease in sheltered workshops across the country as more people are viewing sheltered workshops as signs of segregation. Some advocates for sheltered workshops cite the impracticality of all individuals with special needs being able to find work in the community and point to the stresses and dangers associated with ill-fitting job placement attempts. Although John Martin, Director of the Ohio Department of Developmental Disabilities (DODD), acknowledges that there are not enough resources, supports, and community jobs to replace the services offered to more than 18,000 Ohioans currently attending sheltered workshops, and that he does not want to disturb people who are happy where they are, he also believes that more options for community employment need to be pursued to avoid people going straight from high school into sheltered workshops (Price 2014).

This thesis focuses on one folk group that is experiencing this stage of transition and seeks to understand how people cope in their daily lives with the changes that occur after high school is over, social worlds are altered, and expectations of adulthood evolve. Having known many of the individuals on an Ohio Special Olympics (OHSO) team for over twelve years, working with several of the athletes in their homes, out in the community, and also working in a day program in a different state with individuals transitioning out of high school, I have witnessed the difficulties and anxieties faced by many when it came to finding and maintaining jobs, housing, relationships, and independence. For many of the athletes and the families I have come to know, Special

Olympics offers more than just a chance for athletes to learn new sports skills, increase their physical fitness, and socialize; it also provides a calendar of activities and traditions that are consistent throughout the year, a network of information gathering and sharing where family members can learn about different opportunities and services that they might not otherwise be aware of, and where parents and caregivers can find emotional support from people facing similar challenges.

It wasn't until after I had completed most of my interviews that I learned that there was a significant movement in disability studies calling for the end of the Special Olympics based on the argument by Keith Storey, Professor of Education and Special Education Chair at Touro University in California, that it increases segregation, reinforces negative stereotypes, does not teach functional skills, fosters paternalism, and promotes handicappism, to name just a few of his key criticisms. Storey claims, "Like all segregated programs, the Special Olympics is unable to deliver important quality-of-life outcomes for people with severe disabilities and often diminishes the possibility of achieving those outcomes" (Storey 2008, 140). While I will go into more detail delineating the various arguments for and against inclusion and segregation with regards to the Special Olympics, as well as in education and the workplace, throughout my thesis, I would like to call attention to Storey's claim that very little research has been done concerning the Special Olympics and that "there is no research suggesting that the Special Olympics is effective in providing quality-of-life outcomes (as outlined by Felce 1997) for participants" (Storey 2008, 138). This is precisely where a folklorist can provide potential insight into what might contribute to various understandings of

“quality-of-life outcomes” and new perspectives on what it means to belong to a Special Olympics community through the lens of a folk group and all of the possibilities that entails. This thesis, therefore, offers not only a new understanding of a folk group, but also suggests how folklore can contribute to existing literature on the transition process for people with intellectual disabilities, their families and caregivers, and how the intersection of folklore and disability studies can have a valuable impact on our current understandings of the perspectives of those with intellectual disabilities.

I organized the dissertation according to the central issues that emerged in my data. These are based on the practices of the team and especially concerns about Special Olympics as part of the larger debates about inclusion. I am particularly interested in the related question of how people with IDD are credited or discredited with having the necessary awareness to understand the concepts of inclusion and stigma that are so central to these debates. Using ethnographic methods, I describe the team members’ strategies in self-presentation and relationship formation, the understanding and performance of competition (including issues of safety and team sportsmanship), communicative competence, and deception. In addition to observing their practices in sports events, I collected data on individuals with IDD who have served as mascots for groups without disabilities. These data combined are helpful for a discussion of how the individuals with IDD manage their self-representations, their experience of stigma, and characterizations of them. I then consider the same issues of inclusion as they are applied in the domain of employment. These areas are tied together by the larger question of the expectations people have of individuals with IDD and the ways that lower expectations

actually serve to minimize inclusion more profoundly than activities that are inclusive or exclusive.

In Chapter Two, I describe a Special Olympics team using the folkloristic framework of the folk group. I begin by reviewing some of the basic premises of disability studies in general, discuss intellectual disabilities and communicative competence, and then turn to a discussion of how folklorists have approached disability. Folkloristic analyses can be separated into those that focus on physical disabilities, those that deal with both physical and intellectual disabilities, and those that consider intellectual disabilities. I examine literature on changelings (Narváez 1991), narrative analysis of local character anecdotes (Tye 1989), and critical inquiries into issues such as empathy, entitlement, performance, and competence through the works of Amy Shuman (2005; 2013; 2015). I then highlight work in disability studies that corresponds most closely to my research interests in transition and ethnography with people with intellectual disabilities. I suggest that although some scholars in disability studies have begun to explore the importance of ethnographic work on transition and narratives of people with intellectual disabilities, they could benefit from a folklorist's use of narrative analysis and performance theory.

Chapter Two features a brief history of the Special Olympics on a national and local level. I introduce its goals, mission statement, and motto ("Let me win, but if I cannot win, let me be brave in the attempt"), as well as the athletes, coaches, and families I interviewed. Finally, I describe what qualities stand out as unique and significant to this particular group. Through this framework, I will address the arguments for and against

inclusion as they relate to the Special Olympics. I will also cover what I witnessed through interviews and participant observation that either confirmed or rejected some of the opponents' criticisms.

In this second chapter, I also explain how my work with the Ohio Special Olympics (OHSO)² team corresponds to the now-accepted definitions of a folk group. Folklorists have expanded their concept of what constitutes a folk group from early definitions of a community bound by shared language, geography, and traditions. In her essay on folk group, Dorothy Noyes points out the contradictions involved in defining a folk group by attempting to contain it from the outside as a cohesive community while also highlighting the tensions and inconsistencies from within as each member has a unique role, thereby resulting in "the impossibility of a neat definition of the group." (Noyes 1995, 449). Noyes' definition is an elaboration of Richard Bauman's essay "Differential Identity and the Social Base of Folklore" (1971), which was foundational in the paradigmatic shift from textual to performance-based approaches and serves as an entry point into the complexities and nuances associated with the performance of identity and group membership. Bauman considers ethnicity, religion, region, occupation, age, and kinship (but not differential abilities) in his exploration of how texts and performances "differentiate the exoteric from the esoteric" (1971, 38). Disability is also, to use Richard Bauman's formulation, a differential identity often used to describe others but not oneself. Taking it a step further, what does the term "disability" mean to those

² All names of teams, athletes, and interview participants have been replaced with pseudonyms to protect the privacy of those involved. However, because of the close-knit ties and familiarity of the group members, true anonymity is not possible since it is likely that many would recognize themselves and others based on certain shared experiences and characteristics.

who have been assigned to a stigmatized group by virtue of externally imposed and socially-constructed values and criteria? By revisiting Jansen's (1957) concept of the esoteric and exoteric factor in folklore through the lens of disability, I argue that disability is an unstable category that can be powerfully stigmatizing, neutrally valued as little to no difference, or positively marked as signifying strength over adversity. Additionally, disability and difference can provide points of connection that might not otherwise be possible and these relationships become a new type of kinship based on shared difference (Rapp and Ginsburg 2001).

Chapter Three provides a description of the group, including a history and the organizational structure of the group. I provide a brief description of each of the athletes I came to know rather extensively over the years as a volunteer, direct care provider, and ally. Some of the athletes participated in interviews, and for others who did not participate in interviews, I interviewed their parents or caregivers. This chapter covers my methodological approaches to ethnographic research when trying to understand how individuals in the group perceive themselves and others. Before going into the analysis of my data, I will explain my research methods, selection of informants, and challenges and strategies used for communication. I address some of the ethical issues of working with people who often do not understand the consequences of being spoken for, rather than speaking for themselves, or who necessarily rely upon allies to speak for them.

Although Jansen's work on esoteric and exoteric folklore has often been used to explain how groups identify themselves and others, this becomes complicated when working with individuals with intellectual disabilities who may or may not self-identify

as “disabled” or see disability as something that applies to them because it hinges on relational conceptions of normalcy. Chapter Four builds on Jansen’s framework to gain a greater awareness of how the various athletes understand the concept of disability and what belonging to a Special Olympics group means to them.

Chapter Five explores competition and how expectations of performance shape identities. As members of this Special Olympics group, athletes are held to certain standards and an ethos that has been maintained by the coaches for years. The Special Olympics coaches are mostly responsible for creating an atmosphere where the athletes can be physically active, safe, and learn new skills. They are also instrumental in teaching good sportsmanship in the athletes, curbing inappropriate behaviors, and promoting positive self-esteem, which are all culturally and socially specific values. In some cases, the goals of Special Olympics lead to inconsistent practices—some of which, like hugging, are not tolerated in this group but are highly-publicized traits in other Special Olympics groups. I was interested in learning how these standards were established, and through my research, I gained insight into how the coaches translated their philosophy into practice for athletes with varying physical abilities, cognitive abilities, and social skills.

Because the group I am researching is in a transitional phase of life (ages 18-30), and the goals of the Special Olympics are to promote positive social skills, physical fitness, and increase one’s inclusion in society and employability, I analyse expectations as they relate to jobs, friendships, relationships, housing, and independence (from the perspectives of both the athletes and their caregivers). It became increasingly apparent

during my research that certain topics, such as loneliness, sexuality, independence, and adulthood, had vastly different meanings and implications for the athletes and their parents. Narratives shared during interviews I conducted highlight issues of safety, the dignity of risk³, paternalism, and constructions of (a) sexuality, all hotly-debated topics in disability studies. The narratives I was told offer insight into how these issues are created and interpreted from various perspectives. This chapter also explores shared narratives and anecdotes that are similar in form to cautionary tales and inspirational tales in relation to employment possibilities, failures, and responsive strategies to not meeting previously-held hopes for post-high school opportunities.

Scholars such as Bauman (1977), Bauman and Briggs (1990), Briggs (1986), Goffman (1963), Hymes (1971), Jenkins (1998), and Shuman (2011; 2013) have studied the construction of communicative competence in society to understand how rules are created, who chooses to follow them, and how compliance and resistance are enacted. Conforming (or not) to rules demonstrating social competence have consequences for whether or not a person is accepted into a particular group or community. In Chapter Six, I examine the idea of competence and how individuals with disabilities are often perceived to be lacking in multiple areas of competency according to the deficit model that defines them as being disabled. Because the perceptions of the parents and athletes I interviewed reflect multiple levels of competency, although not necessarily in what we

³ The term “dignity of risk” is discussed heavily in literature on transition for individuals with IDD because it encapsulates the viewpoint that allowing people the opportunity to choose, take risks, and make mistakes (within certain safety parameters) affords them access to greater wisdom and learning from experience that otherwise would not happen if they are denied opportunities due to overprotection (see Johnson and Traustadóttir 2005, and McDonald, Keys, and Henry 2008).

might think are typically recognizable forms, I use this chapter as an opportunity to interrogate the boundaries of social appropriateness and the constructed nature of communicative competence. One person might perceive the act of following certain rules as a demonstration of competency, whereas another might interpret the ability to circumvent authority as a display of a higher degree of competency. This leads us to question, as Richard Jenkins does, “Are there any human competences which are not locally defined and culturally variable?” (1998, 227). As folklorists, we often seek out spokespersons, cultural brokers, or translators who demonstrate a certain level of performative competence. This practice has to be reevaluated when working with people with intellectual disabilities. Does competence rely upon the ability to produce a coherent and linear narrative? Is it about being “authentic” or telling a phenomenological truth? Or is it reliant upon the capacity for self-reflexivity?

In Chapter Six, I continue to address some of the aforementioned questions as I explore how ideas of competence are tied to value-laden concepts such as innocence, manipulation, and deception, which can have very real and significant consequences for those who possess, and those who lack, power. I argue that in the quest for inclusion, there is often a requisite construction of innocence apparent in personal narratives and Internet depictions of those with disabilities as poster children or mascots. At best, these stories give people a momentary sense of inclusion; and, at worst, they construct a shadow of inclusion based more on pity than acceptance, concretizing the status of the disabled as a caricature. In contrast to the perception that people with intellectual disabilities are perpetually trapped in a state of infantilized innocence, lack the

capabilities for strategizing, or are predominantly interested in pleasing people in positions of authority, I encountered numerous examples in my interviews where my informants demonstrated resistance and regained control over the interview, leading me to reconsider the implications for our understandings of power, resistance, and compliance.

Chapter Seven, on employment, returns to the recurring core themes of stigma, inclusion, discrimination, and considers how although the process of transition is intended to proceed smoothly into employment in the community, the process is far from smooth (and often disappointingly unsuccessful). This chapter demonstrates how narrative analysis proves useful when combining the study of the stigmatized vernacular (Goldstein and Shuman 2014) with Karen Barad's notion of "discursive entanglements"—moments of "intra-actions" where contradictory or overlapping discourses are subject to continuous reconfigurations and slippages based on highly specific contexts that then spawn new discourses—to analyse the categorical framing of individuals with IDD as they seek to gain (and maintain) meaningful employment in the community (2007, 74).

In my concluding chapter, I revisit the significance of the move in educational, recreational, and institutional settings away from segregation and towards inclusion. As someone who has experience working in a multitude of roles in a variety of segregated, integrated, and inclusive settings, I am interested in the underlying issues that emerged through my ethnographic data. How do expectations help or hinder inclusive efforts aimed at integrating individuals with IDD into the community? Where and how might

natural supports and job coaches help bridge the transition into the workforce? How can staff training help create a more successfully integrated work environment? In what ways might kindness interfere with setting and achieving high expectations? As a folklorist, I learned that success and failure were often predicated on the performance of ritual behaviors that translated beyond the Special Olympics and into the workplace and general community. What if Special Olympics is one of the most crucial environments where people with IDD can learn how to perform ritual community behaviors? Finally, how can we as folklorists best contribute to the interdisciplinary dialogues concerning intellectual disabilities? Following Diane Goldstein's call (issued in her 2013 American Folklore Society's Presidential Address) to make sure people know "our field's expertise is in local knowledge, narrative, and expressive culture"—if we profess to be rooted in local knowledge with our ear to the ground, then we must do justice to that honor and demonstrate the utmost respect to those whose stories we share, insights we offer, or experiences we attempt to document. Furthermore, we must utilize that expertise to "make sure patients, victims, survivors, and culture-bearers are not run over in the process" (2015, 138).

Chapter Two **Special Olympics as Folk Group**

Literature Review on Folklore and Disability

My review of the literature includes the following: 1) a discussion of the intersections in the fields of folkloristics and disability studies; 2) a summary of research on Special Olympics; 3) a discussion of the concept of inclusion; and 4) a review of the literature on folklore and disability. Before exploring the possible new directions folklorists could introduce to the field of disability studies, it is necessary to provide a survey of how the three categories of disabilities: physical disabilities, both physical and intellectual disabilities, and intellectual disabilities have been treated in folkloristics. I will consider four of the ways that folkloristic research intersects with disability studies. First, I will discuss the work of Marilyn J. Phillips. Second, in a discussion of research on changelings, I consider how folklore has been used to make sense of disabilities. Third, I turn to Diane Tye's work on local character anecdotes. Finally, I discuss Amy Shuman's recent work on disability and folklore.

Approaching physical disabilities from a folkloric perspective in her chapter "Straight Talk from 'Crooked' Women" in *Feminist Theory and the Study of Folklore* (Phillips 1993, 396–410), Marilyn J. Phillips employs a feminist lens to explore the personal experience narratives of women who have physical disabilities. Her goal is to better understand how, citing Bogdan (1988), the "disabled body, like the female body, is a socially constructed symbol of powerlessness and deviation, created by social organizations and imbued with meaning by cultural ideologies" (Phillips 1993, 397).

Combining a feminist approach with the work of disability studies author, Robert Bogdan, Phillips was one of the first folklorists to apply both of these approaches to the field of folklore. This particular foundational move demonstrates the ease with which the different fields can complement each other and it is thought-provoking to follow Phillips's investigation into how culture shapes the non-normative body and vice versa (Phillips 1993, 398–99) as she explores the women's narratives in relation to the body. Although she does touch on issues of invisibility and assumed asexuality associated with disability, which are of particular interest to my research and also common themes in disability studies discourse, her emphasis on physical disabilities potentially excludes those with intellectual disabilities and thus limits the potential for inclusiveness that is offered through the documentation of disabled women's stories. The disproportionate amount of academic and social activism work that focuses on physical disabilities as opposed to intellectual disabilities is apparent in a cursory examination of publications in disability studies, and while I am not intending to criticize scholars for concentrating their efforts, I do use this as an opportunity to reflect on why there is more available research on those with physical disabilities rather than intellectual disabilities. One of the arguments in disability studies is that while some people with certain physical disabilities might be limited physically, they still have more access to upper-level educational positions and other places of visibility and power (i.e., Stephen Hawking, Tom Shakespeare, Tobin Siebers, etc.). And while there are individuals who have featured prominently in disability studies and academia who acknowledge having mental disabilities (i.e., Temple Grandin, Margaret Price, etc.), they do not have the intellectual,

developmental, and cognitive disabilities that preclude many from receiving mainstream education or the adaptive technological assistance that might enable them to communicate in a more culturally acceptable format.

This emphasis on communication is significant, particularly when as folklorists, we find much of our data through collecting and analyzing narratives. In addition to the struggles associated with developing rapport, capturing ideal contexts and performances, and appropriately addressing the ethical issues involved with power differentials and our obligations to our informants, attempting to represent our informants' thoughts and words to the best of our abilities can be even more daunting when their ways of speaking do not fit with typical narrative patterns. More work is needed to offer folklorists further instruction into gathering narratives from people with intellectual disabilities. It is important to pay increased attention to bodily and interactional cues, to look beyond the importance of the spoken word, and to place more of an emphasis on participant observation conducted over an extended period of time (when possible) in order to learn more about subtle but powerful forms of communication.⁴

Rather than focusing on narratives by the people with disabilities themselves, a second way in which folklorists have approached the topic of physical and mental disability is through textual and narrative analysis of fairylore and changelings. Scholars such as Peter Narváez, Gisela Piachewski, Ann Helene Bolstad Skjelbred, Barbara Rieti, and Susan Schoon Eberly provide textual and historical analysis of folklore relating to

⁴ Michael Angrosino's ethnographic work, *Opportunity House* (1998), has been helpful in exploring the richness and variety, as well as the difficulties and complexities that arise when working with people with IDD. His incorporation of a fictional blend of ethnography and life history approach offers a unique perspective on truth, authenticity, and the issues of speaking for oneself and others.

changelings (Narváez 1991). These authors explore the explanatory and cautionary functions that changeling tales fulfill. As explanatory tales, the stories sometimes serve to absolve the parents of their responsibilities for having stigmatized children; as cautionary tales, the stories might be used to deter others from making fun of children who do not fit the typically healthy and socially acceptable mold for fear that similar ailments will be cast back upon them.

A third way folklorists have discussed individuals with both physical and intellectual disabilities is through their work on local characters. Drawing on Sandra Stahl's work that associates the local character anecdote with the genre of personal experience narrative (Stahl 1975), Diane Tye (Tye 1989) links these anecdotes to the personal narrative through their form, while noting some of the complications associated with the potentially blurred boundaries. Although they might be brief and lacking certain formalistic characteristics such as an introduction and conclusion, local character anecdotes contain an element of exaggeration necessary for the character to be a "character" (Stahl 1975, 295 in Tye 1989, 188). Tye further categorizes local character anecdotes into exploratory and explanatory anecdotes: the former explore characters' personalities and lifestyles; the latter justify the "character's presence within the community" (Tye 1989, 191). In Tye's study of explanatory anecdotes in a Nova Scotian town where people who do not fit into the community's sense of normalcy are thereby viewed as somehow stigmatized, we encounter the character depicted as a victim due to circumstances often beyond their control, which sometimes give them more freedom to behave unconventionally (195). Similar to the changeling tales previously mentioned,

these anecdotes operate on an assumption that the individual is innocent of any wrongdoing that might have caused their stigmatized status and the anecdotes serve as a way to alleviate the individual from being responsible for their differently valued status. Local character anecdotes can also be a means to exert social control and ensure those who are considered less fortunate are protected. In the Nova Scotian community where Tye did her research, certain areas where people tended to congregate and interact provided opportunities for anecdotes to be created and circulated. In other words, Tye's model understands a community in terms of networks and nodes of connection in which local character anecdotes circulate.

In the community where I have conducted my research, the contact zones are less intensely focused on particular shops or areas where the majority of community members visit and engage in daily activities (as they are in the Nova Scotian community Tye studied). Instead, the Special Olympics community is comprised of a larger group that meets infrequently and has few points of connection and smaller groups, usually based in schools and neighborhoods, which meet at least weekly and establish multiple points of connection. Everyone in the smaller groups potentially shares in the larger community through identification with the group's motto, expressions of pride, and a sense of shared purpose. I say "potentially" because not all members of the smaller groups express any awareness of the larger entity. A sense of community pride and belonging in the local smaller group can be observed at school-related activities, community festivals, sporting events, casual and spontaneous encounters at local shops and restaurants, and, for some

of the participants, through the Internet and social media sites where networks of familiarity are created.

Although the communities of Nova Scotia and Special Olympics are quite different, Tye's work on local character narratives is nonetheless useful for understanding the larger network of the Special Olympians. Some of the athletes are known as local characters and are recognizable in the community because they have been featured in news stories or appear in social media. I experienced this firsthand in casual conversations with community members when I was asked about the topic of my research. Once people learned of my work with the Special Olympics team, I would often be asked if I knew a particular person or would be told an anecdote about someone they referred to as a type of character, not necessarily someone they knew in depth, and their impressions conveyed the Special Olympics athlete as sometimes cute and likeable, strange and mentally imbalanced, or as someone they did not know much about but recognized as belonging to the local community.

Finally, exemplifying the benefits of interdisciplinary scholarship, Amy Shuman (2005; 2011; 2015, and with Diane Goldstein 2012) has made several significant theoretical contributions to the fields of folklore and disability studies through her work on narrative analysis. In her book *Other People's Stories: Entitlement Claims and the Critique of Empathy*, Shuman (2005) explores how narratives both unite and alienate, highlighting notions of identity, trauma, and (un)tellability. In the chapter "Speaking from Experience," Shuman focuses on narratives about disability to explore the idea of experience (and, as she states, "the privileging of the authenticity of personal

experience”) from phenomenology’s interest in the realities of everyday experience, through Benjamin’s suggested connection between lived and shock experience, to feminist understandings of experience through narrative. Not only do “narratives about disability provide an obvious site for observing empathy and entitlement, as well as nostalgia and sentimentality,” as Shuman argues, they “also raise important questions about the failed promise of narrative, be it the promise to provide an untold story or a counter-narrative to medical discourse, the promise of greater understanding, or the question of who is served by that understanding” (Shuman 2005, 151). Shuman’s analysis of Temple Grandin’s narratives and positional stance is particularly relevant to my research because she highlights the complications of empathy and entitlement as they are applied to narratives by people with disabilities. In the quest to understand the experiences of people we often view as stigmatized, disenfranchised, or lacking a certain type of power or “voice,” we often look for cultural brokers or “translators” (the term used by Shuman and Grandin) to speak for the collective experiences of the group. This move, however, is precisely what Grandin and Shuman caution against because of the danger of silencing others’ experiences, the multivocalities and complexities that are inherent to individual experiences, and the harm in potentially minimizing people with disabilities’ full personhood. These issues are particularly relevant for understanding the controversial status of the Special Olympics.

The Special Olympics: History, Global, Local, and Criticisms

The history of Special Olympics began in the early 1960s when Eunice Kennedy, who was disturbed by the unfair treatment of people with intellectual disabilities and the lack of safe and accessible recreational places, urged her brother, President Robert F. Kennedy, to focus more attention on the rights of individuals with intellectual disabilities and then created a summer camp (originally called “Shriver Camp”) for people with intellectual and developmental disabilities based on research claiming that by engaging in physical activity, people with IDD would have greater employment possibilities, better performance in the school settings, and overall inclusion in the community. In July 1968, the first International Special Olympics Summer Games were held in Chicago, including over 200 events incorporating track, softball, and swimming activities. In 1971, the Olympic Committee gave permission to the Special Olympics to officially use the term “Olympics” in the title of their organization and then in 1988, the International Olympic Committee (IOC) endorsed and recognized the Special Olympics. Along with providing opportunities for sports competition, the Special Olympics began to include programs directed at providing free health screenings and some medical services to those in financial need (Healthy Athletes), numerous fund-raising endeavors, and “SO Get Into It,” a free program that teaches empowerment, inclusion, respect, and acceptance (Special Olympics 2016).

In a *New York Times* article on the Special Olympics (August 1, 2015), Lawrence Downes touches on some of the complex issues of inclusion and exclusion facing people with intellectual disabilities. Presenting a perspective promoting the unique benefits

provided by the Special Olympics, Timothy Shriver, the current chairperson of the Special Olympics, firmly believes that the Special Olympics offers individual with intellectual disabilities opportunities that they might not otherwise have were they not involved in SO-related activities. Addressing the discrepancies between the worlds inside and outside of the Special Olympics, Downes writes:

This is the conundrum of Special Olympics, an organization so good at making its athletes and the public happy, so bursting with good will and smiles, that nobody has to take it seriously. It has waged a nearly 50-year battle for inclusion and acceptance for people with intellectual disabilities, and people still think it's a track meet. (2015)

Downes' comment is useful for understanding that in addition to the criticism of Special Olympics as insufficiently inclusive, it is also dismissed as just an athletic event. For Downes and advocates of Special Olympics, taking the group seriously would be acknowledging its impact in terms of social justice. According to Downes, Shriver contends that although the Special Olympics might appear on the surface to be simply a sporting event, it is actually a human rights and human justice campaign:

Mr. Shriver explained a perverse truth: The more the world commits to programs for poverty and education, the greater the gap for those with intellectual disabilities. That's because money goes where results are quick and quantifiable, which is not likely for people with intellectual disabilities. The organization reports, for example, that at least 90 percent of children with disabilities in the developing world are denied the right to an education. Money for schools and health education never reaches them. People with intellectual disabilities, an estimated 3 percent of the population, are hidden in institutions, in private homes, in segregated schools, willfully kept beyond the public's vision. And the injustices they suffer — educational abandonment, medical neglect, sexual abuse — often go unanswered. (2015)

Shriver's argument is that in addition to the variety of injustices experienced by many people with intellectual disabilities, their rights and needs continue to be ignored because

they are relatively invisible, made even more invisible by other campaigns for disenfranchised people. Shriver believes the Special Olympics counters this invisibility. My investigation below will consider the ways that visibility works for the participants and their families themselves. Also, as I discuss below, Shriver's position has consequences for how we define equity and equality as related but different concepts.

Downes continues:

Mr. Shriver has a theory. When members of minority groups make progress, he said, it is because "deep down most people know they are the same as us, as me, whoever the dominant majority is. "But with our group it's like, 'No, no, no, they are not the same. They are not like us. They are not going to go to medical school if we give them a scholarship. They're not going to become engineers,'" he said. "We labor under the barrier, the attitudinal barrier, that this population is too different to matter." (2015)

The foreignness, or degree of difference, Shriver describes here, is central to questions of stigma and folk group. As Erving Goffman explains, stigma is always based on a perception of someone else as different (1963). Each folk group identifies itself as sharing some common characteristics that are different from others (Oring 1986). Disability studies as a field rarely explicitly articulates the idea that people with intellectual disabilities are "not the same," and instead often points to the shared humanity of people with different abilities (Davis 2006). The very complex issues of difference, ability, and folk group are central to my project. Disability studies uses a concept of identity based in racial studies and is interested in observing a fundamental human equality that has been obliterated by social injustice. As I will discuss, people with intellectual disabilities do face obstacles to full inclusion. One question is whether, as Timothy Shriver argues, Special Olympics offers opportunities that would not otherwise

be possible. Another question is whether Special Olympics further constrains already excluded people. Shriver argues that the athletes are different but that they still matter, and that the Special Olympics gives them the opportunities to show what they can do (Downes 2015). As I will discuss below, this is a position supported by many of the families who participated in my research project.

Reviewing the mission of Special Olympics is helpful for understanding these questions. As of 2015, the Special Olympics includes more than 4.5 million athletes and 80,000 competitions worldwide. Represented by the motto “Let me win, but if I cannot win, let me be brave in the attempt,” the mission of the Special Olympics is “to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community” (Special Olympics, Inc. 2016). To what extent this group’s outcomes have matched its intentions and its ability to evolve with the changing viewpoints and policies that have occurred over the past forty years is debatable and warrants further exploration into how Special Olympics functions today. Does membership in a group such as the Special Olympics cause more harm than good because of the stigma associated with intellectual disabilities? How do we best approach an understanding of what group membership means to those most closely involved?

In his article, “The More Things Change, The More They Are the Same: Continuing Concerns with the Special Olympics,” Keith Storey offers a valuable

discussion interrogating the Special Olympics and before proceeding with my research and analysis, I first must take into account some of his important insights (2008). First, Storey criticizes the Special Olympics for being segregated since membership is exclusively based on having an intellectual disability. Second, he argues it reinforces negative stereotypes by evoking sympathy and pity and contributes to further stigmatization based on the words often used to describe the Special Olympics athletes. According to Storey, the language used by the media in reports about Special Olympics can be offensive, polarizing, reductionist in that it focuses on the athletes' disabilities rather than other aspects of their identity, not the language used by the athletes to identify themselves, and "lumps all the people in the group together in spite of their individual differences" (2008, 135). Third, Storey says that the events and activities lack a "functional purpose" and are often age inappropriate. By "functional purpose," Storey means that Special Olympics often adds athletic events that would not be found elsewhere such as "softball throw" (135–136). Additionally, large Special Olympics meets often have extraneous activities such as face painting. Fourth, Storey describes the organization as paternalistic and argues that it perpetuates a cycle of dependency because the coaches and volunteers are non-disabled and the athletes are the recipients of services rather than being in control. Fifth, financial resources promote corporations rather than assist in helping individuals with disabilities gain employment in the community. Finally, Storey states there is a lack of evidence-based research showing that the Special Olympics is effective in providing quality-of-life outcomes in the areas of physical, material, social, productive, emotional, or civic wellbeing. The majority of Storey's

arguments fault the Special Olympics, through its maintenance of segregation and exclusivity, with continuing to increase the divide between the individuals with IDD and the rest of society—what Goffman would refer to somewhat ironically, as “normals” (1963, 12–13). Based on these factors, Storey argues that the Special Olympics should be disbanded in favor of more integrated recreational programs that combat stigmatization and promote greater inclusion in society.

Building from the work of Storey and other scholars in disability studies, Counsell and Agran contend the “Special Olympics’ antiquated lifeworld view of people with disabilities has largely resulted in outdated program practices supported by steering mechanisms that, altogether, run counter to today’s emerging proactive lifeworld view of empowerment” (Counsell and Agran 2012, 253). They do cite the Unified Sports Program (a subsection of the Special Olympics) as a program that moves closer to a more integrated system as it creates partnership opportunities for people with and without disabilities to participate together in sporting events. However, they note that the Unified Sports Program is much smaller and geographically limited than the Special Olympics and because it is based on pairing athletes of similar age and abilities, it limits access to those individuals who require more extensive supports (253). As I mention in Chapter Three, my research includes both integrated and not integrated (more typical) Special Olympics teams. In a *New York Times* article by Dan Frosch about a Unified Sports basketball team in Colorado (February 12, 2012), he interviews Andrea Cahn, the senior director of Project Unify, who states that the interaction that occurs in Unified Sports transforms all of the students involved and creates opportunities to “pull back the veil of

the unknown and make people real.” According to Cahn, some of the students with IDD felt alienated before their involvement in Unified Sports. Since participating in Unified Sports, they are now experiencing more positive interactions than before with their general education teammates. What is it about Unified Sports that increased positive interactions among athletes with and without disabilities? Is this only possible means of fostering positive relationships? What types of relationships are possible for those students, with and without disabilities, who do not have the skills, physical or cognitive abilities, or desire to play particular sports? And how does a competitive game and the generally-accepted ethos of sports (one team wins and the other team loses) change when inclusion, not athletic elitism, is the goal? These questions and controversies form the backdrop of my inquiry, although, as I will discuss, the group I studied did not engage in any of these debates and instead regarded Special Olympics as an unquestionably positive experience.

Inclusion

The topic of inclusion is a source of contention and debate by many in the fields of education, policy, ethics, and disability studies (Bérubé 1996; Charlton 2000; Grigal and Hart 2010; Hall and Wilton 2011; Shakespeare 2006; Williams 2011) and is a central theme to this chapter because I am interested in what is at stake when we talk about inclusion, how this relates to the construction and perpetuation of stigma and the stigmatized vernacular, and how categories of normalcy and acceptance are locally constructed. It is particularly relevant for folklorists because it directly relates to emic

(local or insider) and etic (outsider) understandings of labels such as disability and normalcy, how labels are esoterically (relating to one's own group) and exoterically (relating to an outside group) applied, how stigma and value are attached to these terms, and ultimately how performance provides the stage for identity expression and management. I will return to a more in-depth discussion of esoteric and exoteric later.

On a basic level, the movement towards inclusion is a response to the discriminatory beliefs that translated into very real and horrific practices (eugenics, forced sterilization, institutionalization, to name a few) against people with disabilities (Carlson 2001; Shakespeare 1998; Siebers 2008; Snyder and Mitchell 2006). Deinstitutionalization was intended to promote integration in the community but due to lack of funding, awareness, and adequate supports, many people with intellectual and developmental disabilities continue to be isolated, segregated from the community, and unable to access the often taken-for-granted rights and freedoms that are afforded those without disabilities (Johnson and Traustadóttir 2005; Stroman 2003). Segregation decreases the possibilities for interaction between people with and without disabilities, contributes to a fear of the unknown, and increases the likelihood of misconceptions, stereotypes, and stigmatization.

Although there has been a nationwide movement to end segregation and promote inclusion for people with intellectual and/or developmental disabilities, a recent investigation by the group Disability Rights of Ohio (DRO) argues that the state is doing little to support people becoming integrated into the community and that this is a violation of federal law. Citing the Americans with Disabilities Act (ADA) of 1990 and

Congress's acknowledgment that isolation, segregation, and discrimination against individuals with disabilities continue to be serious and widespread social problems, the authors argue the state's overreliance on segregated residential placements, sheltered workshops, and facility-based day services is promoting further segregation rather than moving towards community integration (where people with disabilities are able to interact with people without disabilities). They also ask that in addition to making supported employment in integrated work settings a priority, that "integrated day services shall be designed to allow individuals currently placed in developmental centers or ICFs/IID [Intermediate Care Facilities for Individuals with Intellectual Disabilities] to participate in mainstream community-based recreational, social, educational, cultural, and athletic activities" (Sjoberg-Witt et al. 2014). This call to integrate all activities, including recreational and athletic activities, is echoed by some in disability studies who argue the Special Olympics should be disbanded because it fosters negative stereotypes and promotes further segregation and stigmatization (Hourcade 1989; Storey 2008; Counsell and Agran 2012).

In terms of education, inclusion refers to the Individuals with Disabilities Education Act (IDEA) ruling that every child has a right to have an education in the least restrictive environment. Integrating students with and without disabilities from preschool through postsecondary education is a source of considerable debate and one in which I will only present some of the most commonly used terms and arguments. There is a continuum of educational services and student placement that ranges from full inclusion in general education settings without supplementary instructional supports to instruction

offered in a hospital or domestic setting (Hocutt 1996, 79). “Mainstreaming” is the term used to describe when a child is integrated with his or her peers in a general educational setting for some part of the school day; “inclusion” means that “most children will be educated in the general education classroom for most, if not all, of the school day”; and “full inclusion” denotes all children, regardless of their disability, will be educated in a general education setting (and thus no need for a separate special education placement) (79). Proponents for inclusion argue segregation limits the contact zones in which people of different abilities can interact, whereas inclusion provides increased opportunities for social networking and creating new friendships, in addition to ensuring students with disabilities have access to the general education curriculum (Mastropieri and Scruggs 2001; Sailor and Roger 2005). Disability studies scholar Michael Bérubé asks us to think about inclusion as an important means of teaching social lessons in addition to academics; conversely, he asks us to consider what segregation teaches nondisabled students: “The ‘disabled’ are always other people. You don’t have to worry about them. Somebody else is doing that” (1996, 205). Segregation is also criticized for setting a standard of lowered expectations that translates into even fewer possibilities for individuals with intellectual disabilities (Grigal and Hart 2010). Some of the most common arguments against inclusion cite insufficient funding and supports for teachers to give adequate attention to nondisabled students and the concern that the students with more specialized needs will not receive the intensive, highly-focused, and individualized attention and support they need, thus causing them to fall further behind (Murphy 1996; Zigmond and Baker 1996). While these viewpoints concern the time children spend in

school and school-related activities, they do not apply the question of inclusion and segregation outside of the school system and into the complicated territory of recreational activities for people with intellectual and developmental disabilities.

The debate about inclusion resonates beyond school and employment and into recreational activities like the Special Olympics because it highlights the tensions surrounding what it means to be a member of a group or a team, who defines the expectations and ethos of such groups, and in whose best interest those boundaries are maintained.

Stigma, Special Olympics, and Folk Group Membership

Folklorists often study marginalized, stigmatized groups [Myerhoff (1978) on the elderly; Bock (2012) on African Americans with diabetes; and Ferrell (2012) on tobacco farmers] and a folkloristic examination of how groups perceive themselves and others helps us not only to consider some of the criticisms concerning the Special Olympics, but also to elucidate how the Special Olympics works from the perceptions of its participants. Additionally, folklorists have long been interested in the in-group/out group relations of folk groups (Oring 1986). I will return to this research and particularly William Hugh Jansen's (1957) model of esoteric/exoteric folklore later. Special Olympics presents a particular problem in understanding folk groups because it is at the site of a controversy in the Disability Rights movement about inclusion and exclusion. I will review this controversy and then return to a discussion of its particular implications for the concept of folk group and especially research on a stigmatized folk group.

Stigma directly relates to beliefs and assumptions about character and studying the Ohio Special Olympics group (OHSO) provides an opportunity to learn how people associated with a stigma perceive themselves and others; how they create, incorporate, or reject norms and normalcy; and how stigma does or does not affect how individuals perform and manage their identity. Erving Goffman's work on stigma is foundational for beginning to understand the role of stigma in society. He separates stigma into three categories: 1) physical deformities, 2) character defects, and 3) stigma relating to lineage and ancestry. Individuals with intellectual and developmental disabilities do not necessarily fit neatly into one particular category since some disabilities are not visible, nor should people with IDD belong to the second category since it implies an element of will and control over one's abilities and character. Placing the categorical limitations aside, I find Goffman useful because he argues that among all three instances of stigma, the end result is that an individual possesses a trait that can fracture his or her identity and that stigma comes to the forefront.

Goffman is also instrumental to much of the work in disability studies critiquing normalcy because he was one of the most prominent scholars to use the term "normals" when referring to those who do not depart from societal expectations or do not depart from societal expectations (1963, 5). He notes that the stigmatized person is not perceived as a full human by the normals and that subsequent discrimination further decreases the individual's life chances. Goffman argues that while stigma is referred to as

a deeply discrediting attribute, it is fundamentally about social relationships, and what can be discrediting for some can be confirming for another (3).⁵

As Goldstein and Shuman argue, much of the work on stigma after Goffman has been conducted by social psychologists (i.e. Link and Phelan 2001) who have studied the formation of stigma-related cognitive categories, but there has been a significant gap in scholarship as it pertains to the lived experiences of those affected by stigma (Goldstein and Shuman 2012, 115–116). Similarly, social scientist Lerita Coleman calls for a multidisciplinary approach to understanding some of the following: how the stigmatization of specific attributes is linked to maintenance of social control and power by some political groups; how some stigmatized persons overcome their discredited status; and how certain cultures are able to “successfully integrate stigmatized individuals into non-stigmatized communities and utilize whatever resources or talents a stigmatized person has to offer (as the shaman is used in many societies)” (Coleman 1997, 229). Goldstein and Shuman contend that this is precisely where folklorists are best suited for studying, what they refer to as, the “stigmatized vernacular”—not just because of our drive to capture the words and experiences of our informants, but because we are interested in exploring how stigma is socially constructed, performed, and the political implications of such representations (2012, 116). Goldstein and Shuman also deftly address how stigma relates to tellability and untellability (Sacks 1992 and Labov 1967, as cited in Goldstein and Shuman 2012). They employ the term “stigmatized vernacular” to

⁵ I build on this juxtaposition of relative value in the section on Mascots, where one’s disability can foster invisibility and/or “hypervisibility” (Shuman 2012), pity/repudiation and/or celebration/veneration (Bohmer and Shuman 2012).

“capture not only the emic experience of stigmatization, but also the contagion of stigma—the way it spills over beyond the topic into the means of articulation” (116).

Further articulating how folklorists can provide important insights to the study of stigma,

Bohmer and Shuman delineate a folkloric approach that would do the following:

1) attend to how stigma is associated with particular cultural constructions of normalcy by using ethnography to document what is considered normal/abnormal, by whom, about whom, and in which contexts; 2) observe the performative, interactional facets of stigma (‘passing,’ associating with fellow travelers, etc.) as both a dimension of social group networks and as a dimension of performance in everyday life; 3) provide a close analysis of both discourses and interactions to identify how stigma is enacted through different genres, including jokes, narratives, folk drama, etc.; 4) observe cultural expectations of the tellability and untellability of those genres in different contexts; and 5) attend to how stigmatized groups position themselves with regard to whatever is considered normal or ordinary as a part of belonging to a particular folk group. (2012, 202)

By applying this type of folkloric approach to an ethnographic study of a Special

Olympics folk group, I hope to offer insight into the complexities of group identity and individual experiences of those affected by stigma.

Folklorists have expanded their concept of what constitutes a folk group from the community bound by shared language, geography, history, and traditions to the complex dynamics described by Dorothy Noyes (1995) in her essay on folk group. Noyes brings attention to the folklorist’s desire to contain a folk group from the outside as a cohesive community while also highlighting the tensions and inconsistencies from within. Each member can have a unique role, thereby resulting in “the impossibility of a neat definition of the group” (Noyes 1995, 449). Our desire to give power to stigmatized groups by labeling them as a unified community while recognizing the various factions, identities, and struggles for power that occur below the surface makes the application of a

seemingly homogenous label of group a messy endeavor. Recognizing the complexity in identifying the folk group, Noyes begins with Dundes' argument that a folk group consists of any group of people sharing at least one common factor and Ben-Amos' claim that the unifying element is in direct communication and interaction (Noyes 2003, 11–12). Noyes follows the move from an emphasis based on text to performance and interactional analysis by exploring the work of Richard Bauman, who considers ethnicity, religion, region, occupation, age, and kinship (but not differential abilities) in his exploration of how texts and performances “differentiate the exoteric from the esoteric” (Bauman 1971, 38).

Noyes' model helps to expand our understanding of what counts as a folk group by paying attention to networking, a concept already built in to folklore discussions from Dundes' and Ben-Amos's definitions to Bauman's concept of the social base of folklore. These concepts are especially helpful for understanding the relationship between Special Olympics and sports groups more generally. Opponents of the Special Olympics often point to components of competitive sports as justifications for their criticisms. However, Special Olympics is not a typical competitive sports group. In the *New York Times* article on Unified Sports, Dan Frosch observes that, “neither the players nor the crowds seem to mind who scores, commits traveling violations, or hands the ball to the opposing team to take a shot” (2012). In my research, I consider whether the setting of integrated sports and the ethos supporting it are really about normalcy because, as noted in the article, Unified Sports challenges the competitive component to sports and provokes different interpretations of what ideals and goals should be pursued. I suggest that it is misleading

to equate this change in standards as a move towards normalization, even though Unified Sports are intended to promote inclusion and normalcy. In addition to questioning who remains excluded, in my project I ask do Unified Sports teams truly provide opportunities for normalcy or is there an underlying premise of inclusion predicated on an inspirational narrative that, although well-intentioned, still borders on characterizing those with disabilities as mascots, thus reducing their access to full personhood?

The following questions motivate my discussion of these controversies: If belonging to a Unified Sports team is difficult or impossible based on geographic availability and/or the severity of one's disability, and Special Olympics is an outdated program that only compounds stigmatization and segregation of people with intellectual and developmental disabilities, why do some people continue to participate in Special Olympics? Is it a matter of a lack of other viable options or is there something about being a member of this particular group that brings a different set of values and quality of life outcomes to the group that has yet to be explored?

The debate about the Special Olympics provides us with an opportunity to explore inclusion and consider how folkloristic concepts of insider and outsider are useful for understanding the stigma sometimes associated with segregated groups. Storey's argument rests on the idea that a group that is segregated based on ability (or lack of ability) promotes stigma. In other words, the Special Olympics is not like any other sports team similarly organized around the level of competence of the players but instead is stigmatizing from the outset. I would ask, however, if this is over-simplified because

following this logic, would eliminating the Special Olympics necessarily result in the elimination of the stigma?

The folkloristic concept of folk group is useful for understanding Special Olympics and other stigmatized groups because it provides an expanded notion of networking and the multiple ways people construct insider and outsider status. Special Olympics does not conform to the traditional idea of a folk group formed by shared heritage. Instead, Special Olympics is similar to other folk groups that have formed in response to stigma. Recent anthropological research on disability and the formation of new kinship groups is useful here for added analysis (Rapp and Ginsburg 2001; 2011). Anthropologists Faye Ginsburg and Rayna Rapp address the emergence of disability narratives that give people with disabilities and their relatives a sense of kinship that moves beyond the biological family (2001, 534). Ginsburg and Rapp's discussion of kinship adds an important dimension to folklorists' understanding of group insofar as it helps to account for the value of associating with a (stigmatized) group. They observe that disability narratives have the potential to offer insight into the lived experiences of what it means to be affected by disability. They can both "anchor substantial analyses of the social, cultural, and political construction of disability" and help us understand how notions of "rights, entitlement, and citizenship are conceived" (2001, 537–538). Rapp and Ginsburg are particularly useful because they reimagine the boundaries of kinship beyond the biological as people seek more information sharing and support. In short, my definition of the Special Olympics group I studied as a folk group is based on what the authors define as a kinship group. Recognition that one is part of a folk group, and the

shared experience that membership brings with it, represent dimensions of tremendous salience for people who experience stigma:

The cultural activity of rewriting life stories and kinship narratives around the fact of disability, whether in memoir, film, or everyday storytelling, enables families to comprehend (in both senses) this anomalous experience, not only because of the capacity of stories to make meaning, but also because of their dialogical relationship with larger social arenas. Indeed, the transformation of both emotional and technical knowledge developed in kin groups with disabled family members can foster networks of support from which activism may emerge. In other words, the way that family members articulate changing experiences and awareness of disability in the domain of kinship not only provides a model for the body politic as a whole, but also helps to constitute a broader understanding of citizenship in which disability rights are understood as civil rights (Rapp and Ginsburg 2001, 545).

Rapp and Ginsburg suggest that the writings of the disabled and their kin offer an alternative form of kinship based on shared difference and this observation raises questions particularly relevant to my interviews. Many of the parents verbalize the support they receive through the other parents, but do the athletes feel a similar sense of kinship? Do the athletes find companionship and support through recognition of differences based on disabilities or is the membership in the OHSO group the source of the kinship, without a necessary recognition of each individual's disabilities? Before beginning to explore these conceptions of kinship, it is necessary to introduce OHSO and highlight some of its major characteristics. The OHSO and an account of my methodology with its members is the subject of the next chapter.

Chapter Three

Descriptions of the Group, Methodology and Methodological Concerns: Interviewing People with IDD and Their Caregivers

The subject of my research is OHSO, an acronym I have created to represent a Special Olympics team in a Midwestern town. This particular team is associated with the local school district, an upper-middle class suburb of about 33,000 residents located near a city of about 800,000 residents. 92% of the residents of the suburb list themselves as white; 4% list themselves as Asian; 1% list themselves as Hispanic or Latino and less than 1% list themselves as African American. The statistics for the larger city are 61% white, 27% African American, 4% Hispanic or Latino, and 4% Asian. Less than 1% are American Indian. Most of the athletes live at home with their families. A few of the adults have moved into independent living apartments together and some have support staff that assist them with certain daily living skills.

History and Structure of the Group

The OHSO was founded in the late 1980s by a physical therapy specialist at a local school who also taught adaptive physical education. In the beginning, the OHSO focused on swimming and figure skating. A middle school special education teacher took over leadership of the team soon after, and he passed the mantle to other teachers. Starting in 1992, Coach Pete, the head janitor at the school who had worked as an assistant coach and who was himself an athlete competent in all of the sports played by the team, took over as head coach. He started a Special Olympics basketball team in response to knowing a teenage boy who had been skilled at basketball, was hit by a truck

while riding his bike, and suffered a traumatic brain injury. When the teenager was able to return to sports, he wanted to play basketball but was unable to play on the mainstream team. Coach Pete initiated the team so this young man would be able to continue the sport. (The now adult man continues to play basketball for OHSO and often gives motivational speeches of gratitude at OSHO events, thanking the group for being his “family”).

Staff at the school have continued to serve as administrators, managing the finances and any bureaucratic responsibilities as part of the larger Special Olympics organization (C2:6/13). One of the coordinators, who was a teacher at the middle school but did not have any children on the Special Olympics team, created an advisory committee to delegate some of the responsibilities. Parents have also always played a role in organizing and funding the team. One of the parents is currently in charge of fund-raising and another parent, who serves as the treasurer, helps with investing the extra money. Confirming one of Storey’s criticisms that the Special Olympics lacks leadership and administrative roles held by those with IDD, this particular team does not have anyone coaching, on the board, or administrative committee who has an intellectual or developmental disability. It is hypothetically possible for organizations to include people IDD in such positions, as evidenced by several prominent organizations in Ohio that do prioritize inclusion of people with IDD among their leaders and committee members. OHSO, in addition to the larger Special Olympics organization, could, then, improve

their inclusiveness by expanding the profile of their administrative and leadership groups.⁶

OHSO is a non-profit organization, and everyone involved serves as a volunteer, including the head coaches. Coach Pete took on coordinating responsibilities in the 2000s and then in 2013, he split the duties with a co-coordinator, Coach Nick (C1). Coach Nick is a middle school special education teacher and has been involved with the Special Olympics since he was in seventh grade. When he was eleven, he moved next door to Gary (A4), a boy his age who had IDD. They shared common interests in sports and had fun hanging out with each other, so when Gary told Nick about how much he enjoyed the Special Olympics, Nick decided to volunteer. Nick began volunteering in the special education classrooms at the school where he now teaches, became a camp counselor for children with disabilities as a teenager, and then a direct care provider when he was eighteen. In college, Nick majored in Special Education and has helped out with the Special Olympics over the years until he became an official co-coordinator in 2013 (C1:11/13).

OHSO participates in a different sport each season, with a few sports overlapping during the seasons. Some Special Olympics groups offer Unified Sports, which “brings together equal numbers of athletes with and without intellectual disabilities, of similar age and ability, to compete against other Unified Sports teams” (Special Olympics of Ohio 2015). The goal of Unified Sports is to promote social inclusion, inspired by the

⁶ People First of Ohio, Project STIR, OSDA (Ohioans for Self-Determination Association), and the Olmstead Task Force Advisory Group are several organizations that make it a priority to have members with IDD on their advisory boards and as spokespeople.

belief that “training together and playing together is a quick path to friendship and understanding” and that having “sport in common is just one more way that preconceptions and false ideas are swept away” (Special Olympics 2016). Some of the sports that offer Unified options are the following: alpine skiing, basketball, softball, bocce, Nordic skiing, figure skating, golf, bowling, soccer, tennis, and volleyball. OHSO has only one Unified Sports team—a softball team—because of the number of athletes and volunteers required to participate in practices and games and the difficulty in coordinating everyone’s schedules. After conducting my interviews, I learned that there are extensive rules and regulations specifically pertaining to Unified Sports, and there can be a great difference between the ideal Unified Sports team and how Unified Sports can work, or not work, at a local level in practice. The divisioning rules and coaching practices alone warrant further exploration, but for the sake of this thesis, I will point to three aspects of the Unified Sports that I observed. First, according to the Special Olympics websites, athletes with and without intellectual disabilities are supposed to be of similar age and abilities. Since intellectual and developmental disabilities is a generalized category encompassing such a vast range of strengths and limitations (physical, mental, intellectual, and emotional), it would require a large pool of participants to choose from in order to create a team that has athletes of similar ages and abilities. In the case of OHSO, the athletes without IDD were in their twenties and thirties and were all quite athletic, but the athletes with IDD (although also in their twenties and thirties) were not at all similar in abilities. Second, softball is a sport that involves swinging a metal bat, catching or hitting a fast-moving hard sphere, and a certain amount

of speed and ability to run (and sometimes slide on the ground) to touch bases. Safety was a huge concern for many of the parents, support staff, and audience members, and since many of the athletes had the desire to participate but not necessarily the hand-eye coordination and gross (large body movements like running) and fine motor control skills (ball-handling), there was a heightened degree of risk and people got hurt. Perhaps this could have been managed better had there been more people of similar abilities on the team, but it would have required the athletes without disabilities tempering their play so they were not playing to the best of their abilities, and from the perspective of the coaches, and to some extent, the athletes and parents, it was more important to win than to moderate the team's efforts to keep things "fair." To clarify, coaches could make strategic choices to either give everyone an equal chance to play or to position the players in both batting order and field position to maximize the chance of winning. Third, it is not clear how this Unified Sports team's inclusiveness helped to dispel preconceptions, dismiss false ideas, and promote friendship and understanding. One parent noted that it was not even clear if everyone was operating with similar motivations, levels of awareness, and sensitivities. Some athletes, coaches, and parents were more interested in equal participation, and other were more interested in winning. When it came time for the statewide competition, one of the athletes with IDD was not given an opportunity to play at all and remained on the sidelines (not a choice made by one of the coaches I discuss in this thesis), although that seems to contradict to the overall ethos of inclusion, understanding, and friendship. In other words, unified sports did not necessarily live up to its promises of greater inclusion.

Additionally, some sports banter, trash talking, and name-calling that might be commonplace in other sports (Robidoux 2001) do not translate well into the Special Olympics, nor do they mesh with goals of teaching good sportsmanship. This was apparent when someone without IDD teased one of the SO athletes about a characteristic behavior that was linked to his disability. The nickname was picked up by other athletes with and without disabilities and it became a source of amusement for some. (I have deliberately not provided any identifying characteristics of this athlete beyond gender.) After one instance where this athlete stepped up to the plate and was teased, the athlete struck out, walked off the field and over to their caregiver. I asked the caregiver about their exchange, and he explained to me that he and the athlete had agreed on something fun they could do after practices whenever a situation was difficult, frustrating or upsetting. The athlete had asked that they do this, and the caregiver understood it as a response to the experience at the plate. While this athlete might not be able to articulate what his disability is or how it affects him, he knew he was being made fun of for striking out. The coach for this event did not respond to the name-calling and in fact was complicit in it. Coach Pete (not the coach at this event) often used such occasions as teachable moments for everyone, both to model good sportsmanship by teammates who might say something like “better luck next time,” or “good try,” which were the most typical phrases Coach Pete used, and to model good behavior following the frustration of not making a basket or hitting a ball. Typically, Coach Pete would remind the athlete of something that had worked on at practice that might increase the athlete’s success. Coach Pete’s demeanor was always encouraging, and he had no tolerance for bad sportsmanship

on the part of either a frustrated athlete or the teammates, including toward athletes on the opposing team. Teaching empowerment and increasing a person's self-esteem are undermined by subjecting them to ridicule, no matter how innocent or playful it was intended to be. The boundaries between what is playful and part of "normal" sports activity and what is harmful, is constantly negotiated by the participants.

In the fall, OHSO has a soccer team, which comprises both school age and adult athletes, and competes with other teams around the area. There is also a soccer skills group that practices kicking, dribbling, and ball handling. In the winter, OHSO has two adult teams that are divided into separate divisions based on abilities, one youth team, and a basketball skills team (adults and children). There is only one female athlete on the adult basketball team and although she is one of the smaller and younger players, she is very competitive and often scores in each game. Swimming and bowling occur during the same time as basketball and each have one co-ed team with both adults and youths. In the spring, OHSO has a Unified softball team for the adults and a tennis team. The only sport that includes all ages, genders, and abilities is track, which starts in the spring and goes through the summer. People participate in different events based on their abilities and preferences. Some athletes walk, run, throw a softball, long jump, or play bocce. OHSO has won state tournaments in soccer and basketball, but they have not participated in national tournaments.

In 2015, there were roughly 60-65 athletes total, and approximately half were under the age of 22. One of the local counties has 500 Special Olympics athletes and people must try out for different sports because there are limited spots available.

Currently, no athletes on the OHSO team use a wheel chair and no one is visually impaired, although some wear glasses and two of the athletes are hearing impaired. The ages of the athletes change from year to year but the youngest is usually around eight years old and the oldest are in their forties. The athletes have a wide spectrum of disabilities, some more visible than others, ranging from Down Syndrome, Autism Spectrum Disorder (ASD), Traumatic Brain Injury (TBI), Fragile X Syndrome, etc. Although the disabilities might vary in type and severity, the only thing required to participate on the team is that the individual must have an Individualized Education Plan (IEP).

The financial structure of the organization includes raising funds for uniforms, payment of referees, special events, and the purchase of occasional gifts for the coaches. The local schools have allowed the OHSO group to use their gym facilities at no cost, which has saved the group a considerable amount of money. The larger Special Olympics of Ohio organization allots different street sections to various groups in order to stand and ask for cash drop donations, and OHSO could pursue funding in this manner, but Coach Pete says this is not very enjoyable for the athletes (C2:9/15). For alternative sources of funding, parents have initiated and organized fundraising events. These include a yearly golf outing and a yearly wine tasting, both of which are reported to be quite lucrative. In addition, a local charity organization typically gives the group funds to participate in the annual state track meet where some of the students choose to stay in the local college dorms for a night, supervised by parents. The group travels to tournaments out of town for basketball and softball (if they succeed in winning the local tournament). In these

cases, the families pay for transportation and lodging as needed, and most of the athletes are accompanied by at least one family member. The three track meets are all within an hour's drive of the OHSO community and the families arrange their own transportation. Also, the track meets typically have a tailgate gathering and are social events in which all of the families contribute potluck food and someone is in charge of bringing a grill to cook various meats. The athletes receive their uniforms each season and return them at the end of the season. The team purchases new uniforms as needed, usually every few years. Once every five years (and also for every new participant), the team purchases warm-up clothes that the athletes wear over their uniforms when they are practicing, preparing to compete, or when they are done competing.

This group is not representative of all Special Olympics teams, even in the local area, but it is a team that operates specifically as a folk group because it is a geographically-based group of athletes and their families who share common traditions and use the group as a means to socialize, spread information, reinforce values, celebrate rituals, and encourage physical activity. First and fundamentally, OHSO is a network of athletes, coaches, volunteers, friends, teams, etc. Second, OHSO is a network that operates like a kinship network for the parents, coaches, and volunteers. Third, I have paid close attention to the other networks implicated in the lives of the individuals with disabilities—these networks are discussed at the Special Olympics events and play a significant role in their lives. It is noteworthy that OHSO, in this particular community, is the center and thus it is where I begin.

I participated in many whole team events for over twelve years. I also conducted extensive interviews with some of the athletes and their families. I will return to a discussion of how I selected these participants in my methodology section. Here I will briefly introduce them, along with a reference code for their pseudonym. In my descriptions, I attempt to be careful to avoid labeling someone as, for example, “high/low functioning.” These labels are often harmful to people as they make assumptions about what someone can or cannot do. Instead of relying on labels, I have tried to describe how the individuals interact in the world.

The Athletes

I provide these descriptions to aid the reader but they are skeletal. They inevitably do a “partial” job in describing complex individuals (Clifford 1986). Many of the issues that arose during this research are methodological and I turn to those questions in the next chapter. Rather than attempt to make these descriptions consistent, which would inevitably mean that irrelevant information would be included for some, I have provided a core of consistent information for everyone and then added information relevant for each person. This is consistent with ethnographic life story research, beginning with Myerhoff (1978), one of the earliest ethnographers in this area, through Catherine Kohler Riessman’s recent work (2015). I have deliberately decided not to reiterate this information, particularly their disabilities, in discussions of the individuals because I do not want them to be seen through the lens of their particular disabilities because that would inevitably be the most dominant attribute.

Chris (A2)

Chris is a twenty-five-year old Christian and Caucasian male. He identifies as heterosexual and has had crushes on girls, but has not had a relationship with anyone. At one point he did have a crush on a young woman he knew from high school, but they never had a relationship. Chris is not sexually active. His parents are divorced and he lives with his mother and his stepfather, Laura (P9) and Mitch (P12). He has an older sister who lives in a different state. Chris has Down Syndrome and wears glasses. He is athletic and takes pride in lifting weights and being physically fit. Chris participates in Special Olympics sports during each season, including basketball, soccer, track, and softball. Chris speaks in sentences, has some difficulty with articulation, and sometimes stutters. He enjoys being around other people and his mother says he particularly thrives in social settings, such as Special Olympics events and church gatherings, because “he likes being one of the guys” (P9:7/13). Laura says that she is not sure how Chris would articulate his awareness of what Down Syndrome is, although he is aware that he has been diagnosed as having Down Syndrome, and that he seems to know that he is different but she believes it does not seem to matter much to him because he has been so accepted and it is something that he has been living with since he was born. Chris can be rather shy at times and although I have interacted him frequently over the years, I do not have an official interview with him. When I arranged to interview his mother and stepfather, Chris was not at home, so my information is based on observation and interviews with his parents.

Derek (A3)

Derek (A3) is a 29-year-old Jewish, Caucasian male. He identifies as heterosexual and has had a couple of girlfriends, including one from the team. He is not sexually active. His parents are divorced, and he lives with his mother, Eileen (P5). Derek has an older brother who lives in a different state. Derek does not have a specified diagnosis. His IEP lists him as “low incidence,” which means that he belongs to a category under the IDEA (Individuals with Disabilities Education Act) that represents 20% of all students with disabilities and may include: intellectual and/or developmental disabilities, hearing impairments, orthopedic impairments, visual impairments including blindness, deafness, deaf-blindness, other health impairments, traumatic brain injury (TBI), autism spectrum disorders, or multiple disabilities (Inclusion Resource Notebook 2015). His speech is sometimes difficult to understand, but he loves to communicate. He has low muscle tone and high reflexes and has had physical and occupational therapy since he was two, when his disabilities were first acknowledged by physicians. Derek has a degenerative bone disease called Camuratti-Englemann and wears orthotics (Supra-Malleolar Orthosis, or SMOs) to support his ankles. Eileen (P5:9/13) says that she was told by the orthopedic surgeon that he would not be able to walk past his twenties, but his physical therapist has used a technique called manual integrative therapy, and his condition has actually improved. Far from not walking, Derek continues to be an active athlete who runs in all sports. He has difficulty with some of the activities—for example, he does not dribble as well as some of the other athletes in basketball—but he participates in sporting events every season. In some areas he demonstrates maturity and independence, often

recognizing inappropriate behavior from opposing team members, and he gets along well with his teammates. However, he does not seem to have the capacity to be self-reflective about his disability, so my discussion of him is based primarily on observations and interviews with his mother and caregivers.

Derek reads and writes fluently and will spell out a word if he thinks someone does not understand what he is trying to say. He reads the sports section of the newspaper every day and frequently looks up sports and movie information on the internet. He often asks for help understanding “what happened” in newspaper accounts about complex relationships and especially scandals; although he can read the words, he does not understand abstract concepts and asks for concrete explanations. I have had frequent interactions with Derek for over twelve years and have asked him questions on numerous occasions, but many of these occurred when I did not have a recording device, so most of my information is from his mother, caregivers, observation, and field notes.

Derek has been part of OHSO since he was eight years old, under the direction of the physical therapist who organized the team and asked his parents if he would like to join. He attended special education classes starting in preschool and through graduation. After his parents divorced, his mother moved to another district for high school, but he continued to participate in OHSO rather than his new school team because he regards the team as his primary social network. I will discuss some of the challenges he has faced and the ways that OHSO has helped him to grow later in the dissertation. His family says OHSO is a major part of their lives.

Lewis (A7)

Lewis is a 29-year-old Caucasian male who was raised in a Christian household in a different state and currently lives with his brother and his aunt. Lewis identifies as homosexual, has had boyfriends in the past but has not had a relationship with any of his teammates, and often wears rainbow colors as a symbol of pride. He can read and write to some extent, knows some American Sign Language, can do basic math skills, and works at a zoo on a seasonal basis. Sometimes people have difficulty understanding Lewis' speech, but he enjoys being social and appreciates when people display patience when he tries to communicate. He refers to himself as "a little bit special needs" (A5:2/15) and is outgoing, but can become shy when asked to be recorded because of his speech difficulties. Lewis plays soccer, basketball, softball, and participates in track. For him, the OHSO team is like his extended family, and his brother also helps coach soccer in the fall.

Maddie (A8)

Maddie is a 28-year-old Caucasian female who lives with her parents, Cathy and Robert. Cathy (P3) and Robert (P14), refer to her as somewhat of a tomboy and being competitive, having grown up attending the sporting events of her two older brothers. Maddie has talked about wanting a boyfriend, particularly after attending dances and social events with other couples and feeling like a third wheel. However, when she has gone to dances with a male date and he has tried to kiss her on the cheek and hug her at the end of the night, she has ignored him, which her parents interpret as her being

oblivious to romantic advances. She occasionally mentions the desire to get married and have a baby one day, but her parents believe she is not in a place developmentally to truly understand what this entails. Maddie has Down Syndrome and is active in other groups and networks specific to individuals with Down Syndrome. She enjoys music, watching television, and completing her piecework jobs at a sheltered workshop. Although Maddie was at home when I interviewed her parents, she was not interested in participating in the discussion, so I am relying on my own observations, informal conversations, and her parents' interviews for more thorough descriptions of Maddie and her experiences.

Matt (A9)

Matt is 27 years old, has an older brother and sister, who both live in the same state. Matt lives at home with his mother and father, Evelyn (P6) and Keith (P16). Matt enjoys photography, spending time with his friends, watching football, and writing and singing songs. He has Down Syndrome, wears hearing aids, and has had health issues in the past related to a heart condition. Matt has been invited to give guest lectures to college students where he speaks out against bullying and using "the R-word." Matt has had several girlfriends from the OHSO team over the years and is very emotionally expressive. He hopes to get married one day and enjoys being an uncle. Matt plays soccer, basketball, softball, and track throughout the year and loves the OHSO group because he feels they are like his family.

Nicki (A10)

Nicki is 22 years old and lives with her mother and father, Greta (P7) and Henry (P8), and has an older sister and brother who live in the same city. She enjoys listening to music and singing, coloring, going to the library, watching movies, going to church, hanging out with friends, and going for walks. Nicki has an excellent memory for song lyrics and enjoys singing in choirs, at community festivals, and with her family. She was diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), which belongs to the category of Autism Spectrum Disorder (ASD), when she was two years old, and has also been diagnosed with anxiety issues, a seizure disorder, and has obsessive-compulsive tendencies. Nicki learned to swim when she was very young and has been a competitive swimmer on both her high school mainstream team and for the Special Olympics. She looks forward to holidays, community events, Special Olympics occasions, and has had at least one boyfriend since she graduated from high school.

Patty (A12)

Patty is 21 years old and lives at home with her parents, Rick (P13) and Beth (P1), and two younger sisters. She enjoys being social, having boyfriends, spending time on social media, going to the neighborhood pool in the summer, and going to the bank and getting coffee or a snack by herself at a local shop. Patty has been diagnosed with IDD, ADHD, epilepsy, low muscle tone, a speech impediment, but it was not until her parents had extensive genetic testing done that they learned that Patty has a random mutation on one of her chromosomes (P1:7/13). This last diagnosis is so rare, according to her

parents, that there is no name for it (which also means that in addition to being relatively little information available on the condition, there is also a lack of a support network for those with similar conditions). Patty bowled with her high school team and continues to bowl with the Special Olympics, in addition to participating in track, swimming, and basketball skills, and soccer skills. She would like to be married one day and is not currently sexually active, but her parents are not opposed to the idea of her having sexual relations with someone, as long as protective measures are taken.

Tori (A14)

Tori is 24 years old and lives at home with her mother and father, Maggie (P11) and James (P17), and has an older sister who lives in a different state. She has participated in the Special Olympics since she was nine years old and runs track every year. Tori ran cross country in high school with her mainstream peers and continues to run with her father and/or caregivers. She was diagnosed with Autism Spectrum Disorder when she was younger and she is often influenced by sensory stimulation, she enjoys the sense of smell, touch, and sound, but can also be distracted or overwhelmed by loud noises and changes to her routines. Tori can read very well and reads aloud every night with her father, knows basic computer skills and how to use an iPad, and loves to sing along with music. In addition to participating in Special Olympics, she participates in groups for people with ASD, a book club for people with IDD, and attends a camp for people with disabilities. She has never had a boyfriend and has not expressed an interest in having one, but her parents have observed her batting her eyelashes and becoming more animated and laughing when she is around certain boys.

Methodology

My research for this thesis began with information I had informally gathered from participation observation over the years as an ally and direct support provider to some of the athletes, field notes, and also from continued interactions with several of the athletes and their family members. I first became introduced to the OHSO team in 2003 when I helped record video of track events and practices for the team. I continued to attend sporting and social events over the years, became increasingly familiar with the athletes, their families, caregivers, coaches, and volunteers, and looked forward to seeing familiar and new faces each year. I was fortunate to become a direct support provider for several young women who were OHSO athletes and these experiences helped deepen my understanding of the interpersonal relationships among those inside and outside OHSO, the varying forms of individual communication styles among team members, and the precarity faced by those in transition. I do not know if I would have been able to observe and hear what I did had it not been for the relationships and trust that had been built over the years, and I am honored and indebted to the OHSO group for allowing me access to so many of their public and private moments. I soon realized that transition was a critical and inevitable period and that each family was struggling to access information and services to best prepare the individual with IDD to enter adulthood, but often faced multiple obstacles. This data provided the backdrop for me to pursue interviews with people with whom I had developed rapport over the years and also those who I might not have known as well, but were interested in participating in my project due to the shared understanding of the significance of further research about transition and the role OHSO

plays in their lives. I presented my research project to Memorial University's Ethics committee and after receiving approval, I began collecting formal data through interviews and participant observation in addition to research through online resources and documentation available at Special Olympics events.

My goal was to record audio of each interview with the athletes, family members, and coaches. I conducted recorded interviews with two of the athletes individually in restaurants over dinner, three with athletes and their families in their homes, two interviews with families whose adult children did not want to participate in the interview process, and two interviews with families who asked their adult children to remain out of the room. I met with two of the OHSO coordinators to learn more about how they became involved in the Special Olympics and to share their perspectives as coaches and co-coordinators. In addition to conducting interviews, I also attended Special Olympics events and practices, banquets, and went on an overnight trip to a state tournament.

As I mentioned in the introduction, I was unable to offer my informants complete anonymity since the group members are so closely connected that were any of them to read my thesis, they would likely be able to recognize themselves and others based on certain characteristics, demographics, and patterns of speech. In an attempt to protect the privacy of my informants, I have chosen to exclude from this document any photographs or videos. Additionally, I created a table of pseudonyms roughly based on a random name generator, arranged them alphabetically, catalogued the interview date from which I was quoting, and designated A for Athlete, P for Parent, and C for Coach. I then assigned each individual a number to follow the letter so the reader could reference the appendix

and keep track of the names and their stories. Some of the individuals were referred to by athletes, parents, or coaches, or whom? I knew from years of observations and casual interactions, but were not involved in my direct interviews, so I gave them pseudonyms as well to continue the pattern and protect everyone's privacy to the best of my ability. At this point, there is no particular pattern linking people to their corresponding numbers, which means that A1 is not necessarily linked to P1, nor is P1 related to P2. Finally, the numbers after the colon indicate the month and year of the interview, particularly when there was more than one interview. Therefore, if I were quoting Cathy from an interview in May 2013, I would indicate this with the following code: Cathy (P3:5/13).

One of the first issues I encountered in my research was the complicated notion of "informed consent" and how best to translate the project on a level more accessible to people with differing levels of competency. The second issue I encountered was that many of the parents and guardians preferred to participate in the interviews without their adult children present. This could be due to the following possible reasons: (a) they did not trust my intentions and were acting as gatekeepers to protect their child from potential stress or exploitation; (b) they wanted to speak frankly in private to avoid distressing their son or daughter; or (c) they felt that their child would not be able to comprehend nor contribute to the conversation, so they did not feel it was necessary to include them. Whereas I would have preferred to interview as many members of each family as possible, particularly the athletes themselves (to avoid replicating historical patterns of preferring the words of those in power over the often disregarded and devalued words and perspectives of those with disabilities), this was not often possible.

The third issue that I encountered involved the actual act of interviewing. Based on my prior experience with people with intellectual disabilities, particularly autism, and the effects of using declarative (statement made without expecting response) versus imperative language (question demands an answer), the very act of asking a question can increase an individual's anxiety and shut down further positive communication possibilities. This notion of the imperative language requiring a correct response leads me to think about the interview format itself and how interviews connote other situations where individuals with disabilities have been evaluated and tested, often leading to further exclusion and stigmatization (although each individual might not link the causation between the two). Having attended multiple types of annual and quarterly assessments, individualized educational program (IEP) meetings, transition planning sessions, and performed various assessments (individual needs, daily living, life skills, etc.) required by my previous jobs, I find it difficult, if not impossible, for individuals with disabilities to not be aware of the invasive and potentially derogatory nature of many of the questions. In addition to the subject matter and wording of the questions being insulting (i.e., "Is the individual able to toilet themselves without accidents?"), the individuals are being evaluated in areas where they may very likely have limitations and sensitivities to these topics (i.e., reading, writing, personal maintenance, etc.), and they usually are accompanied by at least one parent, guardian, or caregiver who not only answers the majority of questions, but whose authority trumps the answers offered by the individual with disabilities. However, interviewing those closest to the individual with

disabilities can be necessary to understand where he or she might require support or to articulate ideas, concepts, and provide stories that might otherwise go untold.

The fourth issue I faced was that the majority of the athletes could not articulate many of the issues of identity that we might expect or seek from typical interviews because they lack the ability to meta-narrate or articulate their disability. Because of this, many have learned set phrases and responses that make it difficult for the researcher to understand whether the individuals are trying to please whomever they perceive as an authority figure or whether they are communicating their true feelings. For these reasons, I chose to avoid any question or interaction that would reproduce the set answers they have been accustomed to providing, but also take note of moments of resistance, canned speech, and disjuncture.

Folklorists traditionally seek information from both those who are on the outside, potentially freer to talk and offer controversial or critical perspectives, and those on the inside, who might have access to the underpinnings and historical trajectories that have helped shape the group as they are presently. In the case of the Special Olympics, it might be assumed that those who are most vocal and able to articulate a certain self-awareness and recognition of the significance of what it means to be a part of the group are the cultural brokers, but generally speaking: (a) they are not often the athletes themselves; and (b) if they are, they are not representative of all athletes. In my research, I was tempted to rely more heavily on the narratives of some of the athletes, particularly Matt (A9) and Lewis (A7), who were able to articulate more than others their awareness of disability and its significance. These individuals would be recognized by folklorists and

anthropologists as playing the roles of cultural brokers or allies, and while their narratives were important and offered unique insights into their worldviews, they cannot be taken as representative of the group as a whole. Not only would this be an incorrect and careless assumption, it would signal the need for what Goffman refers to as “heroes of adjustment,” those individuals with disabilities who act as translators between the worlds of the disabled and “normals” and represent a “‘living model of fully-normal achievement’ (1963, 25)” (as cited in Shuman 2011, 165). As researchers, we are left in a type of quandary where a search for patterns elicits a sense of cohesiveness but also a recognition that each unique perspective is a reminder that this group is made up of individuals with very different circumstances, abilities, and perspectives. It is a warning to pay attention to the issues inherent in identity theory when applied to a stigmatized group. It also cautions us not to place too much emphasis on narratives and interviews as the predominant keys to gaining insight into someone’s worldview because communicative competence can exist through the performance of identity in ways that might not be possible through speech.

Unlike some ethnographies that rely on a key informant (Toelken 1998), in my research, in my work, each participant tells part of the story, and none is a spokesperson on behalf of the community. As Toelken reported, research based on even as excellent and forthcoming informant as Yellow Man can have complications. Like Barbara Myerhoff’s study of the elderly in Venice, California, my work focuses on accounts of individuals to better understand a community (1978). Myerhoff studied a stigmatized group, and her description of her project is similar:

The anthropologist...tries to understand a different culture to the point of finding it to be intelligible, regardless of how strange it seems in comparison with one's own background. This is accomplished by attempting to experience the new culture from within, living in it for a time as a member, all the while maintaining sufficient detachment to observe and analyse it with some objectivity. (1978, 18)

Like Myerhoff, I have attempted to portray the Special Olympics group as they see themselves. Life as an elderly person and life as a person with disabilities can seem to be only about obstacles, but as Myerhoff and I both discovered, from the inside the “normal” is what one lives every day. Further, this research combining interviews and observation provides a dynamic relationship between the individual and the group. Rather than make larger, generalized claims, I offer close readings of conversations and narratives that include much-situated context as possible. The accumulative product provides a more nuanced account of the larger social group.

I discovered that these interviews provided the parents with a forum to talk about their experiences in a way that allowed them to give narratives that might not have otherwise been possible in a traditional interview—for example, what they find interesting about their child, how others have accepted or rejected their child, and where they have found support as their child enters different life stages. Whenever possible, if it was not already brought up in conversation, I also asked the parents what terms they used to talk about their child's disability in the home, with their children, and with other people in the community. This information helped me gauge what I could safely discuss when interviewing their children and (I hoped) would help me have a better sense of their child's level of self-awareness and how this relates to etic and emic labels and esoteric and exoteric definitions of disability.

Fieldwork Challenges and Strategies

In the following descriptions of interviews, I discuss particular issues that arose. Many of these issues would have arisen in conversations with people without intellectual disabilities. The interviews were intended to supplement extensive participant observation, and I doubt I would have been able to either recognize some of the difficulties or negotiate them without having already established relationships with the participants in their sports practices and competitions. At the same time, the interviews provided the opportunity to understand things I would not have known through observation alone.

The athletes are accustomed to being interviewed by social service caseworkers who determine what benefits they receive. They are always accompanied by their parents for these interviews, and some are accustomed to having their parents answer questions for them. I have participated in several of these interviews, and I have observed that the caseworkers vary widely in their ability (or interest) in presenting questions in a format that the athlete can understand. Knowing that I could be interpreted as yet another adult asking questions of little interest to them, I was careful to engage the athletes in conversation that resembled our ordinary conversations at sports events. Similarly, in the consent forms, I was careful to use accessible language and frequently translated the consent forms into more accessible language, meaning that I broke down technical terms and academic jargon into ideas and concepts that I felt would be understandable to people unfamiliar with the scholarly fields.

In one interview I conducted with Nicki (A10), I was not sure if we had a mutual understanding of what an interview entailed. Although her parents explained the expectations of the interview process and I reiterated that the interview was about my project involving learning more about her experiences with the Special Olympics and transitioning out of high school, I do not know if she understood how to distinguish between an interview and a casual coffee date. It was not clear if she understood how the interview related to an abstract idea such as a project (I did not use the terms “dissertation” or “thesis”). Many people, not just individuals with IDD, can have ambiguous understandings about interviews, social occasions, and what a dissertation or thesis entails. Nicki appeared to enjoy the experience and was smiling and laughing, perhaps because she was very familiar with the question and answer format since that is how she engages in many interactions with peers and strangers (often asking certain routine questions like what people have had for breakfast, what they are going to have for dinner, what they are doing right now, or what their boyfriend/girlfriend is doing at the moment—which gives her the opportunity to share her own responses for each of those questions). Thus, the interview did not seem to elicit any noticeable distress or anxiety and her answers followed the typical patterns of turn-taking that I have experienced through years of interactions with her. It is possible Nicki views question and answer sessions as a game, but it was the moments where she turned the tables on the interview format and asked me to clarify why I was asking certain questions that struck me as particularly revealing.

In my interview with Patty (A12), she repeatedly made references to my tape recorder and asked me what else I wanted to know. This indicated her awareness of the interview context and the frame as an information-gathering opportunity at the same time she showed resistance to the power imbalance through several means. After Patty informed me about an ongoing conflict she had been having with one of her peers during our car drive, we arrived at the restaurant where we were going to have dinner and conduct the interview. I explained for a second time why I would be using a tape recorder, to which she agreed. I asked her if there was anything in particular she wanted to talk about and she said that she did not care. I then mistakenly assumed she would want to pick up where she had left off regarding the conflict with her peer, so I asked what was going on between the two of them, to which she responded with a long pause and silence. She then said they were fighting and when I asked about what, she responded, “Stuff. And every time I go here I love the mac and cheese.” The extended pause and switching of subjects were two examples of her discomfort at discussing this topic, after recognizing this, I switched the subject and asked her about her transition program. She answered, “It’s good,” followed immediately by asking, “Why do you have that?” pointing to my tape recorder. I again explained that the tape recorder helped me remember things better than if I wrote them down, to which she replied “Okay.” I switched the subject matter again because it did not seem as if she was interested in my line of questions, so I asked her about her involvement in the Special Olympics thinking that was a neutral topic. It is possible that this was not neutral to her, however, because when I asked her if she did swimming, she answered, “Not really. Do you want my

number? My phone number?” At another point in the conversation, she asked, “What else do you want to know?” and encouraged me to ask more questions, but then also asked me why I could not be her new aid worker. This was a prime example of Patty exerting her agency and seeing the interview as an opportunity to ask me to offer something she desired in return—a care worker. I explained to her that I was unable to work as an aid worker at that time, but asked her what kinds of things an aid can teach you and she said, “Be nice to everyone. It’s hard to be nice to everyone. Everyone. Because sometimes they get on my nerves.” These statements reveal her awareness of the interaction as an opportunity to exert her agency not only through using silence, switching the subject, pointing to my recorder, asking why I could not be her aid worker, but also challenging the notion that perhaps she has perceived from others—the assumption that she is amicable at all times. By admitting that it is difficult to be nice to everyone and that people get on her nerves, she is standing up for her right to have complicated emotions, prefer some people to others, and resist the label of the happy-go-lucky person whose disability is ameliorated by overwhelming positivity and congeniality.

Matt (A9), another OHSO athlete, demonstrated his self-confidence and awareness of his social capital throughout the interview by directing the topic of conversation, providing humor and sarcasm, exaggerating tales, and by using the end of the interview as an opportunity to flirt. When I asked him if there was anyone in particular he would like to get to know better, he gave me a knowing smile and said my name. Later on, I asked him if there was anything else he would like to say and he responded, “You’re pretty.” After the interview was over, he also invited me to join his

friends on Facebook, and when I said that I did not like Facebook very much and rarely checked it, he assured me that it was okay, and “at least you’re trying.”

In these interactions, it is apparent that there are different understandings of what an interview means to each person as well as how to describe nuances of different disabilities. What do the interviews offer in terms of broadening our understanding of competence? How is competence evaluated through them? If we look at the notions of power, agency, and resistance, how are these expressed by people who are subjugated to a stigmatized category by virtue of being labeled intellectually disabled? Folklorists have turned to the work of James C. Scott as one of the major scholars in areas of resistance (Noyes and Bendix 1998), but it is not clear how useful he can be when it comes to people with intellectual disabilities. Scott bases his assumptions on an awareness of subordinated status in addition to belonging to a specific group, aspects that are not necessarily present in my research. James C. Scott’s forms of resistance in *Weapons of the Weak* include the following ordinary weapons of relatively powerless groups: “foot dragging, dissimulation, false compliance, pilfering, feigned ignorance, slander, arson, sabotage, and so forth” (1985, 29). For Scott, these practices become weapons when used strategically, but importantly, they all require artifice. Can ignorance that is not feigned also be a form of resistance? I will return to this in an exploration of the athletes’ use of “I don’t know” that is part of a larger discussion about deception. According to Scott in “Resistance without Protest and without Organization: Peasant Opposition to the Islamic Zakat and the Christian Tithe,” these forms of class struggle require little (if any) planning, represent individual forms of self-help, “typically avoid any direct symbolic

confrontation with authority or elite norms” (ital. original), and require little more than “a bit of room to maneuver, a healthy self-interest, and a favorable climate of opinion among one’s neighbors” (1987, 419–420). Scott’s framework for resistance assumes a certain level of reflexivity, not to mention social capital and independence, in order to manipulate and maneuver. Several factors might contribute to a failure to use these strategies or to use them successfully and it would be a mistake to attribute failure only to cognitive.

I was able to see how Tori (A14), whom I have known for years and worked with on a daily basis, was able to communicate her wants and needs even though communicating in an interview setting was not possible due to her refusal to participate. Based on the context of the direct interview, the most definitive and complete form of resistance is the refusal to participate. Tori did not agree to an interview and reacted to me asking her questions by (a) leaving the room and ignoring me; (b) saying “No, I’m sorry, we’re not going to talk about that” or repetitions of refusals and apologies; (c) responding to direct questions with “I don’t know” or “I’m not sure”; (d) answering maybe one or two questions and then becoming upset; or (e) crying. I have learned from experience that Tori does not generally respond positively (in the sense that to respond positively means to interact and engage in the conversation by answering the obligation to respond) to any type of direct questioning from most people, including myself, unless her father is the one asking her a question and then it still depends on the subject matter and the amount of request or obligation that is involved in the question. Certain questions, however, tend to elicit positive interactions. If I ask her something about her

routine, such as “what book are you reading?” or “what are you having for dinner tonight?” Tori will answer quickly without any apparent signs of distress. Inquiring about social situations, how she felt about something, or anything relating to a potentially anxiety-provoking event or change in routine will almost always evoke visible signs of distress (increased agitation, higher-pitched responses, and rapid repetitions of non-committal phrases like “I don’t know,” “I’m sorry,” or “oh no, no, no, we don’t need to talk about that”).

When it comes to intellectual disability and ideas of power, agency, and resistance, we must return to our assumptions of self-identification and examine the possibilities of power and autonomy for people who are taught compliance, obedience, and dependence, particularly because their social and material welfare ultimately depend on other individuals and services. It is possible, however, to look at how the interview format might be an opportunity for resistance. In Robert Baron’s discussion of agency, mediation, and objectification in public folklore and cultural tourism programming, he argues that “[e]very individual involved in social interaction is an ‘agent,’ engaged in actions meant to bring about effects from the social situation” (2010, 65). He acknowledges that the connection between agency and social context is integral and that although power might be exercised by both the dominant and subordinate in a given relationship, he is not suggesting the equality of each party’s ability to affect the other’s agency. Instead, he directs us to what anthropologist Laura Ahearn argues, that there are multiple types of agency—such as “oppositional agency, complicit agency, agency of power, [and] agency of intention”—that can be exercised in any action (65). Many

folklorists recognize and explore power dynamics in ethnographic research. Stigmatized groups, such as those with intellectual disabilities, require particular attention. Susan Ritchie (1993) and Diane Goldstein (2012) examine the tensions surrounding ventriloquism—the question of who is able to speak for whom—and raise critical questions regarding ethnographic work with people with disabilities. Disability studies scholars have also highlighted the crises of representation and issues of power and agency, evident in the motto: “Nothing About Us Without Us” (Charlton 2000) because, as Lennard Davis states, “it has been the rule that the subject of disability, until quite recently, has been written about by professionals who work with, medically treat, or study the disabled” (1995). Building from the special issue of *The Journal of Folklore Research* (2012) on the stigmatized vernacular and combining some of the key works in disability studies (Charlton 2000; Davis 1995; Kittay and Carlson 2010; Williams 2011) and folklore (Briggs 1986; Ritchie 1993; Goldstein and Shuman 2012; Shuman and Bohmer 2013; Baron 2010) on power, agency, and representation, this chapter serves as a way to problematize what we consider foundational to understanding, interpreting, and representing the perspectives of others.

Folklorists and anthropologists know that it is unrealistic to expect our informants to be able to do a kinship chart or categorize the various genres they use to interact and communicate, so how do we find a way to discover what they know and how they classify the world in terms that are relevant to them? Some of my informants display a high degree of social capital and mastery of the interview situation, but others refuse to participate and become increasingly uncomfortable and anxious when confronted with

any type of direct questioning. I understand this discomfort as it occurs on multiple levels—whether it is the straightforward discomfort of being “put on the spot,” asked a question, and then expected to provide an answer, the more particular discomfort of talking about disability and stigma, or both. The inability to provide a reflective answer and the discomfort of the subject matter create a tension that is magnified when interviewing people with intellectual disabilities about their own awareness of their disability and is something that requires great care and individualized attention. This leads me to question the weighted significance of the interview process in the discipline of Folklore and the presumption that people can speak for themselves. Many perceive having a voice as a key to resistance, particularly for marginalized and stigmatized individuals, and we often rely on the interview as the access point that provides someone an opportunity to use their voice. We take for granted, however, that all participants have competency in these settings. Instead, we need to look at how different competencies, settings, relationships, and subsequent power dynamics raise very different obligations for the researcher.

In Diane Goldstein’s 2013 AFS presidential address (2015), she argues for folklorists to apply their unique ethnographic skills and tools for narrative analysis where they are often most needed, namely, in issues of medical and legal discourse. However, these interventions come with baggage and potentially beneficial or disastrous implications. Goldstein captures this complexity when she quotes David Whisnant, who writes, “To engage with public issues and act in a public arena is to intervene—inescapably—in the lives of individuals and in the institutions that embody their

collective will and vision. The question is not whether we shall intervene, but how and with what effects, amid what particular set of historical, cultural and political circumstances and in the service of what values and social vision' (1988, 233)'' (Goldstein 2015). My own experience has brought this necessary move to the forefront while examining the interviewing potentials and pitfalls associated with people with intellectual disabilities. Having been asked to testify in a case involving a young man with intellectual disabilities who had disclosed allegations of abuse against a family member, I became aware that neither the judge nor either legal team had much familiarity with people with intellectual disabilities and that the issue of competency was complicated by the young man's apparently chaotic narratives. Goldstein (2012) explored analogous issues in her *Journal of Folklore Research* article on the stigmatized vernacular regarding Ray's chaotic narratives and Amy Shuman and Carol Bohmer (2012) tackled related matters concerning issues of (un)tellability from refugees. Because of the sensitivity of the case and to protect the privacy of the individuals involved, I will not discuss the details, but I will note that one of the most striking moments was when I was asked if I thought the young man was capable of being manipulated, in the sense that he could be coached to create a false story of abuse. I answered that in some ways, yes, it was possible for him to be manipulated, but that part of our job is to try to manipulate individuals each day to master some skills required to increase independence and functionality. We had been trying to teach the young man how to identify an emergency situation, answer the phone appropriately, and tie his shoelaces—in essence, we tried to manipulate him to follow our directions—and yet, he still was unable to master these

skills. Therefore, to what degree does the ability to be manipulated render someone competent or incompetent? How much of the case was based on his inability to provide what the judge determined to be a coherent narrative? Ultimately, the case was dismissed due to a lack of evidence, but this is not an isolated incident and indicates a potential failing in recognizing different forms of communication.

In an article published in *The Columbus Dispatch* on February 14, 2014, the ties between communication and competency made the headline when a young autistic boy was deemed incompetent because he did not answer the judge's question appropriately. In the article, it states that the judge came down off his bench, sat across from the boy, and asked questions "aimed at determining whether he can recall and describe events and whether he understands what it means to be truthful" (Futty 2014). The boy was reportedly distracted, moving around in his chair, and unable to focus and answer the majority of the judge's questions. The judge asked, "Whether it would be the truth or a lie to say that the courtroom was totally dark. After some prodding, the boy said, 'The truth'" (Futty 2014). The judge ruled the boy to be incompetent to testify against the teacher accused of child endangerment, but it appears that this could be a telling example of how certain truth-seeking missions are carried out without regards to different levels of communication. Perhaps the boy did not understand the abstract concepts of truth and lies, or perhaps he had been told to tell the truth and was answering what he thought the judge wanted to hear. Maybe the entire situation caused the boy so much anxiety and discomfort at being asked a series of questions by a stranger, causing him to respond differently than he might have had he been in a more comfortable setting and spoken to in

a way that minimized his stress. This does not address the issue of whether or not he was abused, but it does highlight the following questions: (a) what are the means we use to best determine what is truth?; (b) who gets the power to evaluate?; (c) what are the varying worldviews of the people involved?; and (d) what are the implications for the people involved when it comes to legality, competency, testifying, power, and agency?

In “Folk Ideas as Units of Worldview” (1971), Alan Dundes defines “folk ideas” as “traditional notions that a group of people have about the nature of man, of the world, and of man’s life in the world” (95) and that the folklorist’s task is to identify the underlying assumptions that are foundational to one’s worldview (96). Although I do not intend to categorize all people with autism or other cognitive disabilities as belonging to one cohesive group and therefore possessing a specific culture, I do think it is necessary to open this definition to different competencies and how they affect worldview. Barre Toelken’s experiences with the Navajo taught him how certain settings (desks lined up in rows, all facing the front) and ways of speaking (discussing one’s personal goals and life history) that he took for granted as somehow natural or standard for non-Navajo people made the Navajo students he was working with extremely anxious and uncomfortable (2003). I apply a similar approach when attempting to understand someone else’s worldview and their preferred modes of interaction to people with varying abilities to examine how our assumptions of getting at the “truth” are fraught with problems. What are some of the ways we access that information? One of the most prominent ways is through interviews, believing these are the methods through which we can get the most direct truths or insights into someone’s worldview. According to Charles Briggs (1986),

folkloristics expanded from the focus on collecting summaries of traditions to looking more at the performances and their contexts. Briggs points out two of the major methodological shortcomings associated with not exploring more fully the assumptions we bring to the interview process. Kenneth Goldstein, according to Briggs, argues “that the interview ‘supplies the collector with an insider’s view of the individual, his culture, and his folklore’ and the ways in which the informant conceptualizes and orders this knowledge (1964, 109, 123)” (Briggs 1986, 120). Goldstein was interested in encouraging collectors to not merely record a song or tale but also, using interviews, to learn the interpretations and contextual understandings that a performer could provide. First, Briggs argues that folklorists need to look beyond the data obtained to assess how the discourse of the interview relies upon communicative norms. The second issue is the lack of significant exploration into the nature of “context”; Briggs argues that contexts are “interpretive frames that are constructed by the participants in the course of the discourse” (12). He recommends interviewers study more closely the signals that the participants are providing each other in terms of what they are saying in an attempt to bridge the gap between text and context (13). In my research, understanding communicative norms is crucial for the interviewer. I attended to frames and signals that alerted me to potential discrepancies among how what was said, not said, and how it was said within the context of the interview.

Citing Cicourel (1974c), Briggs argues that different interpretations of questions and responses can occur when there are linguistic and sociolinguistic discrepancies between the interviewer and interviewee. He points to variances in “class, ethnicity and/or

cultural background,” but does not include (dis)abilities or how this might relate to competence (26). Along with Cicourel, Briggs states, “the only solution to the dilemma is learning about the commonsense understandings and the sociolinguistic background of both parties” (26).

Through the application of Briggs’s thesis that “investigating the meta-communicative repertoire of the group in question is the necessary starting point for research” to the work of scholars in disability studies, such as Val Williams (2011), Booth and Booth (1996), and Ochs et. al. (2004), I argue that it is the researcher’s responsibility to question the metacommunicative norms of each individual and look for the multiple ways in which information is transmitted between participants and contexts in order to resist relying on assumptions of (in)competency. According to Briggs (citing Hymes), “Acquiring communicative competence involves knowing which expressions can be used under what circumstances to convey which meanings” (43). Briggs contends that interviewees “are particularly sensitive to the social and political implications of providing the desired information, because the interview process brings the referential or cognitive functions of language to the fore.” Interviewing can parallel other assessment processes that people with IDD and their families have experienced, so it is vital to consider how the act of interviewing could trigger behaviors or patterns learned from repeated question and answer sessions. The very process of being assessed is stigmatizing because it is a sign that an individual has been singled out as needing services and then, often, segregated from mainstream peers. Moreover, the very nature of talking about

one's disability is potentially uncomfortable; the frame of the interview can create power imbalances as it highlights the visibility of a stigmatized identity.

Some of the questions I faced include the following: 1) how do you talk to people about things that are not mentionable? 2) how do you talk to people about things that are seemingly incomprehensible 3) how do you manage talking to people about their spoiled identity? 4) do individuals only experience stigma when talking to outsiders? and 5) was I an outsider to some or all of the participants in the group?

A premise underlying these concerns is that ...I am trying to understand how the individuals with IDD and their families understand their own sense of normal and also how they manage the effects of a stigmatized identity that is foreign, far from normal, to outsiders. I soon learned that many or even most of the families described themselves as living in a different normal. The individuals with disabilities, their families, their teachers, coaches, and support staff are constantly negotiating the management of spoiled identity or the contours of what counts as normal.

Many of the groups that experience stigma have a world of insiders where they do not have to seek approval or value because they have each other. Not surprisingly, a lot of discussion of stigma is about insider/outsider status (Goffman, Ferrell, ethnic racial slurs).

Interviewing and researching the experiences of stigma require careful attention to the interview process itself. According to Briggs, "sensitive and effective interviewing thus presupposes awareness of the society's categories of speech acts and social situations and the rules for relating them" (cf. Frake 1972 in Briggs 45). We can learn

from scholars in disability studies and discourse analysis, particularly Val Williams, about the ways in which our assumptions and rules might be based on preconceived notions of incompetence. Either the participant is not able to understand what the interviewer is asking, or even worse, that our discourse has the potential to cause stress, if not prolonged anxiety. This is why it is important to understand how one's different abilities, needs, and required supports are discussed within an individual's inner circle. If the terms "disability" or "normal" are never spoken by the athletes or their families and are instead replaced by words such as "different abilities," "special needs," or "neurotypical," or "mainstream," then the interviewer should adopt those words that are most relevant and meaningful to the individual and not impose others that could potentially trigger unnecessary stress. This is, I believe, an extension of what Briggs is alluding to when he discusses the performative capacity of speech and states that the "performative force of an utterance may include a transformation of the relationship between interviewer and respondent(s) or between the respondent(s) and other persons who are present" (46).

Asking about an individual's understanding of the term disability as it relates to themselves and others has the potential to reiterate the stigma associated with the deficit model. It highlights an awareness on the part of the interviewer that this person is being interviewed because they have a disability. I discovered in my fieldwork that through the act of interviewing, I am potentially simulating a similar testing situation where the performance of a test subject has direct consequences for their placement in school, jobs, and in the community. The individuals with disabilities I worked with have been

subjected to countless exams, interviews, and tests and this attempt to dissect their awareness and understanding of the category of disability mirrors those encounters.

When discussing how using the term “learning difficulties” is viewed during her work on inclusive research, Val Williams states:

[It is] actually heard as offensive and the very mention of the words is seen as an embarrassment, even within the confines of our own group. If a word is heard as abusive or insulting, then the very utterance of it can have catastrophic effects, as suggested by Rapley et al. (1998), who cite some of Todd and Shearn’s (1995) data, where very bald, direct questions could certainly have been heard as downright rude” (Williams 2011, 189).

Recognizing the importance of frame and the expectations of what each seeks to gain from the interview is also important. Fieldworkers, according to Briggs, may view the interview as an opportunity for an explicit transmission of data, whereas the respondents might view it as something more, perhaps an opportunity for entertainment, obtaining monetary gifts, or, as I might argue, a chance at personal interaction that might procure a friendship (1986, 49).

Chapter Four

Esoteric/Exoteric Framework for Group Identification

In this chapter, I continue my discussion of examples of fieldwork interviews using William Hugh Jansen's concept of the esoteric/exoteric factor in folklore. I explore how members of the group, including athletes, family, and coaches, define themselves and consider how others define them. I conclude with a discussion of the power dynamics inherent in all fieldwork but intensified for stigmatized groups such as the Special Olympics group.

Disability is not a natural category and it is important to look at how it is understood and used by those who are labelled "disabled." It is considered to be an etic label (medically informed) in that it is supposed to be externally observable and not value-laden (as opposed to an emic understanding that is created from those observed and relates to their worldview) (Harris 1976). This is further complicated in disability studies as many have argued against the medical model as being deficit-based, whereas the social model focuses on the barriers in society as the disabling factors. In response, some have called for a new political/relational model for understanding disability (Davis 2002; Kafer 2013; Shakespeare 2006). The medical and social models are part of what makes the esoteric/exoteric more complex because they hinge upon different values and labels applied to those who are included in the category of disabled and thus excluded from those considered normal, which leads us to questions of power and authority in who determines such categorizations.

More work needs to be done to integrate the fields of folklore and health and disability studies. Significant work in folklore and health includes contributions by

Bonnie O'Connor, David Hufford, Erika Brady, Diane Goldstein, Sheila Bock, Andrea Kitta, and Emily Urquhart. One area of intersection of particular interest is medical competence and youth. Yanna Lambrinidou discusses rights of young adults to discontinue cancer therapy. As I discuss throughout the thesis, competence is also an issue for young adults with intellectual disabilities. In disability studies, this discussion resonates with the pronouncement "nothing about us without us." Both groups face questions of agency regarding their care and life choices. However, unlike the problem facing the cancer patients, where the question is their capacity to make decisions on their own behalf, the individuals I worked with are legally adults, and the contexts of their choices are different. The rationales for choosing or not choosing cancer therapy are quite different from the rationales for assigning competence to athletes in a sports activity or at a job. The athletes are expected to have a level of competence to exhibit good sportsmanship and perform at certain levels, but their competence in a particular sport is not the main focus.

The major differences between disability studies and applied folklore (folklore and medicine) are that the latter focuses on health and wellness, modes of transmission, kinds of practitioners and healers, systems of folk medical belief, and folk remedies, whereas the former questions the institutional nature of the medical model, the problematic aspects of diagnoses, and often rejects attempts at normalization. Disability studies is not assuming that all disabilities are illnesses in need of a cure, treatment, or rehabilitation. Disability studies has different set of research interests, including theories of normalcy, speaking on behalf of oneself, the contrast between social and medical

models of bodily difference, the critique of both pity and inspirational narratives, and issues of access and inclusion. The explicit critique of medical models positions disability studies differently. Disability studies focuses very little attention on either practitioners or healers, rarely considers questions of belief, and has little to no interest in remedies. Disability studies could bring a new perspective to folklore and medicine by opening up a critique of the medical model and encouraging new understandings of normalcy and competency. Folklore can contribute in even more significant ways to disability studies. The study of the diversity of healing systems does not translate directly into disability studies research because disability studies defines itself as not about healing. At the same time, the explicit refusal to place healing at the center of disability generates a discourse of the ways that medical world dominates the experience of a different body. Folklorists understand how these discourses work. Folklorists and disability studies scholars are both interested in stigma and this is another area where both fields would benefit from combined approaches to how stigma is created, experienced, and managed. This is precisely why I chose Jansen's esoteric/exoteric factor to better understand stigma through folk groups.

Folklorist William Hugh Jansen employs the esoteric factor in folklore to represent what one group thinks of itself and what it supposes others think of it and he defines the exoteric factor as "what one group thinks of another and what it thinks that other group thinks it thinks" (1957, 206–7). I categorize these components as esoteric A (what one group thinks of itself), esoteric B (what it supposes others think of it), exoteric A (what one group thinks of another), and exoteric B (what it thinks that other group

thinks it thinks, or to put it another way, how it believes the other group feels it is perceived).

I immediately encountered problems when trying to ask my participants to articulate who is considered the in-group or the out-group because the esoteric/exoteric model assumes stability in the categories of self and other. The group contains multiple layers and membership roles: the athletes and their parents, coaches, and volunteers have different levels of relationships and networking ties connecting them together. They are all part of the same group, but even among the group members, they hold different belief systems, values, and communication styles and abilities. Not everyone is able to give an explanatory narrative defining their worldview, so it is impossible to find out what is in each individual's mind, but that does not deter people from trying and speaking on behalf of others. Identifying who is an insider/outsider, the social circles that overlap and evolve, and who speaks for whom are just a few of the complicating elements encountered when trying to encapsulate the notion of the OHSO as a group. Even among the various OHSO group members, the following are some of the elements of esoteric and exoteric folklore that make it difficult to define clear boundaries of who is an insider or outsider within the group and what values or beliefs are attached to that status position: parents make assumptions about their own children and other people's children; the athletes have distinctive perceptions of themselves and the other athletes; and athletes and family members develop unique relationships with individuals who might have more fluid or transitory group membership (i.e., volunteers, support providers, coaches, etc.). These factors are just within the circle—when it comes to those outside of the group,

there are many people who are categorized as outsiders (service professionals, teachers, mainstream peers, and the “community”) and different members of OHSO hold beliefs, opinions, and share stories and other elements of folklore (esoteric B and exoteric B) about them as well.

Jansen’s model is useful for understanding how people label themselves, how they think others label them, and how they in turn label others, but the awareness of labels is only one mode of articulation and its usefulness is limited by the premise that everyone is capable of articulating and having self-awareness. My concern is that reflexivity, self-awareness, and the ability to communicate these concepts are inextricably linked to personhood and thus a person is restricted from achieving full personhood by either not being aware of their disability or not having “a voice.” In her research on competence and how individuals with IDD construct other selves, Charlotte Aull Davies argues that rather than suggesting low reflexivity is an inevitable result of learning difficulties, it is “more likely due to social practices towards, and cultural attitudes about, people who have been so categorized” (1998, 119). Since some of the parents told me that they do not discuss their child’s disability around their child because they want their child to feel as normal as possible and not focus on the disability, it is possible that some of the athletes I interviewed did not have the language or experience of self-articulation surrounding their disability because they were not familiar with the discourse. However, not being able or willing to discuss their own categorization as disabled while still articulating their perceptions of others’ disabilities signals a need for further exploration

into the different ways in which labels and categorical membership are ascribed, accepted, or resisted.

Esoteric Factor

Focusing on the first part of Jansen's definition of esoteric folklore (esoteric A—what one group thinks of itself), I am interested in (a) how the athletes articulate the label of “disability”; (b) how the parents view their adult child's disability; (c) how the athletes feel about OHSO; and (d) how the parents perceive OHSO. When I asked the athletes to share with me their thoughts on the term “disability,” I generally used the terms preferred by their parents or by the athletes themselves, two of whom used the term “special needs.” Careful consideration and tact are required when discussing labels that are heavily tinged with stigma with individuals who have been categorized according to such labels. I was careful not to use the term “normal” or “mental retardation” because of their stigmatized values, but could the words “disability,” “different,” and “special” be similarly contaminated and potentially influential in shaping one's view of themselves and others? I did refer to mainstream peers as “regular education students” after hearing one of my participants mark the categories as “special needs” and “regular ed.” Ultimately, I used the individuals' emic terms when asking about differentiation, labels, and other categorizing elements associated with identity.

Beginning with how the participants used emic and etic terms, I then began to explore how these terms were used regarding themselves; in other words, did they distinguish their identity in terms of self-ascribed versus other-ascribed? Unlike identity

claims that are tied to ethnicity, evident in Judith Okely's work on Traveller-Gypsies, where she suggests that a "broad definition of Gypsy and Traveller might be 'Not Gorgio'[non-Gypsy]," I did not find cohesive patterns of dichotomous identity claims (1983, 66). Nor was I able to find conclusive evidence delineating whether awareness of one's own category was self-evident or self-conscious, to use Barbara Kirshenblatt-Gimblett's terms as she relates them to cultural practices in Klezmer music (1998). Amy Shuman points out that disability studies "begins with the critique of 'normalcy' as self-evident," so when we question what is considered self-evident or self-conscious relating to the OHSO athletes, we offer a challenge to Storey's criticism that Special Olympics is a group that reinforces stigma. It is possible that it is within the Special Olympics and the OHSO kinship group that the athletes are able to participate as unmarked (Shuman 2011, 158).

I began my interviews with Nicki (A10), a twenty-one-year old who swam competitively with her high school team and on the Special Olympics team, because she was one of the only athletes I was able to interview who participated on sporting teams comprised of people with and without disabilities. I began asking her about her involvement with the Special Olympics because I was interested in learning more about her experiences swimming with both the Special Olympics and her mainstream high school team. I wanted to know if she categorized the teams according to ability levels—in essence, did she mark involvement in one team as different from another and did she attach different values to the two teams? Nicki did not differentiate among the athletes on either teams according to their intellectual or physical abilities or limitations, but she did

say that the practices were harder with the high school team. Because it appeared that Nicki had difficulty answering abstract or generalized questions, I carefully tried to become more specific and relatable while measuring her comfort level and attempting to gauge her understanding of the category of disability as it related to both herself and others.

- O: Can you tell me what the word “disability” means?
N: kinda hard to explain
O: okay. [long pause] Would you like to try?
N: yeah. I’m trying to think how to say it though [long pause]
O: what is a disability?
N: I’m trying to think. It’s something you’re born with.
O: can you think of anybody who has a disability?
N: I’m trying to think. Could it be anybody?
O: you can tell me what you think.
N: hm, I’m trying to think. Hm. I’m still thinking. Tori does.
O: really?
N: yeah
O: what do you think her disability is?
N: hm, I’m trying to think. Down Syndrome.
O: Tori has Down Syndrome?
N: I think she does, I’m just guessing.
O: what is Down Syndrome?
N: hm, I’m trying to think what it is-I don’t remember what it is exactly.
O: why do you think she has Down Syndrome?
N: I don’t know, I’m just guessing.
O: do you know anyone else who has Down Syndrome?
N: my boyfriend
O: how can you tell?
N: what do you mean?
O: is there something-how do you know if he has Down Syndrome?
N: hm, I don’t know.
O: do you know anyone else with Down Syndrome?
N: hm, I’m trying to think. Not really.
O: Tori has autism. Do you know what autism means?⁷

⁷ Although it might appear that I am not honoring Tori’s privacy and introducing the term “autism” to this conversation, this is a close-knit group and it is common knowledge to discuss peoples’ disabilities. Many belong to clubs and associations based around their disabilities. Since Nicki brought up Tori having a disability as something concrete and then identifies certain behaviors as indicators of having a disability, I was interested how she described her awareness of the terms “autism,” “Down Syndrome,” and “disability.”

N: I forget.
O: do you know anyone else who has autism?
N: no.
O: how can you tell that Tori has a disability? What does she do or say that makes you think she has a disability?
N: she talks to herself a lot.
O: yeah? Do you know what she says?
N: no, not really.

This dialogue serves as an excellent example of some of the difficulties that can arise when trying to ask someone about an abstract categorical label of disability as it relates to themselves and others. All of the participants have different levels and types of competencies; for some, discussing things in the abstract may be nearly impossible. In order to make things more understandable, the interviewer must become increasingly specific, and whereas traditional ethnographic methods are geared towards open-ended questions and deter efforts that might lead the informant, these conventional methods do not often work when interviewing some people with IDD. In this example, I was trying to understand Nicki's emic view of disability without attaching a value or stigma to the label of disability while simultaneously trying to ascertain how she gained her perspectives. How did she learn about the categorizations used to identify and separate those labeled as disabled? Was it through hearing about it from a parent, teacher, doctor, athlete, classmate, etc.? Does she view disabilities as specific traits that would be apparent through an individual's appearance or behavior or were the labels re-interpreted to fit her own understanding of difference?

Nicki said that a disability was something a person is born with. She did not say how it affects a person, however, so it was not clear if she thinks of a disability as a factor that makes someone unique or different or whether she was simply repeating a phrase she

had learned but did not fully comprehend. I was afraid that if I introduced characteristics common to certain disabilities I would influence her response. I did not want to impose a sense that a disability is a deficit or something that she might perceive negatively, nor did I want to influence her to think that a disability is something that causes shame because she is extremely sensitive to people being “rude” and judgmental.

Several key points emerged in this conversation that reflect some of the challenges I have encountered when working with people with IDD. As a fieldworker, I needed to assess the competence of the athletes’ communication as well as their particular conversational styles. Although all fieldworkers have to consider the potential power imbalance, this is accentuated in any conversation with someone with IDD, a topic that disabilities scholar Val Williams has explored, and that I will develop further below. Here, I describe examples of my interviews on their emic categorizations of disability. My discussion necessarily encompasses three issues: (a) how they categorize their own and others’ disabilities; (b) their communicative competencies in these discussions; and (c) questions of power imbalance that had an impact on the conversation.

Some athletes responded to my questions by repeatedly saying using conversational markers that constituted a response if not an answer, for example, “I’m trying to think.” For some individuals with IDD, this is a way of using a conversational marker that both performs a competence in the conversational genre by participating in the question and answer session while also allowing them more processing time to create a response. In this example, Nicki repeatedly uses “I’m trying to think” in a manner that suggests she was seeking more processing time and could not provide an immediate

response. It also reflects a lack of assuredness in her knowledge of the various subjects. This was also indicated by the disclaimers of “I’m just guessing” and “I’m not sure” that reflect both her willingness to provide a response and her feelings of insecurity over whether or not she was giving me the correct answer or the response she thought I was seeking. I observed that the athletes I interviewed varied in how they used this strategy. Nicki (A10) sometimes followed with an answer, while Tori (A14) rarely responded with an answer beyond the phrase, “Hmm, let me think.” Matt (A9), the athlete who gave anti-bullying speeches to college students, would react to a question by using a conversational marker, pause, and then respond with either an answer or an admission that he forgot what he was going to say.

Although it might be argued that this varying usage indicates different levels of conversational competence and that Matt is more competent than Tori and Nicki in using this type of marker, it could also be claimed that Matt was more interested in providing a correct response and that Tori and Nicki were either used to someone else filling in the answer for them or that the phrase was a response that resulted in the questioner discontinuing the pursuit of a response. This part of the interview captured Nicki’s ability to follow the catchphrase with an answer, whereas in many other sections Nicki would use this phrase but not follow with an answer and instead would begin nervously laughing and forget the question that had been asked. Tori would also use this catchphrase when I asked her questions, but she would rarely, if ever, follow the phrase with an answer. Because of Tori’s limited tolerance for questions, I generally could ask a couple of open-ended questions but if she responded with “I’m trying to think” or “I

don't know," I would then ask a more specific question with two possible choices. If she did not provide an answer, I would discontinue asking questions because I interpreted this catchphrase as a stalling technique used to resist my attempts to engage her in a conversation. Moments like these highlight the tension and awkwardness that arise as an interviewer working with people of different abilities because "I'm trying to think" could require more processing time, a rephrasing of a question, or a change of subject. Whereas someone without disabilities might be able to say they do not want to continue the interview, some interviewees with IDD lack the ability to speak as directly, so it is the responsibility of the interviewer to become familiar with each individual's speech patterns, body language, and other indicators that signify their preferences and comfort levels in order to better understand and respect an individual's preferred conditions for interaction.

In addition to knowing when to pause, offer further prompts, or discontinue asking questions, the second item that appeared in this excerpt and other interviews was the recognition of the power imbalance between interviewer and interviewee, which signaled a tendency for some people with IDD to want to please people in positions of authority. I am particularly interested in the second component to Nicki's response, "Could it be anybody?" to my question if she knew of anybody with a disability because, as conversational analyst Val Williams observes, discourse analysis "can reveal and unpick how power structures are re-enacted through everyday life" (2007, 47). This interaction between myself and Nicki is an example of Nicki's perception of the power imbalance between the two of us and something that must be taken into consideration

when working with people with IDD. By seeking my approval, she reflects her view of me as someone who is asking a question to which I likely already know the answer, or what Williams refers to as display questions used by a teacher in a classroom (45).

According to Williams, many people with IDD are accustomed to being in situations where other people have the power to approve or disapprove of their choices and this is why I tried to assure Nicki that she could tell me what she thought (94). However, even this move on my part does little to minimize the power imbalance because I am still occupying a position that is essentially giving Nicki permission to speak. She then continues to qualify her answers with disclaimers that she is not really sure, she does not know, and she is just guessing. These qualifiers are a way for her to save face in light of the possibility that she might be giving an incorrect answer.

Due to Nicki's lack of assuredness and my interest in making her feel as comfortable as possible, I did not want to correct her when she did give incorrect information. This leads me to the third pattern which emerged through some of my interviews with people with IDD, that of mislabeling. In this excerpt, Nicki mislabeled Tori as having Down Syndrome but then correctly identified her boyfriend as having Down Syndrome. She did not seem to be able to identify the characteristics that define the category of disability nor indicate specific disabilities themselves. Nicki was able to identify that Down Syndrome is related to the concept of disability but was not able to go into further detail, nor was she able to define autism. Autism Spectrum Disorder, unlike Down Syndrome, is referred to specifically as a spectrum so it is understandable that it is difficult for anyone, with or without disabilities, to define. Nicki incorrectly categorized

Tori as having Down Syndrome but associated Tori talking to herself as a something out of the ordinary, a marker signifying Tori's membership in the category "disabled." When does talking to oneself become a negatively-marked category-bound activity?

Placing someone in the category of having a disability because they talk to themselves indicates a level of competence in recognizing substantive communication and the social rules that determine when and what type of speech is appropriate, but is this competence challenged when the person does not recognize similar actions in themselves? Goffman states that a "stigmatized individual exhibits a tendency to stratify his 'own' according to the degree to which their stigma is apparent and obtrusive," (1963, 106) and in Nicki's case, she observed Tori's behavior as obtrusive but did not mention physical characteristics associated with Down Syndrome, leading me to wonder whether this means of classification must be learned and that her worldview places a higher value on differences in behavior rather than appearance.

I would also add that this does not reflect an inability to associate appearance with a stigmatized category, because several of the athletes have identified being obese as something that is undesirable. I have witnessed several other Special Olympics athletes engaging in self-talk and Matt's mother informed me that when she attended a lecture on Down Syndrome, the lecturer stated that the majority of people with Down Syndrome participate in self-talk. Researchers claim that self-talk is an important factor in young children to help them develop higher-level thinking and self-directional skills (Patti et al 2009). Although there has been relatively little research done concerning self-talk and

people with IDD, studies on self-talk behavior with people with Down Syndrome suggest that it is incorrect to interpret self-talk as hallucinatory.

Based on my conversations with the parents of adult children with IDD who engage in self-talk, framing the behavior as positive or negative depends on how the self-talk affects their children and others. If the self-talk is perceived as helping an individual “work things out” and acts as a self-soothing mechanism, it is viewed as positive because it serves as a calming behavior; conversely, if the self-talk is seen as a source of anxiety and disrupts an individual’s equilibrium and their interactions with others, it is viewed as a cause for concern. Nicki, who has been observed talking to herself, did not recognize this behavior as self-talk and did not frame it as unusual or a sign of disability although it does seem to cause her stress. Perhaps she did not recognize this in herself because she has expressed the belief that she was speaking to people who were outside or in another area, therefore she did not believe this to be talking to herself. This lack of self-reflexivity could be attributed to her cognitive abilities, so although she might view talking to oneself as a marker of disability in another individual, she was unable to categorize her behavior as similarly marked.

When I asked Nicki if she knew of anyone else with autism, she replied “no.” Could this be because Nicki did not recognize the characteristics associated with autism that often vary among individuals? Nicki has been diagnosed with autism spectrum disorder and I knew that her awareness of autism had grown over the past several years because her family and doctor had discussed it with her, she and I had talked about autism, and she had gone from not wanting to discuss it or say the word “autism” because

she thought it was a bad word to being able to talk about it without getting upset. Was this an indicator that she had initially felt a sense of shame or stigma attached to the label and had become more comfortable as she was involved in a non-shameful discourse among people she trusted? She had also developed an ability to identify some of her behaviors as “tics,” whereas she had previously expressed that she did not know why she kept doing certain behaviors, such as sniffing or tearing paper. It is unclear why she did not name herself as someone with autism but it could be because I asked if she knew “anyone else” with autism and did not directly ask her. It is also possible that although at times she had displayed more comfort in discussing the topic of autism and disabilities, talking about it in this context still caused her discomfort and she was attempting to save face or manage her identity by keeping that information private.

Asking someone about their own disability can be much more problematic than talking about disability as it pertains to others. As Charles Briggs says, “Sensitive and effective interviewing thus presupposes awareness of the society’s categories of speech acts and social situations and the rules for relating them” (1986, 45). Accordingly, I noted that for the most part, the OHSO athletes did not discuss their disabilities, but neither was it a taboo topic. Further, talking about something that contributes to someone’s status as stigmatized can be perceived as invasive. I was able to discuss individuals’ disabilities with them and their parents by focusing on descriptive categories without appearing judgmental. According to Val Williams, who discusses how the term “learning difficulties” is viewed during her group work on inclusive research, her colleagues with IDD hear this label as offensive and even mentioning the label can have catastrophic

results (2011, 189). This was apparent when I asked Nicki (A10) about her disability after she had discussed other individuals on her team who have disabilities:

- O: Do you think that you have a disability?
- N: Why are you asking? I just want to know.
- O: I'm just curious.
- N: Yeah, I do. Yeah, I think I do.
- O: What do you think it is?
- N: I forget.
- O: Are there times when you feel like you have a disability?
- N: Sometimes.
- O: When?
- N: I don't know when, but sometimes.

As the only moment in the interview when she challenged a question, this is significant as a point of resistance. It also reflects an underlying connection between disability and the stigmatizing effect it has, to the point where even the mentioning of it causes tension. Additionally, this is a powerful example of where Nicki changes the footing and turns the interview back on the interviewer, asserting power and signifying that there is something potentially unsettling in the question.

Several of the athletes spoke of being able to identify others as disabled based on appearances, behaviors, or differential abilities that served as markers signifying them as something other than non-disabled. When I asked Patty (A12), another Special Olympics athlete, about her understanding of the term "disability," her statements reflected her understanding of disability as something that was observable through physical and behavioral characteristics.

- O: can you tell me what your definition of disability is?
- P: I don't know.
- O: how do you know if somebody is disabled?
- P: I look at them to know if they're disabled
- O: how can you tell?

P: the shape of their head
O: the shape of their head?
P: yeah
O: but some people-can you tell physically?
P: no.
O: so then what do you do?
P: I don't know. My boyfriend has a disability.
O: what's his disability?
P: he can't walk right
O: he can't walk right?
P: yes, he's in a wheelchair and I don't know.

Patty proceeded to tell me that she could tell that another teammate had autism because, as she put it, "my dad told me she has autism." I asked her how she could tell and she replied that this teammate was mean to everyone and there were times that she cried or became angry for no apparent reason. Patty went on to name another teammate who has Down Syndrome and a different athlete who has autism, but when I asked for more specifics as to how she knew they had disabilities, she said, "I can just tell."

It was unclear from our conversation how much of her awareness of disabilities was a result of learning about peoples' disabilities from other people and how much was based on her interactions and own perceptions. I was unable to ask her about her own self-awareness of her disabilities because her parents were not comfortable discussing this with her since they were concerned drawing attention to her disabilities might upset her and make her feel less "normal." This leads to one of the sticky points that arose when discussing self-identification and understanding of one's own disability. I did not want to focus on a person's disability as their most important or identifying feature, but if it could be argued that by discussing labels and diagnoses a person with IDD could minimize the power of the stigma and move toward advocating for the support they need

on the path to independence, then this type of silence might reinforce the taboo. On the other hand, I am troubled by the awareness that for this chapter, I am focusing on the topic of disability in order to better understand how individuals identify with a group whose membership is based on the fact that they have been diagnosed with a disability. By my very selection of this line of questioning and topic selection, I am focusing attention on the most stigmatized aspect of their identity while not paying equal attention to the many other facets of their personality that reflect their likes, dislikes, strengths, competencies, and other unique traits that reveal their full personhood.

29-year-old Lewis (A7) measures disabilities in three areas: intelligence, behavior, and social interaction (how those with disabilities are included in mainstream culture). Lewis uses the terms “special needs” and “regular ed” to differentiate people with and without disabilities. He also talks about people being “sometimes” special needs, which challenges us to reconsider the categorization of disabled as a permanent or static category. Lewis first began talking about how someone was disabled based on how well they could read. He then went into categorizing specific friends from the Ohio Special Olympics team and said that two of his teammates are “sometimes special needs” (A7:2/15). For example, he says that his friend Nina (another Special Olympics athlete who has since moved to another city) knows math, when she takes her time, so this decreases her disability. Lewis remarks that Derek (A3) is able to memorize sports statistics, which makes him less special needs. Lewis considers himself somewhat special needs (he made a gesture holding his thumb and forefinger about three inches apart) and said his friend Victor (OHSO athlete) is only a little special needs (gesture of one inch

apart) because he goes to college but sometimes has seizures and forgets things. His friend Charles (not an OHSO athlete), who cannot talk and is in a wheelchair, is not very special needs because he took regular education classes like American Sign Language, pottery, and woodshop, but his friend Hank (former OHSO athlete who currently has three jobs in integrated environments), who is able to talk and walk, is “a lot special needs” because he is compulsive with food, eats until he throws up, and is loud in public places. Lewis also mentioned two other athletes who have bad tempers and do not always follow the rules at Special Olympics events and practices—characteristics that (to Lewis) made them more special needs than others. Lewis’ categories of what it means to be disabled demonstrate a keen understanding of how normative behavior through following social rules can minimize one’s status as disabled, as does inclusion in mainstream activities. His rationale demonstrates an understanding of both competency and temporality. From an outsider’s perspective, one might think that being able to walk and talk would signify someone as less disabled and having more access than someone who has difficulty with communicating and mobility. Lewis’ perspective, however, reflects that being competent in areas such as demonstrating social skills is more relevant in terms of minimizing one’s disabled status.

Not everyone identifies disability with stigma. Derek (A3), like Patty (A12) and Lewis (A7), is able to name different people and their corresponding diagnosed disabilities. He says that everyone on the OHSO team has a disability; he identified two fellow athletes as having Down Syndrome, one of whom also has difficulty hearing, and named three individuals on the team who have autism. When asked about Victor, one of

his OHSO teammates who just graduated from college, Derek said he did not know what his disability was because Victor did not tell him. Derek adds that his mother has difficulties because she does not understand football or where the ball is, so it seems that Derek correlates having a disability with struggling with something. However, there have been occasions where Derek has associated “disability” with something that makes someone different in a way that they can do things other people cannot.

Derek has been able to memorize names, places, birthdates, and sports statistics from a very young age. His mother, Eileen (P5) shared a story (P5:9/13) that when his sister’s elementary class was exploring the topic of diversity and disability, they invited Derek to come in and speak to the class. Derek had been given a sheet of the students’ names that also had their corresponding birthdates listed. At one point, the class began playing a memory game and two students were not able to state their birthdate but Derek surprised the class by being able to state the students’ correct birthdates. The class was excited by Derek’s skills and said that he was smart. When asked what his disability was, Derek also said he was smart, suggesting that he may believe that a disability is not necessarily a deficit, but rather something that makes someone different from the rest. Derek’s understanding of disability is evolving (as is the case with several of the other athletes). On the one hand, he knows that he has skills that other people lack and this makes him different; on the other hand, he understands that disability can also signify something that makes a person different because it means they struggle with something. It is possible that Derek has a growing awareness of stigma related to his understanding of the concept of embarrassment.

Whereas some OHSO athletes were unable or unwilling to provide an easily recognizable meta discourse about their own disability, others have grown accustomed to discussing their disability. When I ask Matt (A9), “What is a disability?” he answers, “In my case, disability means—I really don’t know. When I first was born, I didn’t know I had Down Syndrome. When they told my mom, I knew I had Down Syndrome.” Because this particular interview was with Matt and his parents at the same time, it has an interesting dynamic that I did not see in other interviews where I interviewed parents with their adult children or parents and athletes separately. In the interview with Matt and his parents, Keith (P16) and Evelyn (P6), I saw that the interview frame opened up possibilities for parents to learn more about Matt’s perspective about topics that perhaps they had not specifically addressed with him in the past. For example, after Matt answered the question about disability, his mother asks, “When do you think you noticed that you had Down Syndrome?” to which he replies, “I was—I was looking in the mirror and I could tell I had Down Syndrome” (A9:10/13). We could be tempted to latch onto Matt’s reflexive statement as an epiphany, where the way he sees himself collides with how others see him, thereby potentially offering us insight into Matt’s inner world and his understanding of how disability is constructed. His mother became very animated and began trying to determine when this took place so she asked what grade he was in, which school, and then tried to determine his age when he first understood that he had Down Syndrome by trying to match it to the teacher he had that year. The promise of a coherent narrative supporting Matt’s claim that when he looked in the mirror, he could tell he had Down Syndrome, slipped away as his mother continued to question him to find out how

old he was when this occurred. At first Matt said that he was in sixth grade but then after further questioning, he said, “I remember having Down Syndrome when I was in first grade.” It is important not to discredit this conversation as coming from an unreliable narrator due to the changes in the story; the circumstances under which he learned of his Down Syndrome or the grade that he was in at the time has little relevance compared to the act of the narration itself. Although Matt’s narrative is not completely linear or consistent, it still reflects a level of competence in understanding how the categories of disabilities are created and applied. For Matt, this could be an example of esoteric A as well as the point where etic and emic converge because a disability is something that a professional diagnoses and informs the individual’s family, but is also made apparent through reflexivity based on what other people observe and identify as signifying markers of a disability. It is possible that Matt is talking about an actual encounter with a mirror, or perhaps he is using metaphoric language to describe what he feels is the moment when he saw himself as others might see him and his outward features associated with Down Syndrome were first recognizable, or perhaps something else entirely. Rather than devaluing Matt’s narrative for lacking consistency or coherency, it is more useful to consider what these moments reveal about Matt’s understanding of Down Syndrome as it relates to himself, Matt’s mother’s (and my) desire to learn the stories that reflect his inner world, and how Matt might have been performing the role of the storyteller to provide us with the narratives we so desperately wanted to hear.

Matt’s awareness of his own disability corresponds to others’ (etic) categories, but his descriptions of other people are more inconsistent with regard to etic categories. Matt

says that he met a man while he was working at the hospital and recognized that the man was disabled because he had trouble walking and used a wheelchair. He also identifies him based on another aspect of his appearance—the way he dresses—and says, “He always dressed in like a tie, a nice shirt.” Matt places great importance on dressing well and taking pride in his appearance so remarking about someone’s well-dressed appearance in addition to their use of a wheelchair reflected Matt’s generally positive portrayal of people with disabilities. Based on this interview, I developed the impression that he did not see any disability as an obstacle. He spoke highly of his girlfriend, another athlete on the OHSO team, and did not seem to notice or pay attention to anything associated with her disability. After this interview occurred, Matt ended his relationship with this particular girlfriend and fellow teammate. He told me that she said and did things that scared him and made him feel uncomfortable. He was referring to her behaviors that can be characteristic of her particular disability, but he never used the term “disability” and only referred to her actions and words in specific situations that upset him.

I also tried to identify if Matt felt he was treated as someone with a disability based on others’ perceptions of what it means to have a disability. When asked if people ever treated him differently, he says, “No, they treat me pretty good, but my parents on the other hand...” to which everyone responds by laughing. Matt uses this as an opportunity to make a joke and present a positive perspective, and yet he admits that he had been struggling to find a job. Because Matt has a certain level of awareness and an ability to talk about disabilities, he had been selected to give talks to college classes about

bullying and disabilities. When asked about the topics of his talks, he answers, “I told them it’s okay to be yourself and don’t worry about anything. With people who has a disability, they may have like Down Syndrome or scoliosis or autism and we need to be patient with them and don’t be impatient. Don’t go too quick or go too fast.” Matt relates this idea of disability to the concepts of expectations, pace, being yourself, and having difficulties in certain areas. I will go into more detail later (Chapter Seven) about how he has learned to adapt to the pressures and expectations he has experienced in a particularly hostile workplace, but it is important to note that Matt expressed that he put a great deal of effort into performing tasks and meeting expectations and that it could be exhausting. It is also significant to note that throughout this conversation, Matt switched to the use of second person when describing preferred attitudes towards people with disabilities, and he deftly performed the roles of lecturer, comedian, good son, and key informant, demonstrating a complexity of understanding of stigma as well as disability.

When athletes did not articulate their awareness of disability, I spoke with their parents, who provided their own perceptions of how their children viewed their disability. Some believe their children are not able to be reflexive about their disability because they have known nothing different; in essence, if a person has always lived with a certain condition, how would they know what it would be like to not have that condition? Other parents say that they feel this lack of reflexivity and self-awareness is due to the very nature of their child’s cognitive impairments, preventing them from communicating a meta-awareness. Maggie (P11), Tori’s (A14) mother, admits that she is not sure how

much her daughter understands about disability as it relates to herself or others. As she states:

You know, it's funny, after she comes from camp, she'll say 'those were special needs and autistic people' and I'll ask her 'what does autistic mean?' and she'll go 'I don't know,' so I don't know what she thinks. I think there are kids, or people, with autism who are aware that they have that. I don't know if she really understands that-that she's different, or I don't know.

It is possible that Tori is not able to recognize the categorization of disability that is applied to herself and others, but that she is repeating what she has heard from the discourse at the camp where there might be a certain level of pride. Although there are certain times when Tori makes her needs and intentions very clear, there are other times when much of her behavior is based on imitation, so it can be difficult to determine how much value is placed on the action or saying. Therefore, although she identified the camp she went to as a place where the campers are people with special needs and autism, to what degree she understands the meaning behind her words is unclear.

Laura (P9), Chris's (A2) mother, relays a similar sentiment about not knowing exactly how much her son understands about disability. Laura admits that this is a tough question to answer and that she has tried to learn Chris's perspective on the matter, but still is not sure what he thinks. She believes Chris is aware that he is different and that he has Down Syndrome, but that she does not know what he would say if you asked him to verbalize what it meant to have Down Syndrome. According to Laura, the most that she can infer from what Chris has said in the past (she did not give examples) is that he is aware that he is different but that he felt accepted by many people. The idea of being different does not bother him that much and since it is something that he has always lived

with, he does not know a different reality. Laura uses the example of someone experiencing the transition from having vision to not having vision as traumatic whereas a person who was born blind might have less difficulty with their blindness because they had known nothing different. When asked about Chris' understanding of others' disabilities, Laura says that she thinks he is aware that the athletes on the OHSO team have disabilities, but that he does not point out the differences (P9:7/13).

In an interview with Nicki's (A10) parents, Greta (P7) and Henry (P8), I asked them if Nicki understood that the Special Olympics is a group that is based on athletes with disabilities and they said that they believe her understanding is somewhat vague because, according to her mother, "even her awareness of her own [disability] is somewhat vague." Greta said that Nicki has acted inquisitively and asked if someone has a disability, and when there have been times when her parents have explained certain things as being part of someone's disability, Nicki has said, "Is it all right to say that?" or "Don't say that! That's judging!" indicating that she was aware of some negative value associated with being disabled.

Nicki's apparent awareness of her own disability is unclear and changes from time to time. Her parents say that she has said things that suggest she is not aware that she has a disability, but there have been other occasions where she has refused to be categorized as disabled. Henry gave an example of taking Nicki to see different doctors to address her seizures or obsessive behaviors and when the word "autism" originally came up, Nicki was very sensitive about the term and expressed that she did not want autism and she did not want the label applied to her. Her parents explained to her that

yes, she did have autism, but that everybody has some type of issue that affects them. Later, however, when Nicki was attending a school meeting and the school psychologist repeatedly mentioned autism, Henry said Nicki did not even blink. He interpreted her lack of reaction as acceptance of something she has and he recalls Nicki asking him if other people have autism. Interestingly, Nicki has also developed an avid interest in the movie “Forrest Gump” and although when asked what she likes about the film, she will say she likes his hair or thinks he’s cute, her parents believe that at some level she appreciates the story.

Patty’s (A12) parents, Rick (P13) and Beth (P1), spoke about their daughter’s infatuation with wanting to develop a relationship with someone who is typically developing and that, like some of the other athletes they have observed, this takes priority over relationships with those with disabilities. When asked how they felt Patty viewed herself esoterically in relation to her membership in a group of people with disabilities, Beth said, “I think she recognizes the special needs kids but I don’t know that she sees herself that way, you know, necessarily, I think that’s part of it” (P1:7/13). Patty’s parents did not feel comfortable with me talking to Patty about her own disability because they said they try not to discuss her disability with her in order to help her feel more normal. Therefore, it is difficult to know how Patty perceives the term “disabled” as it applies to her because she has not been encouraged to engage in the discourse as it relates to her.

Her parents believe that Patty might be aware that she is disabled but this is something they have inferred from observing her in terms of alignment with those with and without disabilities. Beth proceeded to explain that there are moments when Patty

goes along with the typically-functioning kids and does not seem to feel aware or insecure about her differences but then there are other times when she seems to be more aware, as Beth states, “you can tell because she stops and she’s processing, ‘Oh, I’m not- this isn’t-I can’t participate.’” Patty’s father explained that she would then cope by acting silly and trying to make people laugh, particularly when she cannot speak due to her speech impairments. Beth said that she has improved over time but she still sees Patty stop and get a look on her face that seems to say that she is outside of her element and reflects an awareness that she cannot compete. Rick witnessed a similar moment of insecurity and self-consciousness when Patty was at her weekly book club gathering. Although the members of the book club are all people with different levels of disabilities, the group’s facilitator is an attractive young blonde woman whom Patty adores and always wants to sit next to during the reading. Rick noticed that when it came time for Patty to read, she began to struggle and started to cry. Even though she knew that everyone else at the table had a disability, she wanted to show the leader and Rick that she could read too. Rick said that although Patty can read relatively well, it was not to the level that satisfied Patty. Beth states, “She wants to be like everybody else, but then she’ll get over it pretty quickly, but it’s sad to see it though. So sad.” Beth explains that Patty wants to be “like everybody else,” but having attended these book club gatherings with Patty and her peers, I have observed a wide range of reading, social, and verbal skills, so perhaps Beth intended to say that Patty wanted to be more like the facilitator rather than her peers with disabilities. The sadness that Beth experienced from Patty’s distress that she was not able to perform like everybody else was echoed by Rick who admits, “I’m

crying right with her, you know, because she can't read and the thing that pisses me off that is that she could be reading better if she hadn't been locked in a resource room with a teacher who thought that she'd never be able to read and that's exactly what happened." Patty has learned to read, and while it is not clear if her reading level meets her expectations and/or those of her parents, this moment offers a glimpse into how Patty's disability and limitations have been perceived by herself and those around her. This is a particularly poignant account of both the child's and parents' desire for acceptance based on normalized standards that perhaps Patty will not achieve in this area.

Moments where Patty recognizes her limitations are marked as negative because of the value placed on passing. Moments like these are not isolated; instead, Beth gave another account of whereas they have tried to help Patty be "more natural," because of Patty's disability and peoples' reactions to them, Patty has faced rejection in the form of not being invited to events that she used to attend with her typically-functioning peers. Beth says that when Patty was younger, she would be invited to multiple birthday parties but then when she would have a seizure, Beth would have to go and make sure she was okay. As Patty grew older, according to Beth, "there were no more birthday parties; there were no more invites, there was nothing."

Are the parents part of the in-group and makers of esoteric folklore or do these positions and groupings shift based on who is being compared and contrasted? Applying Jansen's framework, this situation does not fit neatly into an esoteric category because it is based on the parents' observation of their child's behavior that they interpret as a moment of seeing oneself as others see you, which they then categorize as sadness at not

being able to pass, thus blurring the lines between insider/outsider, self/other, and projected notions of what each other is thinking. In the case of some of the parents, how do we categorize their perceptions of their child's disability in relation to the other athletes on the team and their disabilities? I will explore this further in 0, but as Nicki's (A10) parents have observed, just because Nicki is in a group with other people with IDD, she does not find an automatic zone of inclusiveness by virtue of being disabled. In fact, they argue that some of the athletes have less capability to try to cope with behaviors that can be off-putting, such as when Nicki stares.

Greta (P7) explains that Nicki's (A10) "social issues really affect her ability to have friends, even among those who would be friends because they were outliers like her and she could be one of the-one among the outcasts-she'd be with the outcasts-she was an outcast among the outcasts" (P7:6/13). According to Greta, Nicki is unique among the group because she has not seemed to find good friends on the OHSO team. Her parents say that she has had difficulties with schoolmates in the past who have teased her. When asked if they had seen anything similar occur at the Special Olympics, they replied that they have never seen or heard of her being bullied and that Nicki always looks forward to going to events. Henry (P8) and Greta believe that Coach Pete (C2) would do something to stop any potential bullying behavior if he was aware of it but they admit that it is a large group with many athletes and volunteers and it is hard to know if everything is seen and observed. Henry explains that he did not think that many of the athletes were prone to being bullies because, as with deception, "you almost have to be, you know, very adept at a lot of social rules to even know how to bully...even though they're in a society that's

like *Lord of the Flies*” (P8:6/13). Greta argues that “they’re fickle-sometimes their malice comes out in just their fickleness because they’ll go up a pecking order fast...if someone’s paying attention to them, it’s a little higher status—they’re not missing a beat when it comes to that.” In this example, the categorization of esoteric is further complicated because it appears that even the parents have differing interpretations of what they believe are the potentials for good and malicious intentions among the OHSO athletes. For Henry, bullying is something that is intentional and happens over a certain amount of time, whereas for Greta, bullying can be incidental and opportunistic.

Exoteric Factor

Returning to the framework of esoteric A (what one group thinks of itself) and esoteric B (what it supposes others think of it), how the parents and athletes do or do not use labels has consequences for how they feel about inclusion. For some of the parents, these esoteric factors can be based on observation, positive or negative interactions, anecdotes, fears, projections rooted in their own preconceived notions and concerns about stigma, or optimistic hopes for a tolerant community outside of their group. I do not have examples from my interviews with the athletes about where any of the athletes mention not wanting to hang out with people with disabilities, but I do have examples of this from both parents’ accounts and from my own observation. Moments reported by the parents and my observations understandably lead to the construction of exoteric folklore, particularly regarding interactions between those individuals and groups with and without

disabilities. These instances and recollections offer potential insight into ways inclusion can work, as well as the beliefs, barriers, and behaviors that contribute to exclusion.

In high school, Nicki (A10) participated in swimming and choir with her mainstream peers, but as the new students came in each year and her school age peers graduated, she was teased by some of the younger students because of her disability. Her tendency to stare and laugh inappropriately are behaviors that have caused her to be somewhat alienated in both the OHSO and at school, particularly in her segregated class where some of her peers get irritated and upset by behaviors that they might lack the patience, cognitive ability, and maturity to understand and tolerate. Her parents have struggled to have the school do more than the bare minimum to get her moved on to the next level until she is no longer under the school's jurisdiction. Some parents have found the push towards inclusion in the school system has been less about truly supporting inclusiveness, but rather about cutting funding and eliminating any activities that might be viewed as segregating and highlighting people with special needs. However, as Nicki's mother, Greta (P7), points out, this becomes problematic when, even though it is written into Nicki's Individualized Education Plan (IEP) that she has the same opportunity as the regular students to attend any of the social events, there has been little to no facilitation provided to ensure that Nicki is included. Greta even asked some of the school administrators, "'Do you hang around with a lot of mentally retarded people yourselves?' They said, 'Well no.' I said, 'That's the point. It doesn't typically happen in the natural course of things'" (P7:6/13). She had hoped that the same officials who were touting the benefits of inclusion would recognize that they did not have friendships or

relationships with people with special needs. As such, they could not expect teenagers to have the confidence, maturity, and social skills to go out of their way and develop such relationships without any instruction, facilitation, or motivation. Even Nicki's father, Henry (P8), admits that when he was a teenager, he was unfamiliar with people with disabilities and did not know how to interact with them and it really was not until they had a child of their own with disabilities that he became more familiar with people with disabilities.

Henry (P8) also talked about the school's push toward inclusion as a fallacy that didn't represent real world effects in the community for people with disabilities. He states that it is not often that people living in a suburban community have much contact with people who have disabilities and he believes it is a "foreign and frightening" thing for people to know how to deal with Nicki. Both he and Greta say that people are generally pleasant to Nicki at first, they will say hello, but then withdraw a bit and try to move on. In order to combat this and encourage Nicki's connection to the community, Henry and Greta have focused on Nicki's strengths, swimming and singing, which have enabled her to create stronger connections in the community through mainstream activities. They have also joined a local church that has been open and accommodating towards people with special needs and Nicki has sung at the church and at the yearly neighborhood festival. She continues to go to the high school football games and library events, but in terms of finding employment, she has not had success. Her parents recall a doctor once telling them that part of the problem with finding her employment related to the modern age and that if they lived in an agricultural setting, Nicki would likely be able to help out

on the family farm. Now, however, they have to worry about her being supervised to not only keep her on task but also in a safe environment because they worry about someone taking advantage of her. For Nicki's parents, inclusion in the community and the "real world" is fraught with its own issues of danger and although they do not want to restrict her from some integration in the community, they have a responsibility to monitor and control the potential associated risks.

These issues of safety and risk may seem to represent different concerns about inclusion, but actually, these issues are central if not always articulated. The scholarly literature on transition frequently discusses what is called "dignity of risk" as a major feature of inclusion. It directly relates to how people with IDD are perceived by those closest to them and strangers, assumptions about what it means to be an adult, how an individual gains knowledge through experience, and what is at stake when risks can lead to failure. Many parents and caregivers are concerned about people with IDD being taken advantage of, which is an understandable concern (as it is with parents of children without disabilities), but this can become increasingly problematic when parents become extremely overprotective to the point where inclusion is no longer an option. When individuals with IDD are not given the opportunity to participate fully in the community, not only do they not have more opportunities to learn and develop new relationships and experiences, but those community members without disabilities do not have the opportunity to interact and learn more about individuals with IDD.

Living in the same community as Nicki's family, Patty's (A12) parents, Rick (P13) and Beth (P1), also believe that residents have very little exposure to people with

disabilities, and no exposure to anyone like Patty. As a result, people do not have experience interacting with someone such as Patty. When I asked for clarification about this exoteric factor regarding how they viewed the people in the community and their views on people with disabilities, Beth says, “they don’t know how to be patient and they just don’t have the experience and I don’t mean that they don’t want to, some don’t, but they just don’t understand that this is unique and you have to treat her a little bit differently, be more patient.” Rick remarks that community members, referring to those without connections to people with disabilities, think that everyone with a disability is the same, and this results in the belief that people with disabilities belong in the same group. He adds that “everybody thinks, ‘well, yeah, you got a kid with a disability, just get another kid with a disability, relationship, everybody’s happy’” (P13:7/13).

When talking about others outside the OHSO group, Rick sometimes conflated the groups of the school, community, and society as a whole and this was possibly because he views the school as a microcosm of society. He spoke in frustration about the emphasis the school places on rewarding service hours and giving back to the community, but feels that much of this is empty and more focused on the end result of getting into a good university rather than actually contributing to those who are in need and local. He tells the story about Patty’s high school graduation ceremony when she was crying on stage but none of her classmates acknowledged she was upset or tried to comfort her in any way. To him, this was an insulting example of the hypocrisy where people tout the importance and value of service hours and the merits of the National Honor Society but do not help the person in need next to them. Regarding Patty and how

she does not fit in, he believes much of her value is determined by her ability to be productive, “which is what society wants, they want productivity, they don’t want a liability. But you know, I think about giving these talks to the school, I fantasize about this [laughs] and I think, well, you know, in the wild, abandoned hyenas, with somebody like Patty, would attack it and kill it. That’s what you’re doing. You’re not killing it, you’re just ignoring it and hoping it goes away. Or dies on its own. It’s the same thing, you know. And you call yourself human beings and Christians? Bullshit.” In this example, Patty’s parents viewed the school, the students, the community, and society as the outside group, and they also consider some of those within their extended family as outsiders because of they lack the ability or willingness to see Patty for all of her capabilities. Beth and Rick spoke of their frustration that people do not recognize Patty’s above average perceptive and social intelligence and that no one seems to give her a chance. Rick says that it takes time to learn these things about Patty and that he even has to press his sister to have a relationship with Patty. Beth states that this is the case with her husband’s entire family, which is surprising because Rick has a cousin with “special needs,” but that “it’s almost like they’re afraid of Patty-not that they would catch it-but it’s like the unknown” (P1:7/13). Rick adds, “they don’t have the time to understand,” to which Beth posits, “they should know, but I guess it’s just too close to home, you know.”

Maddie’s (A8) parents, Cathy (P3) and Robert (P14), live in the same neighborhood as both Nicki (A10) and Patty’s (A12) families. Cathy and Robert feel comfortable and familiar with many people in their neighborhood and relatively close-knit community, but worry that it has also given them a false sense of security. The

community might seem safer than other larger, more urban areas, where there is not the same type of familiarity or frequent interaction, but her potential to meet the expectations of an adult are often undermined because she is viewed as youthful and innocent. Her parents speak of how her height, gender, and young looks have been cited as some of the qualities that make it more difficult for her to be employed, independent, and more included in the community. Characteristics such as her short stature and youthful appearance make her appear seem younger than her 28 years and this concerns her parents. Considering Maddie's trusting demeanor, her parents worry she will be taken advantage of, so they are extremely concerned with her safety:

C: I just think their vulnerability-and it doesn't even matter if it's inclusion, it's just the thought of them living independently with caregivers who may be marginal, you know, it's just they're vulnerable. You always worry. Are they going to be taken care of? Are they going to be okay? There are so many people out there that take advantage of them. Like I said, we come from a very small, close-knit community where she ended up becoming a very trusting person because she could. But then we started worrying about, you know-like she hugs everybody and that's typical of Down's but she really knows all these people.

Despite all of their efforts and years of training and interventions, Maddie was unable to be employed in the community and is now at a sheltered workshop. Her parents say that she is higher functioning than many of the older people there, but they seem optimistic that there appears to be younger people coming into the program. Cathy and Robert also acknowledge that although they are aware of the growing anti-pieciwork movement, Maddie really enjoys pieciwork and routine. When asked if they were concerned that Maddie might regress if she is not more challenged, her parents mention how potential characteristics and consequences of her disability have been presented to them.

C: Definitely we worry about it because with Down's, there's the possibility of Alzheimer's and that's kind of a scary thing that we don't like to think about. There are diminishing skills, diminishing capacity, as they age. It's certainly not a given, but it's one of those-when the kids are born, we did have a lot of advantages from the time that they were infants because Down's being so popular of the disabilities, we had booklets that they would publish. The DSA [Down Syndrome Association] was not the way it is today, but we did have a small association and a built-in support group from infancy on. And we would get these 17 pages of complications of everything that could happen with a kid with Down's. So you would just worry yourself to death. But that was one of the-of course, there's the heart problems and the respiratory problems were right there at infancy-but looming further down the road was the Alzheimer's. So we do worry that maybe at some point in time, her capacity will diminish.

They also speak about some of the struggles they faced with inclusion and the school system in terms of Maddie being categorized based on her disability and compared to previous students in the school system with Down Syndrome. Cathy acknowledges that there were "good" and "bad" teachers, but one of the issues seems to be that some of the teachers, who are responsible for making the assessments that hold a great deal of weight in determining future outcomes, base their assessments on stereotypes and past encounters:

C: They had another young lady [referred to as "Lisa"] with Down Syndrome who was at least 10 years, maybe 15, older than Maddie, whose personality was different-she was not as easygoing and as-she had a bit more of an edge to her, or Nathan, who was all boy. He was a mess like our son was a mess. I mean it was just boy. But they would compare them, like "remember Lisa was very, very stubborn" or that her mother was very, very aggressive or assertive and so they would come up with these preconceived notions of what a young girl with Down Syndrome was like and I'm going, 'No.'

R: All stereotypical

C: Yeah, it was very stereotypical of them to do those things. I used to sit in conventions with teachers because even though we were a social work union, a union of social workers primarily, we were part of the AFT [American Federation of Teachers], and I remember sitting in meetings with them and they were talking about inclusion and it was like-they were so, so-it was supposed to be an inclusion conference but they were anti-inclusion and it's just like you're listening to them talk about 'I don't want some kid with Down Syndrome sitting in the back of my class, coloring, while I'm trying to teach' whatever. It was just-even the high school staff over here-because I would sit in because I was a member of [a Special Education Resources Center] the parent advisory thing, and I would sit in on some of these staff [?] and they wouldn't necessarily know that I was there. And it's just like, oh my god, you just don't know how dumb people are. I sat next to a teacher at one who asked me about my Mongoloid child. And I'm going like, 'What century were you born in?'

These parents' narratives highlight the exoteric categorizations of those outside their kinship group, those who do not know how to interact with people with disabilities.

Based on their experiences, it is understandable that they find the OHSO group to be a source of connection, information sharing, and support for themselves as well as an opportunity for social engagements and lasting contacts within their kinship group.

Support professionals, teachers, mainstream peers, and even family members can reject the individuals with disabilities by not recognizing their full personhood and humanity, so I would argue that the security and kinship provided by OHSO is something that many do not find elsewhere and eliminating the Special Olympics would be a misguided attempt at decreasing stigmatization.

My argument is based on observation of how the athletes acquired skills in Special Olympics that would be helpful to participate in the community as fully as possible. I explored the athletes' understanding of not only their disabilities but also their perception of membership in OHSO. The majority spoke of it as being a place where they

met and saw their friends. None of the athletes said anything negative about the Special Olympics; in fact, when I asked Matt, “Is there anything you don’t like about Special Olympics?” he answered, “No, the people there are my family.” This sentiment was echoed by many of the parents who cited OHSO as being like a family, where they received support, and also found valuable information regarding jobs, services, and resources that they were unable to access through other venues (even from service professionals who were responsible for providing this type of information). While OHSO is an exclusive and segregated group based on disability, it also offers a sense of Rapp and Ginsberg’s (2001) kinship model that might not be possible with integrated groups because this type of kinship is predicated on the shared experience of disability.

Although the athletes remained consistently positive in their remarks about OHSO, some of the parents criticized Special Olympics for not providing significant physical challenges, but these criticisms were outweighed by the positive aspects of kinship and belonging OHSO provided. One of the only criticisms of OHSO that arose from my research related to expectations and competition. Based on the premise that the Special Olympics is about improving one’s physical fitness and challenging one to push one’s limits through competition, some parents felt that there was not enough emphasis placed on vigorous exercise and that competitive standards were set too low for people to truly improve their skills and increase their personal best.

One couple also admitted that although they had reservations about enrolling their daughter in OHSO because of the stereotypes and stigmatization associated with the Special Olympics, they discovered it had unexpected benefits in addition to regular

exercise: social events to put on a social calendar and the ability to belong to a group of peers without an age limit, because although their daughter had been part of a mainstream team in high school, she had not developed any significant or lasting friendships with her mainstream peers. Nicki's father said that because of all the involvement of the group members, OHSO gives his daughter "the opportunity to succeed in whatever small ways that are provided...I think that's been an eye-opener—pre-conceptions that I brought to it, the hopes I had for my child after all, that this is a good thing for Nicki."

Patty's (A12) parents, Rick (P13) and Beth (P1), mentioned sharing information with other parents as one of the positive aspects of OHSO involvement, but they were also surprised to find that some of the other parents were under-informed about the special education system and their child's rights. Specifically, they felt that the school district was taking advantage of this lack of knowledge and not providing better services for those with disabilities. They also described difficulties with logistics such as transportation, and achieving a balance of the activities with their work schedules and long workdays. This makes it difficult for them to get Patty to as many activities as she might like. Social opportunities for Patty were also seen as a benefit to OHSO participation, but they said that it was difficult for her to make friends on the team because so many of the athletes differ in their levels of ability and social skill. These barriers can make it difficult for people with disabilities to connect on the same level and find things that they have in common.

Matt's (A9) mother, Evelyn (P6), speaks very highly of the OHSO team and says it is wonderful because it "gives persons with differing abilities the chance to participate

in sports as well as socialize with friends” (P6:7/13). She is well aware of the argument that the Special Olympics promotes segregation and does not create diversity, but to her it seems that it is not a very realistic argument because she feels that there are not many opportunities for inclusion unless someone is a particularly-gifted athlete. Matt was able to participate in integrated sports, such as soccer and tee-ball, from kindergarten until third grade but was then phased out of those teams at the same time he began participating in OHSO. She views this as a positive transition for him since it allowed him to compete at a more “even level” and also enabled him to develop more friendships that have continued after high school.

Laura (P9), Chris’s (A2) mother, also talks about the importance of the Special Olympics as a community where Chris is able to make friends. According to Laura, Chris is very social and needs to be around other people:

Whether they are his friends, like through Special Olympics, because that’s a really nice community and it gives them friendships and independence and achievements that they normally would never have had. It gives them a community and a social outlet that they’re kind of all on the same – they’ve all got something that they’re struggling with that makes them different – of course we all do, but it’s just that community where they’re really accepted unconditionally and it’s so cool (P9:7/13).

In addition to the sense of continuity and social stability the OHSO has provided Chris through his friendships, it has also been a source of information sharing and support between the parents. Laura says the transition process has been very difficult for Chris in terms of finding employment and that although she knows the teachers have tried to find out what works best for Chris and interests him the most and giving him chances to try different things, he has not had enough intensive training in one job to make him able to

be competitively employed. She learned from other OHSO parents that this was a similar occurrence they were experiencing and Laura mentioned the possibility of hiring a job coach and paying out of pocket for the services until Chris has more training and experience to be more competitively employable. Had she not heard this approach from another parent, it is not clear whether that would have been something they could have considered as a possible option to increase Chris's employability.

In Cathy's (P3) view, OHSO gives her daughter Maddie a sense of continuity and friendship at a deeper level than she had experienced in high school:

The best thing I think was the camaraderie, having true friends, because she always had-the kids at [the high school] were always really nice to her. They were sociable but they weren't-they were not going to hang out with her in high school. I mean, when they were little, it was fine, but they were still kind of more caregivers than friends. But they were always sweet to her. And she felt really close to all of those people, so I think the biggest thing for us is that since high school has ended and since she's not around these people, she now has her own friends. And friends who are going to be lifelong friends (P3:5/13).

Having a social network for both the parents and their children is something that neither Cathy nor Robert expected, but it has turned out to be the most important outcome from participating on this OHSO team. Cathy says that over the years, they have met many people from different socio-economic backgrounds through the Down Syndrome Association, Challenger baseball, and the Special Olympics, and she although does not know why, she feels like parents of children with disabilities are the nicest people in the world:

There's just—it seems like the people who get the kids with disabilities have the hearts—and I don't know if we just had the hearts to begin with or we just developed them because we had them—really really nice people, supportive people, very independent and resourceful. Just people who can

deal with a lot and still have a great attitude, no matter what hand they've been dealt, kind of just really high quality people (P3:5/13).

Both Cathy and Robert have been involved in social work for years; they have had experience as both parents and service professionals in the field of social services. Cathy explains that they have met good people but that many of the problems in the field of developmental disabilities relate to bureaucracy and a lack of coordination and information sharing among the service professionals and families. For Cathy and Robert, the parents have been the ones they have gone to for support, help, to learn about resources, and are the ones upon whom they can rely. Cathy explains:

You can find a nice service coordinator, but for the most part, they have no idea—they're in their own little world and they have no idea what's happening out in other parts of the community that are providing similar services. Most often you'll be telling them things about things they don't even know anything about. So that's always been very frustrating for us because we're thinking like—I remember when she was in infant stim [stimulation] and it's like—we're going, 'My god, we know the system, we know the resources and we're struggling and what about all these people who aren't as well off as we are in terms of education and background and stability and financial resources and whatever? How the heck do they even negotiate this and how do they get the services that they need to get when you're the one telling the providers what might be out there?'

In this comment, Cathy is referring to the resources she has identified and used for her daughter and pointing out that even with all of her resources and social capital, she has been frustrated in her efforts to find inclusive employment opportunities for her daughter. She is absolutely correct that the system is difficult to negotiate and that people with fewer resources (both she and her husband are social workers) would have difficulty navigating the system. In contrast to the obstacles families face in obtaining resources in the community—whether for employment, transportation, or health related benefits—

Special Olympics is intended to be easily accessible for everyone. Additionally, she is highlighting the importance and ability of the OHSO group, as opposed to the bureaucratic system designed to assist those with disabilities and their families, to provide the network of support, information sharing, and friendship so critical to those trying to navigate the labyrinth of disability services.

According to Cathy, if your child is diagnosed before they reach the school age, there is a fear about the transition and how to find support, but that you find support within the groups where you share experiences during the various stimulation and intervention programs. Once your child enters the school system, there is support through the school for the next thirteen years or so. However, the transition out of high school is another intimidating milestone because the next steps and the available support systems are uncertain. Because this is one of the most significant areas of difficulties facing the families, I explore it in greater detail in Chapter Seven, particularly as it relates to post-high school employment and [lack of] opportunities.

The esoteric factor (what a group thinks of itself and what it supposes others think of it) in OHSO is fostered through events, rituals, and kinship. The esoteric factor is one way a group defines, strengthens, and defends itself. Looking outwards from within the group, the exoteric A (what one group thinks of another) aspect can also contribute to a sense of belonging, “for it may result from fear of, mystification about, or resentment of the group to which one does not belong.” (Jansen 1957, 207). I thought that I would encounter exoteric folklore about other groups from the OHSO, perhaps in the forms of stereotypes, rumors, slang, nicknames, or jokes about those who are outside of OHSO.

Who would be groups outside of OHSO that might be significant to the OHSO athletes? Were there any groups that were a source of tension, conflict, or competition with OHSO? I incorrectly hypothesized that some of the athletes would feel a sense of separation, possible resentment, or admiration, from groups or teams from which they were excluded based on their disabilities. Since many of the athletes I spoke with did not categorize themselves as different from other people or those without disabilities, there was not a clear distinction between “us” and “them.” There were repetitions of sayings that could be interpreted as the start of trash-talking about an opposing team during a competition, but it seemed to be imitative and a performance of what a sports team is supposed to do to psyche out the opposing team. These instances were rare and quickly corrected by the coaches because those behaviors would be considered poor sportsmanship.

I did encounter exoteric A and B folklore about the Special Olympics from both the perspectives of the OHSO parents and caregivers and from those who were not members of the Special Olympics (but still held strong beliefs and opinions about what the Special Olympics signifies). There is no lack of exoteric folklore about the Special Olympics from those outside of the Special Olympics. The stigmatization of the Special Olympics that Storey and some parents refer to coincides with Jansen’s claim that the more distinctive or distinguishable a group, the more likely the occurrence of exoteric folklore about that group. The Special Olympics can be the butt of jokes, some of which I prefer not to repeat because they are hurtful, but a very public joke was made President Barack Obama appeared on the Tonight Show with Jay Leno in 2009 and referred to his

bowling skills as being “like the Special Olympics” (Storey 2008, 134). Even when it is portrayed in a more seemingly positive light, such as the Oakland Tribune headline declaring “Special Olympics’ Athletes Win Smiles: Races belong to not-so-swift, not-so-strong” (135), Storey would likely argue that it could never have value because it is always tinged with stigma. Even when the narrative is meant to be inspirational, it is still patronizing and does little to promote inclusion.

I looked for patterns indicating how people in OHSO conceived of outside groups but ran into complications concerning who constitutes the other. None of the athletes I interviewed framed group membership using an “us vs. them” mentality, which could indicate that the majority of those I interviewed did not differentiate various group identities or that they did not regard outsiders as antagonistic to them. Two of the athletes I interviewed participated on some of their high school’s mainstream sports teams in addition to the Special Olympics, but did not claim a preference for one team over the other. When I asked Nicki what was different about her high school’s swimming team versus the OHSO swimming team, she said that the high school team worked on different strokes than the OHSO team and that the OHSO team did not practice the butterfly stroke because it was too hard and she could not do it. For Tori, who was a member of her high school’s track and cross country teams, it is unclear what social significance these experiences had for her. One of Storey’s (2008) arguments is that segregated recreational activities inhibit friendships and meaningful social relationships between people with and without disabilities, but does inclusion and integration lead to greater possibilities for friendships? From what I observed with both Tori and Nicki, some of the mainstream

students were more friendly and said hello to each of them, and while I do not want to minimize the effect this had on Tori and Nicki as well as their mainstream peers, it would be unrealistic to claim that these experiences led to equally reciprocated friendships. Nicki's mother had hoped the few friendships she had made would extend beyond high school but saw that once Nicki's peers went on to college, the contact between the peers diminished. Tori's mother said that some of Tori's teammates invited her over for sleepovers and one girl from her high school wrote a prize-winning essay about her experience running with Tori, but Tori did not seek out friends on either team and although she does continue to participate in social activities that her parents arrange for her, these are not things she would pursue on her own.

Although both Nicki and Tori competed in mainstream and Special Olympics events and it would be interesting to learn their perspectives on the experiences, both have a form of autism spectrum disorder that alters their expressive language abilities. Nicki does not articulate the reasons or preferences for group membership for the sake of being a member of a group, but she participates in rituals, traditions, wears the appropriate uniforms, and will say that she is a part of certain groups. Tori does not differentiate between us versus them because her understanding of self and other is not typical (i.e., she often views Facebook posts on other people's walls as being directed towards her, has a difficult time understanding that people on television are not speaking directly to her, and also has concerns that if she talks about someone or discusses something that is meant to be private, that person or her neighbors might overhear). For Tori, everyone belongs to "us."

Regarding the esoteric and exoteric factor as relating to one group being antagonistic to the other, this is not a value that is reinforced by the coaches. Although the Special Olympics does involve competition, the OHSO coaches do not motivate by emphasizing their athletes' superiority in comparison to other teams; rather, the coaches consistently teach the importance of teamwork and striving to reach one's personal best. If anything, OHSO is one place where there is a wide range of acceptance of difference and this falls under the imposed norm of good sportsmanship. Trash talking and showboating are swiftly corrected by the coaches and reinforced by limiting an athlete's participation if they continue to violate the norms. Interestingly, sometimes the athletes are not competitive enough and risk being disqualified by running in the wrong direction in a track event or touching someone to help them go faster. In spite of OHSO placing more value on the social aspect, how to be a good sport, and how to be a part of the team rather than on winning (which has been criticized by some parents), there are some instances where the rules of competition take precedence and it is noteworthy to observe how the athletes align themselves with what matters most to them at the time. An example of this type of disjuncture in which competition and good sportsmanship were in conflict occurred at a track practice when the athletes were running the 100-meter dash. One participant, Janet, was heading towards the finish line, far ahead of her teammates, but before crossing the line she turned around and noticed one of her teammates was walking in last place. Janet stopped, ran back towards the girl, grabbed her hand, and they both ran forward together. When confronted by a volunteer who informed them that they would not be able to do that during a real competition because they would get

disqualified, Janet shrugged her shoulders and the two girls linked arms and walked away. In this example, although the norms and rules prioritized competition, winning, and individuality, Janet rejected those values in exchange for reaching out to someone as a friend and creating a social bond that was more important at that moment than being the first to cross the finish line.

Exploring the values associated with the Special Olympics provides insight into how OHSO functions as a folk group that provides opportunities for learning social skills potentially translatable beyond recreational sports into places where the majority of people do not have IDD and/or are not as accepting of difference. Although the majority of athletes with whom I spoke did not place a significant amount of distinction between insider and outsider group membership, the parents were highly attuned to those who they viewed as outsiders, and sometimes adversarial, groups such as the school system, service professionals, doctors and medical professionals, and the community (particularly those unfamiliar with people with intellectual and developmental disabilities). This was reinforced through my observations of transition (high school to adulthood) meetings and Individual Education Program (IEP) meetings where parents and individuals with IDD were warned by the school administrators of the standards held by the “real world” and informed of the ways in which the child deviated from the norms upheld by “typical peers.” Sometimes this meant that in the real world, things move at a faster pace and those who do not keep up lose their job. In the real world, employers and employees change and just because one boss is accepting of people with disabilities, it does not mean the next boss will be. And in the real world, typical peers are self-sufficient and

independently motivated to complete tasks (even the ones they find disagreeable) to the satisfaction of their employers. For those who require more processing time due to cognitive impairments, more maturity that comes from time and experience, or more opportunities to discover what motivates them and how to advocate for themselves, this abstract construction of the real world makes inclusion and acceptance even more difficult to obtain.

The esoteric/exoteric model provides a good starting point for understanding a stigmatized folk group such as OHSO. However, it leaves open some of the central contradictions that sustain the group, especially the idea that many athletes, parents, and Storey (2008) would agree with: that involvement with the Special Olympics negatively stereotypes people with disabilities at the same time the parents and athletes have created sustaining kinship networks around the experiences resulting from being stigmatized. The folk group is central to their lives and to their daily efforts to combat the stigma of disability. Storey, and others, would also argue that the Special Olympics does not represent the real world. The parents and some of the athletes agree that those leading OHSO sometimes prioritize the development of social skills rather than competition, but the “real world” of competition is itself an artifice, and the parents and many of the athletes know that they would never be able to “really” compete. Instead, having social skills can occasionally open otherwise closed doors. While more opportunities for integration and inclusion need to be provided to help combat the negative effects of stigmatization and segregation and promote greater opportunities for understanding and acceptance between those with and without IDD, the experiences of OHSO participants

and their parents suggest that it would be a mistake to disband all segregated recreational activities without first learning more about the benefits group membership provides to those who find kinship through the shared experiences of disability and stigma. Although it is an over-simplification to reduce the controversy about inclusion and Special Olympics to a question of whether Special Olympics offers the kind of competition found in other sports. As I discuss in the next chapter, an in-depth ethnography of how competition works in Special Olympics reveals it to be complex and nuanced.

Chapter Five

Competition: How Expectations of Performance Shape Identities

In his work on Canadian sports and national identity, folklorist Michael Robidoux cites Pierre Bourdieu's assertion that the "modern definition of sport is an integral part of a 'moral ideal,' that is, an ethos which is that of the dominant fractions of the dominant class" (Robidoux 2002, 211). In Victorian Great Britain, this ethos was evident through football's transformation from a vernacular sporting activity involving violence and brutishness into a middle-upper class activity that was taught to young men because, as Bourdieu explains, it was "conceived as a training in courage and manliness, 'forming the character' and inculcating the 'will to win' which is the mark of the true leader, but a will to win within the rules" (Robidoux 2001, 36). In Canada, hockey provided a venue for Canadians to embody a masculine and national ideal, reflecting "qualities that have been valued in patriarchal relations: stoicism, courage, perseverance, and proficiency" (2002, 222). Building on Robidoux's notion that sport reflects national identity, if hockey symbolizes more than the need to define a national identity by offering "insight into the actual imaginings of what this identity entails" and providing "Canada a means by which to be distinguished," what are the discourses creating the identity of the Special Olympics and its athletes? (222). How are the values of the dominant classes, predominantly those without disabilities, projected onto those with IDD and responsible for shaping an identity through recreational sporting activities? In this chapter, I will be exploring questions like these as well as how Special Olympics differs from other sports activities, if this difference is a contributing factor to why the Special Olympics is considered stigmatizing by promoting a different standard of competition that undermines inclusion

in the community, and how competition intersects with other dimensions of sports activity. These dimensions include the following: (a) competition and discourses of safety; (b) competition and good sportsmanship; (c) competition and the related achievement of “personal best”; and (d) the larger category of expectations that crosses these dimensions. I argue that there is an underlying connection between the expectations placed upon people with IDD that is based on values determined by a capitalist economy, one that values competitive labor and the ability to be productive in order to be an esteemed member of society, and the criticisms of the expectations and values promoted through the Special Olympics, where competition among people with different competencies is less important than building self-esteem, social networking opportunities, and coping with winning and losing. The Special Olympics is also a unique arena where tensions between the ethos of acceptance and the celebration of individual differences meet strict requirements for normative, or what might be called socially appropriate, behavior.

By virtue of its name, the Special Olympics is associated with the internationally-recognized Olympics that features competitive events from the best players from around the world, but I am interested in how the culture surrounding the Special Olympics makes it “special.” Professor of Special Education, Keith Storey, criticizes the Special Olympics because in the Special Olympics, “there is a lack of skill acquisition, and much precious teaching time of functional activities is lost” (2008, 136). This concern centers on the valuing of function over form and links to the idea of preparing people with IDD to be included in the greater community at large. Storey defines functional curricula as

“teaching skills that have direct and immediate utility in persons’ lives within their communities and contribute directly to the attainment of greater independence, self-sufficiency, and quality of life,” whereas form refers to the specific motor act (as opposed to function, which focuses on the outcome that the activity achieves) (135–36). He gives the example of teaching someone to pass a basketball but that person not being able to pass a ball quickly and accurately to teammates during a game, which is a case where the form does not necessarily result in a functional outcome (136). By focusing on the functional application of handling a ball in a team-oriented sport, Storey misses the other skills (coordination, socialization, sportsmanship, etc.) that could also be learned from recreational activities. This is a complicated issue that requires further examination to understand the values that are applied to the expectations, approaches, or techniques, and interpreted significance of the outcomes on an individual and team level.

Safety

The discourse of the Special Olympics puts safety first, which is apparent in the sporting options available to Special Olympics athletes. Whereas the International Olympics features boxing, rugby, ice hockey, and wrestling, the Special Olympics either omits these contact sports or has surrogates such as floor hockey and modified judo. While it could be argued that allowing judo, football, basketball, and floor hockey in the Special Olympics could be potentially dangerous because of the potential for aggression, direct contact, and violence, the discourses of safety and sportsmanship are inextricably intertwined and control is exerted from the coaches and caregivers to manage these

interactions and the expectations are that the athletes will be compliant. I believe there is an underlying reason that is an additional, but unspoken or unrecognized reason why certain sports and behaviors are allowed and others are not. In his article, “Sport and Social Class,” Pierre Bourdieu discusses how sport became a specific practice, “endowed with its own specific rewards and its own rules, where a whole specific competence or culture is generated and invested,” and a means through which a supply is intended to meet a social demand (1978, 820-822). The Special Olympics maintains the traditional emphasis on good sportsmanship that was established through the International Olympics Committee, but I believe that the culture of the Special Olympics is not only about providing physical activities and opportunities to build self-esteem and friendships—it is critical to the sustainability and success of the Special Olympics to maintain as level of a playing field for competition as possible and that potential sites for aggression and violence are deterred and/or carefully controlled.

Some of the athletes lack the motor skills, hand-eye coordination, and physical stamina to move safely and quickly out of the way of oncoming athletes and balls. One of the coaches who coaches basketball and track said, “We’re very much safety first. The most important thing in any game is that everybody walks off the field. Nobody goes to the hospital; nobody gets cut up.” In order to facilitate this emphasis on safety, the coaches have divided certain sports where there is a fast-moving ball (soccer, softball, and basketball) and a potential for getting hurt into different teams—one being the regular team where the ball moves between athletes at a more traditional pace and another that focuses strictly on skills.

Basketball is divided into groups based on age and ability, with a school-age team consisting of athletes twenty-one and under and those twenty-two and over playing on the adult teams, which are also separated into divisions based on the athletic abilities and skills of the team members. All teams are co-ed, although male and female athletes are separated in track relays in order to comply with the organization of Special Olympics track meets. Because of size differences, however, some athletes are more prone to injury even though they might have adequate skills. Pete (C2), who coaches basketball, gave an example of a female basketball player who was very skilled, aggressive, and faster than anyone else on the court, but she kept getting run over by other players because “some of these guys are so big, their coordination does not stop on a dime, they’d stop on a nickel. They’d take three extra steps and run her over. She’d be all bruised up. She eventually stopped playing. We even tried putting her in different positions. I tried telling her to not get so close, but she knows how to play and she’s just very aggressive. She was a really good athlete.” The OHSO basketball coach has now started a second adult basketball team that is divided by skill level. He admits that some of the parents and athletes might not be pleased with these divisions because it might break up teams that were made up of close friends, but that safety is paramount.

As certain athletes’ abilities and skill levels improve, the team can be moved to a higher division in order for the competition to be more equal. The coach explains that there is an obvious skill change with each basketball division level. In Division 1 basketball, there are athletes who have no physical limitations and are able to run and dunk the ball with two hands. One of the OHSO athletes is in Division 4 because he is six

foot four and can rebound and dunk, but he is not able to shoot the ball well. Currently, the OHSO basketball team competes at a Division 5 level, but some of the athletes' skills and abilities are improving and the coach feels that the OHSO team will soon be bumped up to Division 4 because they will have around five athletes who can play basketball very well—whereas Division 5 teams only have, at most, two or three athletes who have high skill levels and the play is usually slower and less aggressive than the upper divisions. Coach Pete emphasizes the importance of enabling athletes with different abilities to have more success and enjoyment on the team than he and a group of four or five other people decide to place the athletes. He adds that these divisions are not necessarily permanent and that although for some, height might always be an issue preventing them from excelling against bigger opponents and possibly warranting increased safety concerns, he believes that if someone improves, they will have the opportunity to move up to the next level.

Like basketball, soccer can also be dangerous because of athletes having different sizes and abilities. The coach says that some of the men that play soccer on the opposing teams are 40 years old and very big and fast. The OHSO team might also have older athletes who may not be as big or fast. He has witnessed athletes being run over and struck in the face with the ball on multiple occasions. It is not just the physical aspect of uneven abilities that concerns him, but also the mental toll that it can take on the players because, as he said, "If you're scared, you're going to get hurt." The softball coach has a similar approach to safety and is careful to ensure that his players can protect themselves with a glove—if they cannot protect themselves, they are separated into a softball skills

team that does not actually compete against other teams. Pete says that in both sports, a ball comes at an athlete very hard and fast and if a player goes out in the field in a constant mode of protection, then they are placed on a skills team where the emphasis is more on having fun, learning to play, and not being afraid rather than on competition. Pete adamantly asserts that learning never ends and there are always possibilities to increase each individual's skill level:

At some point in time for every person, you can learn. Maybe the light just goes on at a different time for everyone. You can see footwork changes in defense in basketball. Maybe at one practice you can say 'Try this with your feet' and, all of a sudden, it's working... I don't want to ever think that they can never play on the team because they're learning skills, we just have to find a way to increase the skill level and that's a learned thing. And I don't ever want to think that a ceiling is reached.

Belief in the possibility for growth and learning is highly valued by many of the families and is likely one of the reasons Coach Pete is held in high esteem by players and families alike—particularly when much of the discourse in meetings throughout school and transition is that someone has reached a plateau, often resulting in services being removed or directed elsewhere but can be interpreted as service professionals giving up on a person with disabilities.

Sportsmanship

While the coach emphasizes the importance of leveling the playing field in terms of matching athletes' skills and physical abilities to peers with similar skills and abilities in order to ensure their safety and enjoyment, he makes it clear that the value of good sportsmanship was paramount to his teaching style and the ethos of the OHSO team. Not

having certain skills and abilities are not barriers to having the opportunity to experience some element of a sport if an athlete wanted to try, but displaying poor sportsmanship is a significant offense that can, and does, result in athletes being prohibited from playing on the team. Pete has said on multiple occasions that the Special Olympics is more about the social skills and values it provides rather than competition, and teaching good sportsmanship is a vital component to promoting positive social skills and fostering healthy relationships.

Although socialization is important to many, so is winning, and it is the coach's job to teach his players to learn how to lose for multiple reasons. First, Pete believes working your way back from losing to winning makes winning more special, although he adds, "it still can't be the only possible outcome." When two teams go on the field, one wins and one loses," and Pete states, "Through losing, you learn how to win and how to handle winning." This appreciation for both outcomes can be applied to the value the OHSO team places on a solidarity and the value of friendships that go beyond the sporting events and practices. As Gary Alan Fine discovered in his ethnographic work with two different Little League teams, "life on the team provided different models that the players could use in other groups and in their understandings of how social life should transpire" (Fine 2012, 38). For individuals with IDD who face stigmatization and discrimination and who might not have the abilities to be the best at a skill or job when compared to those without disabilities, this ability to understand how to lose graciously and not be a poor sport is a lesson that has salience because it emphasizes the value that comes from striving to achieve one's personal best.

Teaching the values of good sportsmanship while promoting a healthy competitive attitude is not an easy task. According to Pete, there is a wide range of competitive attitudes among the athletes with some who are more into the social aspect and being a part of the team by wearing the uniforms and others who want to win so badly that they become frustrated by teammates with less skills and abilities. I would add that there are others on the team with even less outright interest in the social aspect, but are perhaps motivated by the desire to follow a routine, meet the expectations of their caregivers, or who are encouraged to participate for the physical exercise aspect in exchange for some type of reward provided by their caregivers after the completion of the activity. In order to accommodate the varying attitudes and abilities, Pete must tailor the teams to their abilities and the situation. Pete recounts a time when a track athlete was upset because one of the people on her relay team was not as fast as she was, so she did not want to run with her. Pete responded by emphasizing how good of friends they were and told her, "Let's not worry about winning but about making our teammates happy and our friends happy, and find happiness in not always winning." Understanding winning and placement can become even more complicated at track competitions because athletes who win are placed in increasingly competitive groups, which can be confusing to some athletes who see their slower teammates winning higher medals. Track and swimming are two events in which a personal time is recorded, so in these cases the coaches will focus more on individual times and personal best rather than medals and ribbons. Additionally, to avoid potential conflicts, Pete generally tries to put athletes that are more competitive

together in situations where a team effort is required, such as a relay or tournament situation.

In tournament games, Pete tells the parents in advance that the team is going to try and win and he will try to play everyone, but he will not promise that everyone will play that game, and if they have an issue with that, to let him know and they will try to work something out so everyone is satisfied. Tournaments are unique because they are about winning, whereas in previous games, Pete deemphasizes winning and focuses instead on working hard and improving. Rather than focusing on the final outcome as one categorized by winning or losing, Pete explains that he emphasizes specific elements in the play that need improvement, such as ball handling or defense, and if they improve in those areas he will say, “We didn’t win, but here’s what we did well, here’s what we didn’t do well, so when we go to practice next time, here’s what we’re going to work on.” He admits that it is not always successful, but that this is his style and that this approach is especially helpful when it comes from athletes because they are friends and peer-to-peer teaching can be received better at times than from coach-to-athlete. He also says that although some athletes are satisfied with receiving ribbons, which are usually awarded to those who come in 4th or 5th place, not everyone is happy with these outcomes and become unhappy if they do not get a gold medal. For one athlete, according to Coach Pete, “It doesn’t matter that second place is very good. He didn’t get first place and the medal is not gold, so mom and I are handling that one... [He’s] really good at basketball, a really fast runner. He has learned that winning is phenomenal and not winning is not. And we’re working with him now that coming in second, coming in third, all coming in

for it is okay.” Pete speaks of another athlete in her thirties who becomes very upset if she does not win a medal in tournaments because “she likes medals better than ribbons.” Pete also emphasizes the importance of being a good sport after a game demonstrated through the ritual of everyone shaking hands after the game. In fact, Pete says that if an athlete will not shake afterwards, he will not let them play in the next game. Although some of the athletes are still visibly upset and might look away, they still have to at least tap the opponents’ hands. As he explains, “If you lose, you have to reward the other team. Just because they played better that day doesn’t make them a better team—it just makes them better that day.”

I observed athletes giving each other support both on and off the field. In one instance I noticed two OHSO track athletes taking aside another and giving him a pep talk while they practiced how they were going to pass the baton in the relay. Pete had commented that sometimes words of support have a greater influence from peers rather than coaches, so I was curious whether any of the teams designated captains. “No, we tried that,” Pete answered. “For the kid that is the captain, it’s wonderful, but for the other eleven who are not the captain, it’s not wonderful. So we stopped that immediately.” He said that this had happened around fifteen years prior and that it was stopped before the season continued because the captain felt in charge but did not understand the nuances that, as Pete explained, “The captain rallies the troops, not bosses them.” In addition to not having team captains, OHSO does not name Most Valuable Players (MVP), but it does have a special award that is given to one athlete each year. At the annual sports banquet, an award that is named after a Special Olympics athlete who was on the team

but passed away is bestowed upon the athlete who has overcome significant hardships (often medical or personal difficulties, like a death in the family) during that year.

Even though OHSO does not have team captains in order to foster an environment that strengthens the team as a whole while recognizing and appreciating each individual's unique skills and talents, Coach Nick (C1) said that it can be difficult for the players to understand their roles and how they should perform their own personal best while also taking into account another's needs and limitations. He gave the example of Gary, an adult athlete who has had difficulties at times with the fluctuation of expectations in performance because on one level, Gary understands that he is at a higher tier than some of his teammates and will sometimes clear a path for someone else to have an opportunity but then gets upset if the referee calls him for travelling while they did not call another athlete for the same offense. Nick said that when an action or slight ignoring of a rule benefits someone else, Gary can be okay with it, but when it negatively affects him, he takes it personally and gets upset. This type of elasticity when it comes to the enforcing of certain rules is not a general occurrence, but is possibly related to the few referees that have presided over non-tournament basketball games. Nick said that the referees "get it" and gave the following example:

They [the referees] see a kid come in from the game and the first time he touches the ball, it kind of falls out of his hands, and the next time he makes a pass, it just goes straight out of bounds, and then he starts dribbling, then he stops and he dribbles again—which you can't do—and then he takes five steps... They're [the referees] kind of like okay, you know, they're letting it slide. I think that's fine. You know, fair is not always equal. And there's a lot people that—adults, children, people without, people with special needs, that don't get that and have a hard time understanding that.

Although Keith Storey does not specifically address the Special Olympics having its own culture around rules, he may object to this type of elasticity in the application of rules because it promotes negative stereotypes based on pity or sympathy and that this further separates the gap between the “normal” and the “disabled” (Storey 2008, 135, 139).

In high school and college sports, the rules are intended to be rigid in order to maintain consistent standards of play, but these types of teams and leagues prioritize competition rather than kindness for the weak. Can the Special Olympics athletes understand these fluctuations in the expectations of play and the different standards based on players’ abilities and settings? Perhaps some can, but while I do not have research supporting the extent to which this is the case, I do think it raises an interesting question about the underlying lessons being taught to Special Olympics athletes that runs counter to typical sports competitions. Nick believes it is situational to the game, but said that when it comes to the playoffs or tournaments, these things do not occur and the referees call everything as it is. This lack of, or perhaps adherence to, consistency can also be a source of conflict and disappointment in certain event, such as a recent Special Olympics swim meet because, at this meet, doing your personal best was not enough to be rewarded. Nick explained that this event had around 250 swimmers, and he recalled that dozens were disqualified for not performing their strokes correctly. The State meet has around 500 participants and Swimmers must meet a certain qualifying time in their area meet in order to qualify. Nick conveyed his disappointment and confusion when he said:

But what I don’t get—what I would like to see, because it is Special Olympics—you see double dribbles and travels in basketball, you see that there are rules in place, but you also see people not always follow that rule to a T. Maybe they’re trying and they come real close, or some of the times

they follow it and other times they don't, there's inconsistencies in their performance, but we had a lot of people get disqualified... What I don't get is why can't they get their ribbon or their medal at the area meet for being there, doing it, doing well, doing their best, but then say, "Okay, but you can't go to State"? I get that.

Nick said that this was an all-day event and that he spoke with a parent as he was leaving who told Nick that they had been at the event for five hours, his daughter swam in one event, only to be disqualified and receive nothing for her efforts. Nick acknowledged, "there are some athletes that have [to] get a ribbon or medal and if they don't, they don't get it. And it's not that it's a bad life lesson that you don't always win something, but then again, this isn't the Olympics. I feel like, at a meet like that, she should've had that opportunity to get something for it." According to the Special Olympics website, all participants should receive an award or ribbon for participating, but I was unable to find anything on the site or in any of the rules about whether someone who was disqualified was able to receive a ribbon for participation or not.

The confusion and disappointment expressed by Nick and the parent reflect a dissonance in the expectations surrounding the goals of Special Olympics. When Nick said, "this isn't the Olympics," he was referring to the expectation that the standards of competition for Special Olympics athletes should not be the same as those for the traditional Olympics and that the Special Olympics is about enabling people with a wide range of disabilities to participate in activities to which they might not otherwise have access. While this might seem obvious, it still lends itself to a gray area that is further blurred when referees and players go outside of the norms of typical competitive sports, by either bending the rules and allowing violations to occur or giving an opponent an

advantage based on their perceived (dis) abilities or limitations. The difficulty arises in part because the players are given conflicting messages. On the one hand, a player is given the message that the goal is to achieve one's personal best—which could be interpreted as following the rules and striving to win—and being rewarded for participating. On the other hand, sometimes the goal is to recognize that other people have different abilities, which can include providing support to allow others to achieve their personal best. Learning to differentiate between striving to win and striving to be a good team player can be a difficult lesson to learn (whether or not an athlete has intellectual disabilities). The Special Olympics athletes can easily misconstrue the message, for example, when they expect that everyone will be rewarded for participating or when athletes are disqualified and do not receive any compensation or reward simply because a stroke was not performed correctly or they did not stay in their lane.

Perhaps the disjuncture results from the frame of the particular competition and the disappointments were caused by a miscommunication in standards and expectations, but it could also be related to a need for a subjectivity that is difficult to define and an awareness of self and others' disabilities that is difficult, if not impossible, for some of the athletes to possess. Nick suggested that “maybe referees, umpires, whomever, maybe they take into consideration the population and that's kind of what I feel like everybody should do is you should be aware of who you're interacting with and know that their circumstances are different, their perception is different, and you might have to adapt and adjust your way of thinking and acting to match that.” This hints at the heart of the issue in terms of society's expectations for those with IDD and how standards must be

individualized and flexible in order to accommodate different needs and abilities. The problem arises when we extrapolate the lessons being taught and learned through the frame of recreational activities like those provided by the Special Olympics to the emphasis placed on being a laborer in a competitive labor market because it is often difficult for employers to understand how to accommodate standards based on different abilities. As I detail in **Error! Reference source not found.**, much of the transition period is based on preparing someone with IDD to enter “the real world” and that world is sometimes faster, meaner, and less accommodating. Is the concern that if we permit certain allowances in Special Olympics that we are not adequately providing the types of life lessons necessary to compete and cope in an environment where the majority of people do not have IDD? What is the danger if the lesson to be learned from the Special Olympics is not about winning, but about learning how to lose—something that everyone, regardless of (dis)abilities, must face throughout their lives?

Sometimes the lessons learned through the Special Olympics and the message of trying to achieve one’s personal best rather than only focusing on winning moves beyond the athletes to those without disabilities. A parent related a story when former Ohio State University football player and co-captain, Simon Fraser, spoke at a Special Olympics track meet. Fraser said that when he saw all of the Special Olympics athletes working towards their personal best without the possibility of becoming a professional player (as he later did), it reminded him of what he should be doing rather than constantly measuring himself against society’s measures of achievement. While I am cautious of critiquing this as a professional athlete finding inspiration in Special Olympics athletes as

mascots, I think the notion that finding value in improving oneself instead of only focusing on being the best in comparison to others is a belief that is promoted throughout the OHSO experience. Interestingly, although Coach Pete is one of the major influences promoting good sportsmanship, he admitted that he used to be a “terrible loser”; when he began coaching OHSO, he was still playing in softball leagues and touch football with the city and would always be angry about losing. As he stated, “I had to practice what I preach. I had to deemphasize winning in my life, which was hard.” One of his greatest influences was a man who had worked with the county as a direct support provider and then went on to a career in Special Education and had experience through playing basketball in college. This man came to speak to the OHSO team and told them that when he played college basketball, he competed against some of the best players around but was not able to win all of the time so he had to learn how to be a gracious loser—as Pete stated, “Never a loser, but how to graciously lose a game.”

Some athletes’ perceptions of competition have evolved through Special Olympics and while the coach has emphasized the value of losing gracefully, the value of winning over losing and the prestige awarded to 1st, 2nd, and 3rd overshadows coming in 4th or 5th. Maddie’s (A8) parents, Cathy (P3) and Robert (P14), have observed her change in demeanor over the years about winning because when she first started with OHSO, she did not seem to care much about medals. As she has gotten older, however, she has expressed disappointment if she gets a ribbon instead of a medal to the point that her parents say they have to watch her to make sure she does not act like a poor sport. When I asked them for more of an explanation, they said that Maddie would get up on the

placement stand and scowl because she has gotten 3rd place. Her dad stated that this is a significant change because “before, it was like even if she got 4th or 5th... it was still a big deal and she would even congratulate the person who got 1st place or whatever. In recent years, she’s become a little more ‘I gotta get 1st, 2nd, or 3rd.’” Maddie also participates in the Special Olympics as a cheerleader and through cheerleading, she has learned to frame the other team as the “bad guys” and will get upset when they win. Coach Pete does not want to encourage this type of emotional investment revolving around the dichotomies of good vs. bad or us vs. them and has taken certain measures to minimize some behaviors. The cheerleaders cheer for the school-age games but only cheered for the adult-age games once before Coach Pete restricted the cheering to the school-age games. Maddie’s parents believe that although the girls and the adult players wanted them to cheer at the adult games, Coach Pete was against this because, as Maddie’s mother said, “we have some hot dogs on that team and he just feels like he doesn’t want them announced.” When I asked what it meant to be a “hot dog,” Maddie’s mother explained:

We’ve got some boys that are pretty ‘Rah,’ you know? Cheering kind of for themselves, you know what I mean? They’re cute about it, but it’s just sort of like if you just pump them up-and it’s typical-we have a son who was super competitive and super athletic-the more attention they get, just like pro players, the more puffed up they get, the more obnoxious they get. There’s that testosterone that kicks in real bad. (P3: 5/13)

Maddie’s mother attributed this behavior to gender, although she admitted that some of the female athletes were also competitive but not to the same extent. I would argue that the young women on the teams are more closely monitored for their behavior than their male counterparts and that this directly relates to the performance of gender and

controlling sexuality. Sportsmanship and fair play, according to Bourdieu, are intended to train individuals in terms of courage and manliness, to form one's character, and instill the will to win (but within the rules), which traditionally separated the aristocrats from the "plebeian pursuit of victory at all costs" (1978, 825). Acting like a "hot dog" or being too aggressive would show less class, civility, and composure. Is it possible that there is an element of danger in the lack of self-control that has greater signifying and symbolic power for men and women with IDD than people without IDD? Cathy and her husband believed that much of it could be due to personality as well and had little to do with someone's disability. She gave the example of their two sons who were at opposite ends of the spectrum in terms of their competitive natures. One son was extremely athletic, excelled at everything he did and if someone said they were going to beat him, he would "swim his brains out and win" whereas the other son would have been intimidated and shied away from competition and team sports but found his niche in swimming because it was more focused on performing one's individual best. Maddie's mother said, "I think that's just a difference in personality, it's not a disability type of thing."

As with any team, there is a wide range of values, beliefs, and performances associated with competition. Some athletes place more importance on the individual win and more particularly, winning 1st place, as evidenced in Chris's joy when he celebrated what he thought was a 1st place victory and then subsequent disappointment when he learned he had placed 4th in the softball throw. He was not comforted by the notion that he had performed his personal best but when he was enthusiastically congratulated and embraced by his teammates regardless of his placement, he appeared to be uplifted and

encouraged by the group's acceptance. For Chris, the participation in the ceremonial award ritual signified an elevated status and this has the potential for multiple meanings and responses in Special Olympics. His exuberance was mirrored by his teammates' enthusiasm and praise, but no one seemed to notice or care that he actually had not won 1st place. Had his celebration gone to the point of disparaging his opponents, that would have been negatively valued for being carried away, going against the ethos of the Special Olympics, and showing poor sportsmanship. The only person who seemed concerned with correcting his interpretation such that his belief and celebration matched his placement was his mother. Then, although his reaction reflected his feeling of having a lowered status, his friends and teammates continued to cheer for him and he perked up and joined the group in a display of *communitas*.

Many of the athletes have learned to practice the ritual of congratulations, which can help someone save face and ease the embarrassment or shame at not performing the way they would like to, and this can be seen when players strike out or hit the ball but do not make it to first place. Ideally modeled by the coaches, volunteers, and spectators, assuring and rewarding athletes for trying their best is one of the rituals of congratulations that encourages a sense of *communitas* and togetherness. Rather than being rituals of destabilization, where someone's status is reversed or extremely elevated, these rituals are more about maintaining equality (Turner 1969, 167). In fact, ensuring that people have similar capabilities and the playing field is as equal as possible is so important to the Special Olympics that divisioning is carefully monitored. At the bottom of the various sports fact sheets, the section on divisioning states:

Athletes in every sport and event are grouped by age, gender, and ability—giving everyone a reasonable chance to win. At Special Olympics there are no World Records because each athlete, whether in the fastest or slowest division is valued and recognized equally. In every division, all athletes receive an award, from gold, silver, and bronze medals, to fourth through eighth place ribbons. This idea of equal ability groupings is the foundation for competition in Special Olympics and can be witnessed at all events, whether it's athletics, aquatics, table tennis, football, skiing, or gymnastics.⁸

Since the maximum number of competitors in a division is eight (the minimum is three), this ensures everyone receives a tangible award of some kind. The divisioning process is critical to Special Olympics competitions because it (a) enables Special Olympics coaches to obtain the start times of their competitions; (b) helps organizers predict outcomes of the competitions; and (c) ensures athletes will be competing against other athletes of equal ability. Individual athletes and teams are grouped by gender, age, and ability.⁹ The Special Olympics also has guidelines, not rules, about divisioning and the gap between the most and least skilled athlete or team in a division and tries to allow no more than a 15% difference between each of the team's or athlete's scores (Special Olympics 2015, "Resources: Divisioning"). In individualized sports like gymnastics or team sports such as basketball, where it can be difficult to assess players' abilities, coaches must submit player rating or skills assessment forms to organizers prior to competition. The game organizers then distribute the athletes or teams among preliminary divisions based on the information reported in the forms. Before the commencement of the formal game or event, "short competitions are held to assess the appropriateness of

⁸Football is the term used for soccer—American football and rugby are not included in the 32 available sporting activities.

⁹ Genders may be mixed in sports and competitions where there are not enough competitors.

athletes' or teams' preliminary division placements" (Special Olympics 2015). In addition to these rules and regulations ensuring fair play, if an athlete or team exceeds their performance in the competition over that of their qualifying round or during the divisioning process, they can be disqualified. This is part of the maximum effort rule but it appears that this could be quite subjective and unless something was specifically quantifiable. In a study on the Special Olympics World Games, the authors noted the downside to this rule is although it is "intended to ensure equity in performance within divisions, it can negate genuine improvements in athlete's performance."¹⁰ Coaches are responsible for alerting competition organizers as soon as possible if they feel there has been a change in the abilities of the athlete between the divisioning and assessment process in order to ensure honest and fair competition. The positive aspects of the divisioning are that it minimizes the potential for mental and physical injury and damage to self-esteem if someone is placed in a competitive environment beyond their skills and abilities and it also encourage a sense of togetherness because it minimizes potential outliers based on skill.

The togetherness and camaraderie are the elements that are most valued by some of the participants, as in the case of a recent Ohio Special Olympics Summer Games competition, but it is also important to look at the values emphasized by observers who are not associated with the Special Olympics. A newspaper's front page featured four of the OHSO's relay team celebrating their fourth-place finish. Two of the athletes are shown holding each other's hand with their arms raised to the sky, one is smiling and the

¹⁰ http://www.specialolympics.org/uploadedFiles/Ulster_Coaching%20Final%20Report.pdf

other has his eyes closed as he kisses the ribbon. Kissing a ribbon or an award is not an unusual celebratory act, but it is not something that is typically associated with a fourth-place finish and yet, this moment is highlighted in the newspaper with the caption, “Olympic Spirit.” The Olympics are one of the pinnacle events of global sports competition and one only has to look at recaps of past games to find stories of inspiration and good sportsmanship as well as stories of embarrassment, shame, and poor sportsmanship (e.g. McKayla Maroney’s crossed arms and smirk of disappointment for receiving the silver medal at the 2012 Summer Olympics). The image of the young men celebrating their fourth-place finish, including the joyous kissing of the ribbon, celebrates “Olympic Spirit” in a way that is idealistic but not typical. Perhaps when Olympic athletes finish in fourth place, they celebrate with extreme joy and this inspires viewers to appreciate that the athletes did their personal best but it also provides an opportunity for observers to feel relief that the athletes are not heartbroken or ashamed of not placing higher.

In the case of the Special Olympics, the added aspect of disability and its associated stigma lends another level of meaning and interpretation to the performance’s reception. If we were to look at this performance in the context of athletes in their mid-twenties, without disabilities, celebrating a fourth-place finish, would we think it was a typical reaction and place it on the front page of a local newspaper? Would we wonder if they were being sarcastic or ironic? Perhaps we would still find it inspirational to see someone take so much pleasure in placing fourth and this would reflect the belief in the Olympic spirit. The unbridled enthusiasm showcased in the local newspaper is accepted

because the gesture is not ironic since we do not assume those with IDD have the guile to be sarcastic. Furthermore, being ironic would be showing poor sportsmanship and although McKayla Maroney was able to put a spin on her smirk, these athletes do not have the same social capital nor would that type of display make the front page of a local newspaper.

I argue that there is an underlying demand to see such an emotional investment in the award celebration, which is the opposite of what Bourdieu would say the bourgeoisie demonstrate with a certain composure, not letting themselves get too carried away to forget that it is just a game, “those who maintain the ‘rôle distance,’ as Goffman put it, that is implied in all the rôles designated for the future leaders” (1978, 824). The uninhibited expressions of joy of Special Olympics athletes in a 4th place finish make the front page of a local newspaper for similar reasons to why there are so many instances of people with disabilities as Homecoming kings and Queens making news headlines—society has an investment in viewing these ritual moments as inspirational, redemptive, and placating. If the people with disabilities can experience so much joy from these symbolic moments, where is the need to fight for social justice?

Not everyone is as demonstrative when they are awarded a medal or ribbon. For other participants, it is not always clear how they perceive competition and the associated pressures, values, and rewards that are connected to different levels and standards of competitive sports. Nicki often sent me pictures of her awards and ribbons from Special Olympics and has always been very proud of her medals and awards she received from participating with both the Special Olympics team and her high school’s swim team, but I

was not sure if she associated the increased difficulty of the practices and strokes with the high school swim team with a greater sense of pressure and subsequent significance of competition, or if there was a decreased attention to competition with the Special Olympics team.

In the following excerpt, it is evident that Nicki (A10) understands that winning and losing are positive and negative emotions that other people experience.

- O: what does it mean if you lose, at Special Olympics?
N: you don't win
O: how's that feel?
N: bad.
O: how come?
N: because people don't-people don't like losing.
O: do you like losing?
N: not really
O: what about second place?
N: I don't care if I lose second place
O: do you care [N starts laughing]—how do you feel if you win?
N: happy

In this excerpt, Nicki stated that not winning feels bad because “people don't like losing,” indicating that she is learned from others how one is supposed to feel if one does not win. When I asked how she felt, she said she did not really like losing but when I asked about second place, she responded, “I don't care if I lose second place.” This could be interpreted as a possible grammatical error meaning that she meant to say, “I don't care if I win second place,” but it could also reflect Nicki's difficulty grasping relational concepts such as greater than, less than, more, most, etc. On both swim teams, Nicki was expected to do her personal best and this was something she continued to improve upon as evidenced by her increased times with the high school swim team. She learned more strokes and increased her speed, but she did not win any events. On the OHSO team,

however, Nicki was one of the fastest swimmers and was able to compete in the State competition.

Because Coach Pete (C2) had shared some stories of athletes who were upset when they felt they were being held back by teammates who were not as fast or skilled and Nicki had greater skills and speed than her OHSO teammates because of her many years of practice, lessons, and participation in her high school swim team, I was interested to see if she evaluated herself differently based on the expectations and performances with both teams and how she viewed herself in relation to her teammates. I asked, “Let’s say you’re on a relay team and the other people go too slow and you don’t win but you went really fast, how does that make you feel?” to which she responded, “Um, I’m not sure.” I was seeking an evaluation that might not have been relevant to Nicki’s belief system (although she does have her own value system and is prone to expressing her disapproval of those who do not behave well or follow the rules); or perhaps Nicki was not able to respond according to how she might feel at the moment because I was using a hypothetical scenario and Nicki could not relate to that level of abstraction. This is one of the reasons that observation is a critical component to my research with this group because many of my informants are not able to articulate at a meta-level about hypothetical situations.

When questioned about their perceptions of Nicki’s feelings towards competition and if it mattered what place she ranked in a competition, both of her parents agreed that from their perspective, it did not seem that the actual place made that much of a difference to Nicki, but that the feedback was what was most important to her. Her

mother, Greta, said that she thinks that part of the reason Nicki is not very sensitive to what place she gets, what ribbon or medal she receives, is because of the way the Special Olympics is designed—everyone gets a ribbon and no one goes home without some type of award (although this is not necessarily accurate, as noted earlier in the chapter where people who were disqualified at a swim meet did not receive any ribbons for participation). On the one hand, it seems as if her father, Henry, is saying that Nicki has no concept of her personal best, that she is always performing her best, but then Greta adds that when Nicki was timed and her personal best was emphasized on her high school swimming team, she began to swim faster. This improvement in performance supports Greta's belief that expectations should be raised whenever possible in order to see what athletes, regardless of their ability or disability, can do and how they can be taught to push themselves and meet greater expectations rather than only expecting the bare minimum. Henry added that the concept of winning has taken on greater importance to Nicki because she recognizes that it is important to those around her and she wants to fit in as a part of the group. For example, her family will watch baseball and football games and Nicki will now ask, "Are we winning?" but neither her father nor her mother believe she truly understands what she is asking because she has difficulties with math and relational values, and it is unclear whether she comprehends that the team with the most points wins. As her father notes, "She engages in these things as if she knows exactly what all of the underpinnings are but I'm not persuaded that she really does." This is an example of Nicki performing competence in engaging in sports talk and recognizing the social component of being on the same team, being a part of a collective group, and thus

signifying a level of social competence. The disjuncture to which her parents refer is that they believe Nicki does not understand the full context and is not able to “pass” as competent, which is what Amy Shuman discusses in more detail in terms of what is or is not considered to be normative communicative competence as she builds on the work of Dell Hymes (2015, 25). It seems that this is an example of Nicki trying to “pass”, but not as competently or thoroughly as one might expect of typically-functioning adults, but isn’t this what many people do in terms of sports talk?

Evaluating communicative competence based on feelings toward one’s involvement in the Special Olympics also proved to be difficult when interviewing Patty (A12). When asked about her views on competition, the following exchange occurred:

- O: how important is it to win?
- P: 100 percent
- O: how do you feel if you win?
- P: I feel good
- O: how do you feel if you don’t win?
- P: I feel like crying
- O: really? Do you sometimes cry?
- P: if I win
- O: if you win, you cry?
- P: yeah.
- O: how come?
- P: because I’m happy to win and I will help all my friends out

Based on this example, it could be inferred that Patty feels very strongly about winning and losing (although it is confusing as to whether or not she cries when she wins, loses, or both) and that winning makes her happy also because of the social aspect of helping her friends. However, when placed in conjunction with her earlier comments about the Special Olympics [see Chapter Four] where she appeared less engaged, answered “nothing much” when I asked her what she played in Special Olympics, and responded,

“I honestly don’t know” when asked what was important to her about Special Olympics, the above comments about crying over winning and losing seem incongruous. Perhaps Patty, like some of the other Special Olympics athletes, understands the concept of “winning” and recognizes it is desirable to want to win, or at least say you want to win, but has a difficult time articulating ideas about winning and the reasons for “motivation” and “competition.”

Not winning is acceptable, but not trying one’s personal best has significant repercussions when taken out of the context of the Special Olympics and placed in the “real world” where not trying is interpreted as a personality deficit. Patty has been criticized by service professionals and teachers for “lacking motivation,” and I have observed Patty walking rather than running during a track practice and wondered if this was indicative of a lack of motivation or whether it is more reflective of Patty lacking other available opportunities that interest her and this lack of motivation could be reframed as Patty demonstrating resistance and exerting some semblance of control. It should also be noted that although a lack of motivation and a competitive attitude is often attributed to a person’s disability, as seen in the example where the mother spoke of her two sons without disabilities who have opposite approaches to competition, how someone approaches competition and demonstrates motivation could be more indicative of one’s personality rather than (dis)abilities. Perhaps the answer lies in looking at what does motivate Patty and based on the comments about her friends, the actions of starting to run when one of her teammates ran back to her so they could run together and then linked arms after they finished the race, and Patty’s parents’ concerns that her motivation and

performance are based on her social needs and her desire to find friends, it seems as if Patty fits into the category of Special Olympics athletes who do find the socialization more important than the competitive sports element.

In another example of an athlete who valued the group culture over the competitive factor, Matt (A9) explained:

Well, actually, winning is not about everything because we'll lose, we'll win, but we don't know where we end up or what place we might get or we have our-[] right? It's not everything. If we win something, and we lose together, and we-we feel happy because we got a people who tells you and cheers you on. And that's the best you can do [] and winning isn't everything."

Although some of his speech was slightly confusing, it was clear that having the support of the team was more important than the actual act of winning. This was further supported when I asked for more clarification to learn if anyone on the team got upset if they didn't win, to which Matt answered, "Like I said before, you win or lose, we have our doubts because winning is not everything. If we believe, we all believe in you. And you do your best. That's all that matters right now." I will explore Matt's performance style in 0, but it is interesting to note at this point how he uses apparently canned speech to a certain amount of effectiveness to support his argument that what matters most in Special Olympics is not the competitive aspect or winning, but solidarity and the goal of doing one's personal best.

The examples in this chapter reveal some of the discourses that surround competition and its significance to OHSO athletes, caregivers, and coaches. Although exclusive to the point that in order to participate, one must have an intellectual or developmental disability, the Special Olympics supports the belief "in the power of sports

to help all who participate to fulfill their potential and does not exclude any athlete based on qualifying scores,” but divides the athletes by those scores to ensure fair competition “against others of like ability.” The intention is for excellence to be measured in terms of personal achievement, “a reflection of reaching one’s maximum potential—a goal to which everyone can aspire.” As Robidoux points out how the culture of a sport can be used to highlight desirable traits and project a desired identity in the case of Canadian and British sports, I argue that a similar desired identity is constructed through the culture of the Special Olympics, namely, that of a good sport who is courageous, kind, and strives to attain his/her personal best. On a theoretical level, this philosophy sounds simple and allows for people with mild to severe disabilities to participate in activities that might not otherwise be possible and the OHSO coaches have fostered an environment focusing on safety, sportsmanship, and working towards one’s personal best. On a practical level, things become more complex if one views the Special Olympics as a platform for fostering physical and mental skills that bolster self-esteem and, ideally, helps prepare someone for inclusion in the community. By examining how competition and expectations of behavior are tied to values associated with motivation and the significance of the drive to succeed in terms of employment, we can begin to uncover the complex requirements placed upon those with IDD to fulfill extremely high and potentially unrealistic standards in order to be recognized as valuable members of society.

Far from failing to meet the goals of sports for children and young adults, one could argue that the Special Olympics exceeds these goals by attending to good

sportsmanship as a primary objective. In other words, the expectation that the athletes will acquiring the skills of good sportsmanship is part of a discourse that respects people with disabilities as capable of meeting an appropriately set standard. As I will discuss in 0, setting expectations and identifying appropriate measures is one of the major means of countering either pitying or finding inspiration from people with disabilities.

Chapter Six

Character, Characterizations, and Community

“Simply Being Themselves”?

In a lecture given by Ann Cooper Albright, Professor and Chair of the Department of Dance at Oberlin College, at The Ohio State University in September 2014, she presented a series of video clips from Disabled Theater, choreographer Jerome Bel’s collaboration with Theater Hora, a Swiss company of professional actors with intellectual and developmental disabilities.¹¹ In the introductory period, each actor stands at the center of the stage for one minute (some do not last the entire time and run back to their peers). In the second act, each actor states his or her name, age, and profession. In the third act, each performer talks about his or her disability. One woman says she has Down Syndrome and she is sorry while another woman asks, “So what?” In the fourth act, seven of the actors perform individual dance routines to music of their choice. Finally, the actors discuss how they feel about the performance piece and some say they are proud while others discuss the discomfort it has caused among family members (one actor was likened to being a performer in a freak show). Watching these performances, I felt uncomfortable, voyeuristic, and as if my gaze was part of a complicit collusion with the creators of the show, who most certainly were not those with IDD themselves. When one woman apologized for having Down Syndrome and began to cry, I felt pressure welling up in my eyes. There were no special effects, no music or lighting cues adding to the pathos to invoke a feeling of sentimentality, but it was still evocative to witness a woman

¹¹ The actual clips Professor Albright showed were longer and more in-depth, but several YouTube clips show segments from different performances.

stand alone at the front of a stage, apologize for having Down Syndrome, and begin to cry. Choreographer Jerome Bel had a similar visceral reaction when he first watched DVDs sent to him from Theatre Hora's director, which was one of the reasons he decided to work on a project with the troupe. When interviewed by *TimeOut New York* about his perspectives and motivations for this piece, Jerome Bel answered:

I didn't have any idea at all. I knew I was there because of this emotion I had watching the DVDs. I wanted to know why I had been so deeply moved. I was crying watching them perform. I couldn't explain this emotion to myself, so I needed to work with them to try to understand this totally unexpected reaction (2013).

Are the tears resulting from a sense of empathy, pity, or something else? I will address the subject matter of tears more thoroughly at the end of this chapter, but I want to attend to occasions and representations in which audiences cry when encountering people with disabilities. These moments are useful for exploring how stereotypes are potentially challenged while still perpetuating stigmas.

Jerome Bel admits that this piece has polarized audiences. His intention is to bring disability out of the hidden recesses, open a space for discourses, and he hopes that through knowledge and education, society will be more receptive to people with disabilities. Bel argues that the stigmatization and taboo surrounding people with disabilities correlates with the late capitalist ideology of progress and that disability, as the opposite of progress, has become unbearable. Since representation is his job and people with mental disabilities are not represented in the public sphere, his "goal was to give a representation of them, a representation of what they are" (Kourlas 2013). I would argue that he is correct to some extent about the invisibility of people with mental

disabilities, but I would counter that there are indeed representations of people with IDD in the public sphere and that what Shuman and Goldstein refer to as “hypervisibility” does not necessitate equality (2012).

Jerome Bel says that it took him four weeks of working with the group to understand that his job was not to direct them, but give them a space to be free onstage:

To step back, to surrender to them, to their freedom, because that is where they are so alive and singular. Their liveness, their emotions, their desires shouldn't be restrained again. They all have to behave a certain way to be accepted by the normative rules of society; I thought theater shouldn't alienate them again. Theater, performance, the stage should be a place of freedom, a place where they could be themselves (Kourlas 2013).

When I first saw these videos, I had no knowledge of the troupe's origins nor the level of Bel's involvement or his politics. As I watched men and women hop, twirl, twist, spin on the floor, do the robot, and one woman imitate Michael Jackson (complete with a crotch grab), I was not sure whether I should laugh, applaud, or denounce the production as exploitative. Was I watching the first time they had performed on stage? Were these performances improvised or scripted, and if so, by whom? Art critic, Sarah Crompton, experienced a similar unsettledness and was puzzled by the audience's indiscriminate applause after the dance performances and asked, “Surely it is patronizing to cheer disabled people doing something purely because they can?” This question resonates with my research with the Special Olympics and the criticism that the Special Olympics promotes stigmatization and a paternalistic attitude. Additionally, how do expectations of abilities relate to how people without disabilities perceive and react to those with disabilities? The tension and potential for misunderstanding is alluded to in a review by Walker Art Center:

Probing troubling questions around identity, discrimination and the narrowness of our own preconceptions, the show features 11 members of Theater Hora, simply being themselves [emphasis added]. The work's carefully constructed tension is balanced with humor and life-affirming joy. Sparking both debate and awe across Europe, the work was the sensation at both prominent theater festivals like Avignon and Brussels' Kunsten-Arts as well as Germany's 2012 dOCUMENTA (13). Frieze praised its "simple, stripped down conceptual clarity" and its "90 minutes of uneasy, preconception-probing estrangement and empathy." And, for New York Times' chief visual art critic Roberta Smith it was simply "transcendent art" (WalkerArt 2013).¹²

In her analysis of the performance and the critics' reactions, Cooper Albright embraces the messy areas where identity, preconceptions, stereotypes, and performance converge.

I am particularly interested in one critic's praise for the members of the troupe "simply being themselves" and Bel's assertion that the stage was "a place where they could be themselves." What does it mean to be oneself? Does it mean that this is a purer and more authentic form of theatre because the performers are incapable of manipulating our perceptions and contriving an artifice? Focusing on one of the most moving and remarkable moments of the performance, I consider the layers of meaning embedded in her performance and its interpretation by various audience members. At one point, a woman comes to the front of the stage, stands in front of the microphone, says she has Down Syndrome and that she is sorry, hangs her head, and retreats into the comforting arms of a fellow actor. Is this the first time she has said this? If she says the same lines repeatedly and cries each time, is this simply a woman being herself or is it too hard for the audience to imagine that she knows that this is a powerful moment, that it has an evocative effect, and as an actor she can evoke these emotions at will?

¹² <http://www.walkerart.org/calendar/2013/jerome-beltheater-hora>

English professor and performance studies scholar, Petra Kuppers, was also attending this lecture and reminded the audience that Theatre Hora is a professional acting troupe who has traveled the world with their performances. Kuppers suggests that we need to be cautious with our assumptions and challenge our preconceived notions of agency. Kuppers' point corresponds to people with disabilities being represented as mascots. As I discuss below, mascots often achieve an elevation to celebrity status during a particular occasion, but this increased temporary status does not necessarily accrue lasting benefits.

Further challenging the audience's assumptions of naivety and authenticity predicated upon the actors' disabilities, Micheal Elber (founder of Theatre Hora) said in an interview with *Arts.21* in *Deutsche Welle* that Lauren, one of the women who cried on stage, has been on stage seventy times and each time she has cried so much that the audience believed it was authentic—"but it's not authentic. Every good actress draws on their experiences so they can say something and cry each time. That's just great acting" (2013).

These excerpts from Theater Hora offer a rich example of how portrayals of individuals with IDD are used and interpreted to evoke emotions of shock, curiosity, inspiration, and empathy. In this chapter, I will review examples of ritual performance of identity among people with IDD to consider some of these issues. However, before turning to my observations about what happens when people with IDD are placed in celebrity-type roles (i.e. Homecoming Queen or King) or otherwise are given what I call "mascot" roles in ritual performance, I will begin by discussing more ordinary

performances of innocence and deception. Bel's presentation of innocence needs to be complicated. In my fieldwork, I was intrigued by stories of deception that served to counter this depiction of innocence, so I will start there on a local level to establish a framework that refutes, or at least questions, the innocence paradigm. Following my observations about innocence and deception, I will summarize some of the important work on performance from a folkloristic and performance studies point of view to set up a model for understanding the mascot performances. I contextualize my discussion of the mascots within recent research in disability studies on inclusion, stigma, and stereotyping. I conclude the chapter by bringing Victor Turner's discussion on liminality into conversation with a disability studies' approach to the problems of inspirational rhetorics.

Communicative Competence and Deception

Continuing to build on the framework created by folklorists who have been exploring the stigmatized vernacular by looking at stigma and the narratives created from both inside and outside those associated with a stigmatized group or identity, I would like to draw from Amy Shuman's expansion of communicative competence, Michael Bamberg's research on positioning in narratives, and Diane Goldstein's examination of untellability. By challenging us to reconsider our categories of competence in communication, Shuman expertly weaves Dell Hymes' research on the ethnography of speaking into the construction of normalcy and inextricably links folklore with disability studies to encourage new dialogues that challenge us to rethink how we evaluate

narratives and the construction of normalcy. Bamberg's work on narrative positioning, combining linguistic analysis based on Labov and Waletzky with the construction and performance of identity, is useful because it looks at not only the narratives themselves, but also the discursive power that comes with how people position themselves and others in roles through such narratives. Goldstein's exploration into chaotic narratives and untellability brings this to the forefront when we consider individuals with intellectual and developmental disabilities and study not only what goes said or unsaid, but also the power of who says what, including our own responsibility as ethnographers in choosing how to frame our informants and their words, actions, or silences.

The conflict surrounding the issue of ventriloquism as examined by Susan Ritchie (1993) and Diane Goldstein (2012), asking who is able to speak for whom, plays a pivotal role in critically thinking about working with people with intellectual and developmental disabilities and the narratives they use, the narratives that are told about them, and the ones that are left untold. Whether it is through the fear of saying the wrong thing, making something more tangible through the very act of naming it, or venturing into territory that is so taboo (particularly with regards to sexuality, abuse, or incest) as to be relegated to the realms of the unspeakable, engaging in ethnographic work with people with IDD is extremely complicated, to say the least. As Goldstein warns, we "have to be cautious about representations that perpetuate negative stereotypes about victims/survivors, and equally as cautious about the sensationalizing that can easily result from the choices we make about which chaotic narratives to include in our publications."

But, if we avoid ethnography with people with intellectual disabilities, could we also not be in danger of adding to the stigma and, thus, to the untellability? (2012, 192).

What are some of the potential risks to undertaking this type of ethnographic challenge? On the one hand, there is misrepresentation, magnification of stigmas, and an amplification of the power differentials between individuals with IDD and those who have the authority to make life-changing decisions for them. On the other hand, there is also the danger of romanticizing people with IDD, where the ethnographer acts as a rescuer or broker to attempt to rectify the misrecognition and misunderstanding of a pathetic other (Shuman 2011, 151). So in an attempt to recognize these hazards, I try to follow Goldstein's directives to continually evaluate the positionality, content, and context of my words and those of my informants (2012, 194) and, following Shuman and Bohmer, in addition to disability studies' scholars who challenge the concept of normalcy, examine what gets taken for granted, and explore how stigma and normalcy produce each other (Shuman and Bohmer 2012, 203).

Elaborating on the thread started earlier with the discussion of Jerome Bel and Theatre Hora's "Disabled Theater," I focus on the use of deception by the athletes in order to better understand the complex problem of their subjectivity as innocent and/or as capable of the kind of strategic thinking necessary for deception. By observing how some individuals with IDD understand and use deception and how friends, family members, and support staff have their own perceptions of the individuals' abilities to use deception, I can explore how easy it is to underestimate the strategic competencies of people with intellectual disabilities. By positioning individuals as not having the potential or

capabilities to be deceptive, we further stigmatize them as not “normal” and maintain a boundary and subsequent power differential denying them full personhood.

Challenging the veracity of someone’s words is dangerous and has particularly detrimental implications when a claim of abuse is made by someone who is disenfranchised and lacking power—a person with IDD. I cannot go into depth due to the sensitivity of the subject matter, but I have encountered incidents where some individuals with IDD reported abuses that upon further exploration were declared to be unsubstantiated, true, or inconclusive. In one example, a young woman came in with her father and claimed that a day program staff member had hit her hand to tell her to hurry up and finish her meal. This was investigated and considered to be untrue because of discrepancies in timing, witness accounts, and extensive interviews and observations, but because she had Down Syndrome, her parents claimed she was incapable of lying. In another instance, a young man repeatedly broke down in hysterics if he was told he had to go visit his father. He said his dad had held a gun to his head, but when asked when, he kept answering “yesterday.” Investigators were confused because although his verb tenses were incorrect, he could describe the weather on the day that this event occurred as well as the color of the gun. How does competence fit in here with our understandings of coherent narratives? An individual’s disability is inherently linked to competence and their ability to provide a coherent narrative has very real consequences that are particularly troublesome when they lack the independence, control, and freedom to go where they want or with whom. In the example of the young woman with Down Syndrome who accused the young man of hitting her hand (who had also created

imaginative stories in the past), her parents' insistence that she was innocent and incapable of lying coincided with a greater exertion of control and isolation as her parents removed her from activities with her peers. The young man's case was dismissed because the judge decided that he was not competent, and his testimony did not provide enough evidence to warrant charges against his father.

These and other cases demonstrate the recurring notion that a person's inability or ability to lie is often based on an assessment of their communicative competence. The often-contentious debate that surrounded these incidents reflects some of the concerns raised by Goldstein, Shuman, and Bohmer (2012) about how stigma distorts assessments of competencies and capabilities. Questions of competence and capability are intricate, highly problematic, and often occur in what Goldstein calls "chaotic narratives." We need to look at the implications of how others position the individuals in certain narrative roles based on an externally-imposed membership in a stigmatized group. In essence, the truth-values that were applied to these individuals' stories were often black and white assessments that a person's words either could or could not be believed due to their intellectual and developmental disabilities. Because deception is morally charged, part of the stigmatized vernacular surrounding people with IDD, and connected to social values and the struggles that many of these individuals face, there is a danger of not recognizing and also discouraging what could be considered a form of creative competence, a push for independence, and a part of someone's developmental process. The desire to represent the individuals as innocent and morally pure obscures the possibility of seeing acts of non-compliance or even deception as acts of competence.

In addition to allegations of abuse, I have encountered less severe cases of “little lies” or alternative truths where it was not clear if what was going on was a chaotic narrative, cognitive dissonance in expressing oneself, or attempts at creativity based on things picked up from others and in popular culture. I address the issues of disability and deception and unpack what counts as deception and competence as they emerged in my work with members of the Special Olympics group. Using the notion of deception as a point of entry into this discussion provides a critical intersection of folklore and disability. Folklore provides us with the tools to investigate these culturally-constructed norms, how they determine what counts as deception, and how adhering or not adhering to these norms is regulated by expectations about stigma.

Most of the individuals on the Special Olympics team are not their own guardians, and my initial interviews were with the parents of the individuals; the decision was left up to them as to whether or not their child would be present. In all but two cases, the parents chose to speak with me privately. This is obviously neither inclusive nor collaborative ethnographic research, and I hope to follow up by presenting opportunities for these individuals to speak in a more independent setting in the future. Given these limitations, I was still able to address the issue of deception and disability by exploring the parents’ narratives about their children and this offered insight into the use of positioning.

My question was, “What is the individual’s understanding of deception and how others use deception?” I did not define deception for my interviewees but left it up to them to provide their own examples of deception, lying, or presenting untruths. I relied

on the most general understanding of a lie as an intentional lie by the speaker with the intention of deceiving the listener. What motivates the individual to lie, the context in which it is used, and the methods used to carry out the deception (not to mention the reaction if the deception is uncovered), are all of interest here.

The parents' narratives recreate a storied world by moving across space and time and recollecting desired elements to portray individual characters attached to particular values (2004, 357). Someone who is deceptive can be venerated or repudiated depending on: (a) how the parents position themselves and their children in the narrative; (b) the particular circumstances of the deception; and (c) what the parent has invested in the character evaluation (possibly viewing their adult children's character development as a reflection on his or her upbringing). Not telling the truth can be viewed as polite and necessary to maintaining social norms in certain situations. If someone spins a good yarn in the right context, they can be highly esteemed, as we have seen in folklore with tellers of tall tales and tricksters as competent performers of deception (Bauman 1986). However, if someone is too good at being untruthful, manipulative, or conniving, he or she can be seen as potentially dangerous to the social fabric. What happens when someone who is already stigmatized with a disability uses that very stigma as a trope to be deceptive about his or her abilities? I encountered several different instances where people with IDD avoided tasks by saying their disabilities prevented them from doing so, although those familiar with them reported they were indeed capable of performing these tasks. In these cases, however, a certain awareness of being disabled was required in

order for the individuals to exert a level of power. What about those who do not have a similar awareness, or who do not self-identify as disabled?

The discussion of self-reflection and awareness opens up questions of intentionality and competence and their relationship to characterizations of innocence and manipulation. Manipulation and deception are linked and are perceived as positive or negative based on the context and consequences. Consider the following examples: when Nicki (A10) was asked by her tennis coach if she had ever played tennis, she answered “yes” although she had never played before. Her mother attributed this to her not really listening or to her “dazed response” (P7:6/13). I observed Nicki not wanting to run with the OHSO team when she was at track practice, and when she was asked why she was not running, she gave a list of excuses (i.e. “I’m going too fast,” or “they’re being rude”) that did not seem to make sense or fit the situation. Derek (A3) also understands that not doing something requires an excuse. Derek has a list of stock phrases that he uses, more or less accurately, when he would prefer not to do something. They include “my hands are full,” “not enough time,” “have to call Dad,” and “the bigger dog wants to be on the left.” He clearly understands what Harvey Sacks (1974; 1992) calls the request-excuse adjacency pair, in which one person makes a request, and the other denies the request with an excuse; but for Derek, it is a unit of dialogue in which he can exert some control, and his mother wonders whether he has learned the routines rather than understood how to differentiate among legitimate and frivolous excuses (P5:9/13). For Nicki and Derek, does the fact that their excuses are unrelated to the required tasks mean that they are lying or they are displaying a type of competence in understanding that rejecting an undesirable

request requires a response—they just have not yet become adept at linking the excuse to the related task? Matt (A9) does not like cleaning his room and when asked if he has completed his chores, he will usually say “yes.” When his father began checking his room, he saw it was not clean. Now Matt understands this routine, knows his father goes to bed at 8:00, and closes his door until that time (P16:7/13). The act of closing the door could be read as a potential form of resistance; at the very least, it is an intentional act to avoid conflict. Chris’s (A2) mother, Laura (P9), pre-packaged a week’s worth of ham and told him he could have one serving of ham per day. She came home one day and discovered all of the ham was gone. She asked Chris where it was and he said, “I don’t know.” After questioning him further, he admitted that he ate it. His mother commented on this incident by saying that he is not a very good liar; he will not look at her when he is telling a lie, and he felt badly about it (P9:7/13). Lewis (A7) invited a man he met online (who happened to be living out of his car) over to his house, but the man would not leave until Lewis’ aunt came home and told him to leave. When Lewis was asked by his aunt how he met the man, Lewis said it was at a Halloween party, which he later admitted was because he did not want to be “busted.” He knew that saying he met someone online would be considered dangerous.

How might we evaluate or categorize these examples? Do any of these scenarios or actions seem “abnormal” or atypical? What we see here are different types and levels of deception, in addition to underlying themes of people pleasing, self-control, responsibility, safety, manipulation, and a desire for independence. Although the contexts and performances might vary, do these things become hard to imagine merely because

someone is intellectually and/or developmentally disabled? Furthermore, what do the attempts at deception reveal about the motivation to avoid conflict and punishment—could these attempts be positively valued as steps towards self-advocacy and independence; and if so, how can we promote their choices and honor their dignity of risk (Perske 1972)?

When it comes to imagining one's child (particularly if he or she has IDD and is stigmatized) being deceptive, many parents have difficulty believing their child has the cognitive abilities to deceive. I am not interested in determining an objective truth, but I am motivated to explore how parents and others position their children as (in)capable of deceit. Narrative positioning is helpful for understanding what might be at stake in characterizing people with IDD as (in)competent in terms of deception and manipulation. When I was working in a different state, I heard parents talk about their adult child being incapable of lying due to his or her disabilities, but also worrying about being manipulated by other adult children with disabilities who seemed to be better at being deceptive and, even worse, not demonstrating proper displays of remorse. The fear was often related to the child's developing sexual maturity and the parents' worries that a more-developed peer with manipulative powers would be a negative influence on one's child.

Discussing their adult children's understanding of deception, most OHSO parents say their adult children are not adept at lying. Patty's (A12) father, Rick (P13), described his daughter's behavior as "extremely appropriate and typical" (P13:7/13). Her mother, Beth (P1), said that if Patty has been given \$10 to go to the pool and is asked how much

she has spent, she will say, “a couple... well, actually, I spent it all.” Her mother followed this by saying, “it’s not like she’s really trying to be deceptive, but she doesn’t really want to tell me what she really did” (P1:7/13). Beth offered an important distinction between lying and “wanting” to tell the truth. Rick added that Patty “understands the white lie” and she “understands how other people use the white lie and she uses the white lie to the best of her ability, too. She does what other people do.” He gave the example that there are times when Patty does not want to do something, so she will sometimes say she is busy. What was the motivation for Patty not wanting to tell her mother that she had spent all of the money? One of Patty’s issues is self-regulation and by spending all of the money she gets on food and beverages; she is risking losing her parent’s trust in her abilities to only buy what she needs. Beth states that Patty was not really trying to be deceptive but that she did not want to tell the truth, and I am interested in how those are positioned as separate categories. When Rick adds that Patty is able to tell white lies appropriately, it seems as if this is valued as a type of compliance to social norms. Could it be that these are all elements of manipulation that are not necessarily positive or negative, but ones that could affect a person’s behavioral patterns as a person with IDD learns what is and is not acceptable and adapts accordingly?

When asked a similar question about their daughter Nicki’s (A10) understanding or use of deception, Henry (P8) said that he could only remember one time when she actually told him a lie, but could not even remember what it was. He remembered Nicki was caught in the lie somehow and that when he told her that she should not lie to her dad, she was very remorseful about it. Henry says that he does not think deception is in

her “toolkit” and that she will generally burst out crying or resort to more elementary behaviors, such as yelling or temper tantrums, as coping mechanisms rather than lying (P8:6/13).

One of Nicki’s most common answers to a question is “I don’t know,” although she often admits that she does know the answer on further questioning. This is an incongruence her parents attribute to her cognitive disabilities. Her mother said, “I don’t really think I’ve known of an occasion where she has truly been able to perpetrate a deceit” (P7:6/13). Nicki’s father says she lacks the abstract thinking capabilities to create the steps necessary to create a deception.

In these interviews, the discussions about the topic of deception position individuals with intellectual disabilities as extremes—either innocent or manipulative, remorseful or unremorseful, which then exacerbates or ameliorates the stigma of disability. Similar to Shuman and Bohmer’s (2012) discussion of veneration and repudiation with asylum seekers, in these cases the seeming incapability for deception is venerated; manipulation is repudiated; and performing remorse makes up for trying to be deceptive. Bamberg states, “Although these [identity] claims are nevertheless locally tied to the interview situation, they bespeak a discourse type that searches across past events (of personal experience) for evidence to make claims of a more decontextual sort” (1977, 341). By positioning a person with IDD as incapable of the kind of strategic thinking required for deception, parents and others perpetuate assumptions and constructions that equate IDD with innocence. The narratives joining innocence and deception as opposing pairs provide an example of what Susan Stewart (citing Gregory Bateson) refers to as

“proper-nots”—namely, two items that are not proper opposites (1978, 63). Using this term, what creates the condition where the opposite of innocence is the ability to deceive? More importantly, I am concerned that these types of absolute categories and performance pairs set up a restrictive framework, where assigning a value to someone not only makes them one-dimensional and obscures contradictions, it implies (and potentially imposes) an inability to progress and develop or, conversely, denotes some type of moral failure. What is at stake in maintaining the construction of innocence? Where does this take us in terms of opening dialogues about what is and is not considered possible in order to preserve this construction of innocence? Interviewing people with IDD and asking them about their use of deception is not straightforward because many are well aware that they lack control and lying is viewed pejoratively. As a power figure, I could potentially jeopardize their relationships with their caregivers upon whom they depend were I to reveal their deceptions. In fact, there were three instances where people with IDD revealed that they had lied or asked me keep a secret from their caregivers and I agreed. I felt bound to honor their wishes because I did not feel they were in any danger and because they specifically asked me not to say anything. I am not certain whether their caregivers would have approved, but this is part of the complicated nature of agency, privacy, and how power is connected to portrayals of identity. By studying the stigmatized vernacular of disability and deception, my hope is that we can begin to see evidence of the construction of significant barriers to people with intellectual disabilities gaining independence and autonomy because of the need to maintain innocence as a static (and untenable) state. In order to maintain that innocence, what people, places,

emotions, and experiences are off limits? What discussions are silenced for fear of potential contamination and spoiling? We need to ask why we need to make them into angels to recognize their humanity (Shuman 2011, 156) and instead look to fostering a more inclusive environment that accepts individuals as they are, not as how we wish them to be. As I discuss in the next section, on people with intellectual and developmental disabilities who serve as mascots for a community of people without disabilities, one of the underlying questions is whether we are selling individuals with IDD short when we conscript them to innocence.

Performance of Identity

Innocence and strategic deception are part of larger performances of identity. Folklore research is especially helpful for understanding the complexity of group practices, expectations, and characterizations. In her article “Group” (1995), Dorothy Noyes gives us a glimpse into the effects of group alignment based on proximity and exposure and the connections that result from growing up with people who are different yet still included in one’s community. The article explores how inclusion and exclusion were based on social, cultural, and geographic norms specific to a particular neighborhood during an Italian festival. Although the Italians displayed a strong sense of ethnic pride and group identity, they considered an African-American man part of their group because they had grown up together. They excluded a woman and a Southeast Asian man from their group in subtle and not-so-subtle ways. In the example of a pole-climbing contest, the virtuosity and athleticism displayed by the Asian man was not a

means for acceptance (although this usually is a way for people to become a desirable teammate in-group sports). The Italians valued the techniques of the Asian man to the extent that they copied his style and approach but did not let him win the prize. Imitation was used as a means not to flatter but to achieve competence. This connection between imitation and competence and how identity is performed to gain acceptance is particularly useful when applied to those with IDD who often struggle to pass as “normal” and yet are either rejected or momentarily accepted as inspirational mascots.

Although she is specifically interested in issues of gender, Judith Butler’s work on performance is also relevant to disability studies as well because of her interest in the maintenance of social boundaries. Judith Butler (1999) cites Mary Douglas as she suggests that the social system and its boundaries can be read by the vulnerabilities that exist at the margins (1999, 168). Butler also works from Iris Young and Julia Kristeva’s notion that expulsion followed by repulsion (170) is helpful to understand how “the operation of repulsion can consolidate ‘identities’ founded on the instituting of the ‘Other’ or a set of Others through exclusion and domination (170). While this conversation is directed at understanding sexism, homophobia, and racism, it also parallels how normalcy is constructed and how its boundaries are policed. The idealization of a coherence linking external performances of gender through words, acts, and gestures to an internal core opens the discussion about how we value a similar type of coherence from people who exist at the margins by virtue of their disabilities (173). Society often requires marginalized people to perform normalcy by offering a false promise of inclusion without recognizing that what they are really looking for is a

particular level of skill and coherence to a performance; even then, those who have positions of authority over people with IDD are still able to shift standards and enforce the rules of behavior that are bound to the categories of the disabled.

The performance of masculinity is one of the ways some of the male athletes on the OHSO team ritually perform their identity. First, this is expressed through physical gestures like high-fives, fist-bumps, handshakes, and side hugs that connect the men to each other—but not, interestingly, through gestures that could be seen as homoerotic, such as slapping each other’s bottoms or engaging in “grabass” (Dundes 1978, 82). While sexual innuendos and teasing someone for acting “like a girl” or a passive homosexual might be acceptable in certain male-dominated sports, displays of behavior that are overtly sexual or derogatory to gender or sexual preference are not allowed on the OHSO team.¹³ The behavior of OHSO teammates is held to a higher standard than what might be applied to other mainstream athletes because so much of their life is regulated in terms of how to compensate for their stigmatized status. Acting like a “typical” male athlete through hypermasculine sexist behavior goes too far since it treads on the doubly-stigmatized ground of intellectual disability and sexuality. A second way in which masculinity, bonding, and a performance of “we” routinely occurs at games and practices is through sports talk revolving around scores, games watched, and sports banter. One of the most significant and fail-proof means of engaging in a moment of togetherness is by shouting “O-H” because inevitably someone will respond with “I-O” since this is one of

¹³ See Robidoux (2001) for an ethnographic study of a men’s hockey team and how the rules of performance and “homogenized masculinity” differ from those generally accepted by the broader public.

the most common call and response chants associated with the state's most popular college football teams, the Ohio State Buckeyes. Another form of unifying sports talk that I observed at track practices was one athlete yelling "Strike!" and then another one responding with "Safe!" This occurred numerous times before, during, and after the practices and I never witnessed an athlete responding with anything other than enthusiasm. Through the use of ritual speech patterns based on a shared enthusiasm for sports and its lingo, the OHSO athletes demonstrate competence can be performed even when it is not substantial in terms of the relevance it communicates. It does communicate a sense of play and camaraderie and serves to establish a rapport between some of the male athletes.

Not all sports talk was used to unify; in fact, there were occasions when it highlighted divisions between athletes who were fans of opposing teams. When athletes Ryan (A16), Matt (A9), Chris (A2), and Derek (A3) arrived at practices, they would begin by shouting for one of their favorite teams that were currently competing in the professional basketball playoffs. The majority of the men began yelling, "Go Heat!" while one countered by shouting, "Go Spurs!" This repartee became increasingly loud as they tried to outdo each other with the highest volume, but it appeared good-natured since many were smiling and laughing. At the next practice, after the Spurs had lost the final championship game, I noticed a couple of the guys started to chant, "Go Heat" when the Spurs fan arrived, but no one seemed to get too aggressive or defensive on either side and when it was clear that the Spurs fan's lacked enthusiasm for engaging in the banter, the other athletes let the subject matter die down. I was excluded from the conversation

because I was not competent in my knowledge about the professional teams or even aware that there was a championship game occurring, thereby supporting the cultural relativity of competence. In this instance, the young men were clearly more competent than I was concerning sports talk and were able to use their competence as a means to find a common ground (Shuman 2015). Demonstrating a sense of inclusiveness and bonding fostered through sports talk, the athletes were able to engage in a banter that was welcomed and reciprocated at the Special Olympics gatherings. When athletes initiated the call and response dialogue, no one said anything to the effect of “That’s not cool” or “I’m not going to play that anymore,” which could be the case with mainstream peers who might have a different sense of when repetition loses its charm and effectiveness in evoking humor and excitement. Similarly, fan behavior in the stands of any spectator sport is a matter of situated group understandings of what counts as cool, cliché, or passé. Put simply, fan behavior is a ritual performance that conforms to a particular group’s conventions.

Performing hypermasculinity or sexism can be perceived as going too far outside of the bounds of what are socially-acceptable norms promoted by OHSO and monitored by the coaches. One athlete is an avid fan of WWE wrestling and uses some of the language and behavior associated with hypermasculinity as a way to gain attention and provide humor. Standing at the start line during a practice round of the 100m dash, Ryan (A16) pulled up his shirt, swung his hips, and rubbed his belly, exclaiming, “Come and get it, baby!” to which the other athletes responded with giggles and laughter. He also shouted “Oh yeah!” and “Turn up the heat!” and other phrases that appeared to be

borrowed from WWE popular culture because when I looked quizzically at Coach Pete (C2), Coach Pete responded by saying, “We’ve got a WWE fan.” Moments like these were generally tolerated until they became too loud and disruptive, at which point the coach would tell everyone to settle down and pay attention. It is also noteworthy to explore other areas where the boundaries of what is acceptable are maintained. Although certain displays of masculinity and sexism might be competently performed, they are still considered inappropriate by the coaches and some of the parents who have an interest in the athletes behaving in socially acceptable ways, and further, who are concerned about the athletes’ lack of awareness of the stigmatizing effects of some behaviors. Some athletes exhibit self-control or embarrassment, but in large part, the parents and coaches consider themselves to be the enforcers in control of the situation. All of the participants participate in a delicate balance between the categories of acceptance and of being out of control.

Another example occurred after a track practice, when I was talking with a couple of the athletes, a parent, and the coach. I had my left hand on my hip and the coach bent over upside down in order to read the time on my wristwatch. One of the athletes chastised the coach and said, “Don’t look at her ass!” and the coach said something about lacking filters and then subsequently corrected the athlete, saying it was not okay to talk like that, which resulted in the athlete telling me he was sorry. In this example, the athlete was performing a ritual act of collusion because the coach was construed as looking, thereby providing the athlete with an opening to make a sexist remark that might be considered perfectly normal for a man of his age. It was also an opportunity to gain a

position of power by altering the balance of coach and athlete since in this instance, the athlete was the one who chastised the coach. Men and women can talk about each other's bodies amongst themselves and although it might not be acceptable or appropriate, it is not abnormal or atypical. However, in this situation, the athlete was not allowed to perform ritual sexism that might have been laughed off as a joke if he were an adult without disabilities. Conversely, perhaps the correction had nothing to do with him being disabled and instead fell under the category of a coach admonishing an athlete for inappropriate behavior, as seen in the examples of the coach quieting overly rambunctious athletes, inappropriate physical contact, or poor sportsmanship. In this case, the athlete was able to perform a particular type of competence in a sexist performance, but it was a competence that was rejected because it did not abide by the social rules mandated by the OHSO. Social rules for displays or talk of the sexual nature are less codified and, I would argue, fall under a general category of coach's discretion. Athletes are typically divided into teams by gender, but it is not clear what types of sexual displays are singled out as inappropriate or not. Based on my observations over the past twelve years, I have seen relationships develop between athletes and male and female athletes kiss, hug, hold hands, and engage in extended kissing and touching. I have also seen the coach remind them that it is time for sports and that they need to wait until they are done with practice or competition. I have not seen displays of sexual affection among athletes of the same sex although one of the athletes is openly gay and often wears pride colors for clothing or accessories. For OHSO athletes, certain competencies are encouraged and applauded whereas others are discouraged and corrected, which

highlights the tension surrounding imitation and competence and how the athletes are often monitored for fear that they will imitate popular culture inappropriately or perhaps risk further stigmatization.

Not all performances of identity among the athletes are hypermasculine; in fact, some of the demonstrations of togetherness challenge traditional notions of what might be considered typical team behavior, not just for mainstream sports but also what is considered typical for Special Olympics athletes and male-female interactions. I witnessed several moments of extreme tenderness and caring among the athletes where athletes used physical gestures to comfort, provide encouragement, and demonstrate a closeness that warrant further attention. At one track practice during the high heat of summer, Will (A16), one of the older athletes, was sitting down on the sidelines of the field with his head hanging. Derek (A3), another similarly-aged athlete, came over, patted him on the back, and asked if he was okay. Soon afterwards, a young girl (at least ten years their junior) came over and gently patted him on the back as well. Two other young men, Chris (A2) and Matt (A9), were nearby and Chris sat cross-legged with Matt's head resting in his lap while Chris placed his hands on Matt's chest. These four young men are some of the most vocal and outspoken engagers in sports talk and cheering, but their performances of togetherness display a fluidity and ease between loud and rambunctious speech and energetic high fives to tender touches of caring that transcend beyond what might be considered typical behavior by sports team members. Coach Pete (C2) feels strongly that certain touches are more acceptable than others and admits that while things tend to go in cycles and rules become laxer at times, things can get out of control, so he

needs to get back to enforcing his “high 5s, handshakes, no hugging” rule. Storey (2008) cites the acceptance and encouragement of hugging between volunteers and Special Olympics athletes as another proponent of negative stereotyping associated with the Special Olympics because not only does hugging infantilize adult athletes and make it appear that those with disabilities require the help of those without disabilities, it blurs the boundaries of what is acceptable behavior in terms of touching strangers (Storey 2008, 137–8). For the OHSO coach, it is not just a matter of regulating touch between athletes and volunteers, but also between athletes, because although it might just be a simple sign of affection for one athlete, it could turn into something more for others, and it can also be upsetting to athletes who are uncomfortable with physical touch. This is a difficult rule to enforce because the group is based on a sense of kinship that fosters a closeness and protectiveness where certain adults (parents, siblings, and caregivers) hug athletes some of the athletes even if they are not biologically related because they are like an extended family.

Another way in which the OHSO athletes ritually perform their identity is through gestures that mark the end of a competitive performance. Judith Butler argues that “acts, gestures, enactments, generally construed, are performative in the sense that the essence or identity that they otherwise purport to express are fabrications manufactured and sustained through corporeal signs and other discursive means” (170). In addition to Butler, Gary Alan Fine and Jay Mechling offer a particularly relevant insight to the stigmatized folk group because, through their fieldwork and analysis, they have demonstrated that children’s folklore is both very dynamic and very conservative owing

what Fine has termed “Newell’s Paradox” (Mechling 1997, 140). In his ethnographic study of Boy Scout troops, Mechling explores one of the predominant themes in children’s folklore—that of appropriating mass-mediated culture. I witnessed this in actions and sayings that were adopted by many of the athletes, sometimes to the point of *ad nauseum* for some of the bystanders (but not the athletes themselves) because the repetition and subsequent round of laughter was considered excessive and overused. One example was the athletes using the phrase “Wassup!” which would begin with a young male athlete saying, “Wassup!” and then the other male athletes would sing a round of resounding “Wassups!” This phrase was from an Anheuser-Busch campaign (1999–2002) that featured some friends calling each other and saying “Wassup!” and was then parodied in more commercials, movies, and sitcoms.¹⁴ I recently heard a radio advertisement for State Farm Insurance where a woman complained about her husband being caught in the past and he is heard saying “Wassup!” in the background, indicating this saying was considered funny a decade ago but has run out of its humorous potential because it is now considered passé. To say that now would indicate that someone is not “hip” to the current popular culture trends, but this did not appear to affect its use or reception among the athletes. Dorothy Noyes states that repetition is made possible by formalization, thus a rhythmic slogan enlarges an individual’s voice by coordinating it with others (1995, 469). In the case of these slogans and catch phrases, the Special Olympics athletes do not appear to be as concerned with the currency or relevance in

¹⁴ <http://knowyourmeme.com/memes/whassup>

popular culture or to the situation at hand, but are more interested with the effects the performance has in uniting the group as a team of insiders.

The second thing that I noticed was the mimicked gesture of bowing down as if in prayer at the end of a race or performed event. Unsure if this gesture was part of a memorial ritual dedicated to someone who was sick or had died, or perhaps a team prayer ritual, I asked one of the athletes what this meant. One of the athletes explained to me that it was “the Tebow,” modeled after a famous football player’s (Tim Tebow) gesture after he had scored a touchdown. Tebow’s performance is high profile and marks the act of a significant sports event—scoring a touchdown. In the case of disability, we cannot make the next step based on the Newell paradox that this is an aspect of popular culture that is being appropriated as resistance. Instead, it is a way of marking membership in the OHSO folk group. This is also something that could be considered out of sync or incongruent because the appropriateness of the gesture does not match the event it is marking—there is a significant gap between running in a relay or 100m dash (and not placing in the top three) and scoring a touchdown in a nationally-televised game. It could be considered stigmatizing by its lack of appropriateness because it seems excessive or out of place. If we were to witness high school athletes without disabilities gesturing in a similar fashion after completing their part, regardless of whether or not they won, would we find it appropriate or would we think they were being silly or ironic? These displays by the OHSO athletes show competence through an imitation of popular culture but could still be a mark of stigmatization because the gesture does not match the occasion and, therefore, signifies not passing. For the Special Olympians, however, it is not discordant

and I never observed someone criticizing a performance as not appropriate or no longer cool. Although I am not sure what it signified to each athlete, I imagine that it represented a job well done.

Do gestures like these reflect an exaggerated sense of competence and is this something that is a detrimental consequence of being segregated in the Special Olympics? Counsell and Agran (2013) cite studies showing that segregated recreational activities result in Special Olympics athletes having an increased perception of their physical competence when compared to those in integrated activities. They argue that although this should be appreciated in terms of heightened self-esteem, particularly in a population that has been marginalized and stigmatized, the overestimation of their perceived abilities does two things: (a) it does not give them an accurate reflection of their abilities when compared to those without disabilities; and (b) it is believed that “when students are informed about their ‘real’ capacity, this will motivate them to participate in more athletic activities in the future (Counsell and Agran 2013, 250). These criticisms point to two themes that are at the heart of the Special Olympics and the inclusion/segregation debate: (a) the values that we project on the self-perception of people with disabilities, and (b) the motivation to be a member of the “real world.” This is exemplified in one meaningful exchange I witnessed at a recent track meet between an athlete, his mother, and his peers. Special Olympics athlete Chris (A2) had just finished competing in the softball throw and had been awarded a medal for 2nd or 3rd place. He was visibly excited by receiving his medal and began shouting “1st place!” while stretching his arms to the sky and waving his fingers in the air. Chris was heading

towards a group of his friends and continuing to shout “1st place!” when his mother intercepted him and gave him a hug, telling him how proud she was of him, but informed him that he actually did not win first place and she was still very proud of him. Chris’s face fell and his head hung down for a few moments while his mother continued to encourage him and praise his efforts. For Chris’s mother, this was a teachable moment where she felt Chris needed to be aware of the true results of his efforts and to let him continue to shout that he had won 1st place would not have reflected the value of truth that is very important to her and a value that takes precedence over pride. Although it could be argued that his self-esteem could have been considered more important than the actual award granted, it could be countered that this was a way for Chris to learn that you can still have pride in your accomplishments, even if they do not lead to 1st place. After all, this corresponds with the motto of the Special Olympics, “Let me win, but if I cannot win, then let me brave in the attempt.”

Mascots

Questions about disability pride and self-esteem are especially complicated when we consider people with disabilities as mascots for groups without disabilities. Mascots maintain an outsider status at the same time as they are accepted with what I will describe as quasi-insiders using Goffman’s categories of “phantom acceptance” and “phantom normalcy.” Folklorists have long been interested in iconic characters who exist on the periphery of communities—not quite insiders, not quite outsiders. We might recognize depictions of people with disabilities as changelings, totems, tokens of inspiration, blind

seers, numskulls, or local characters who have served as motifs in folk narratives and legends [Narváez 1991; Eberly 1991; Tye 1989]. We have only just begun to look at the role these characterizations might play in stigma and in everyday life, and ultimately, the impact these characterizations have in terms of fostering or inhibiting inclusion. In the previous sections, I explored some characterizations and perceptions of people with IDD and how they fostered or deterred acceptance of people with IDD as full persons capable of growth and a range of abilities. In my research and experience with people with intellectual and developmental disabilities, or IDD, and their caregivers, the topics of inclusion and acceptance frequently arose as parents struggled to find ways for their adult children to be accepted in the community. Caregivers shared narratives about times when their children were included by their peers without disabilities and although it could be interpreted that the illusion of normalcy and acceptance was offered through the frame of the mascot, it was a far better alternative to the isolation, rejection, and bullying they feared most. In addition to the narratives that arose from my ethnographic data, I found numerous examples in the media indicating a growing popularity of stories of acceptance and inclusion, specifically in the form of challenging traditional notions of competition by allowing a person with disabilities to accomplish a feat they would not have otherwise been able to perform and the election of a person with disabilities to a high school Homecoming court. I am interested in exploring the values attached to these narratives and characterizations, who is being chosen to occupy these roles, and why. What do these ritualized moments represent in terms of inclusion and acceptance? By exploring these moments and their surrounding narratives from a perspective informed by folklore and

disability studies, I argue that although they may result in positive feelings, a heightened sense of altruism, and a renewed faith in humanity, they can be dangerous when uncritically embraced as a short-term solution to a much deeper problem.

The notion of people with IDD being perceived as mascots for communities without disabilities, either as a source of inspiration or as a person locally known and easily identifiable by many in the community, arose in a couple of interviews with parents of Special Olympics athletes and also with one of the coaches. I first heard the term “mascot” in an interview with two families of Special Olympics athletes. Derek’s (A3) mother, Eileen (P5), told me a story about when Derek was moving into the fifth grade, the gym teacher informed her that Derek would no longer be able to participate in regular physical education (PE) classes because the level of competition was increasing and they were going to start choosing teams. Eileen was distraught and spent the summer worrying because participating in PE with his friends was very important to Derek. In the fall, Eileen discovered that a new PE teacher had replaced the former teacher, and she met with the new teacher to express her concerns. The new PE teacher said he would talk to the kids to get their opinions. Eileen reported, “Apparently he talked to the fifth grade boys and said, ‘Ordinarily in fifth grade, we start to do these teams and we want to know how you feel about it’—not asking anything about Derek.” Paul, one of the big athletic boys who would most likely become a team captain spoke up and asked if it was okay if they didn’t do it that way, but instead did it “Derek’s way.” Eileen said the coach asked, “Well, what’s Derek’s way?” and the Paul said, “we call it Derek’s way—it means whoever hasn’t had a turn gets a turn.” The coach came to Eileen and explained that the

kids were actually panicked about the switch and felt considerable anxiety about who was going to be picked for which team, who was going to be first, who was going to be last, and as she noted, “even this kid who’s going to be definitely the one picking—he doesn’t want to have to pick. He wants to just play it with whoever doesn’t have a turn.”

The coach ended up letting Derek participate in the regular PE class and Eileen believes that Derek made it easier for everybody not to pick competitive teams. Eileen contacted Paul’s mother to tell her how wonderful her son was and his mother told Eileen that Paul had actually been very worried about the responsibility of having to always pick teammates and whether or not to pick his friends or those who are the best athletes, and he didn’t want to be in that position.

Although Eileen was impressed by Paul’s rejection of the competitive model because it created a new set of problems, choices, and anxieties that made him uncomfortable and the embracing of “Derek’s way” as a means through which everyone could have a turn, one of Derek’s special education teachers cautioned Eileen against embracing her son becoming a mascot-like figure. How could this be interpreted as anything less than a positive gesture, an acceptance of someone different from the rest at an age when peer pressure, insecurities, and the desire to fit in create tensions and atmospheres ripe for bullying and exclusion? When does inspiration become a token of characterization? In this example, Paul was able to use Derek as a means to represent a way of being that rejected a competitive practice that did not feel good for many people. By labeling it “Derek’s Way,” Paul and his peers were able to supplement an anxiety-producing practice with a call to recognize fragility and humanity, a way to reject the

impulse to measure, and to let everyone have an opportunity to participate. Was Derek a mascot or was he a source of motivation—and can they truly be separated?

In my second example, Maddie's (A8) parents, Cathy (P3) and Robert (P14), talked about how their daughter was "one of the most popular people in the community." Maddie has two older brothers who were into various sports, and when their friends would come over to the house, she would wrestle and play with them. According to her mother, she "was sort of the team mascot-type person." Cathy said she would never forget being at a baseball game and some of the people that had wrestled with one of her sons came over:

C: They would walk in and they would all come in-these were like hunks of guys-and they would give Maddie a big hug-and just groups of them. And my friend came over and she says, 'she must be the envy of every girl in high school' [laughs] and to this day, she doesn't go anywhere without all these gorgeous guys coming up and giving her hugs and everything.

Cathy also made mention of how the small close-knit community was friendly towards her daughter. While the community has been nothing but accepting of Maddie, Cathy's issues with exclusion have been not with the community, but with the lack of available jobs for Maddie in the community. Maddie now works in a sheltered workshop. I explore in more detail Maddie's experiences trying to find employment in the community in the chapter on Jobs, but for now, I observe that her parents feel that Maddie is happy where she is, and they find comfort in the belief that the sheltered workshop provides her with a safe and stable opportunity to engage in work and social activities.

Not everyone finds solace in their adult child being recognized in the community as the recipient of friendly greetings, and for some parents, this is only a token gesture of

acceptance and does not translate into true inclusion. Patty's (A12) parents, Beth (P1) and Rick (P13), report that although there have been no more invitations to parties, there have been momentary points of acceptance where people are friendly to her daughter, like at the Memorial Day parade when "everyone says 'Hey, Patty! Hi, Patty!'" but that's the end of it." The community members' acknowledgement of Patty at the public parade is better than being ignored, but it is still a rejection because the interaction stops there. According to Rick, "it's like Patty's the town retard." This is a critical moment because Rick is giving an exoteric perspective of how he thinks others in the community view his daughter. His choice of "the r-word"¹⁵ is particularly strong because he knows the stigma associated with that word, and it could be an accurate reflection of his anxieties and anger about his daughter's exclusion. Why does he choose this word and what work is he doing to place his daughter in that category? Beth stated that although it seems as if everyone knew Patty, Rick concluded, "They don't want anything to do with her." Rick said, "I don't think that they think pejoratively about Patty; they just think, 'Well, hi, Patty. I don't know what else to do. See ya later.'" Beth confirmed similar feelings when she added, "They don't know that there is a real person here who has feelings and thoughts and ideas and wants." On the one hand, Rick is placing his daughter in the category of a local character that people know but do not know how to interact with, and yet on the other hand, he qualifies that he does not think the community views her pejoratively. His

¹⁵ I do not feel comfortable using this word because unlike the words "crip" and "queer" that have been reclaimed by disenfranchised groups as recuperable, "the r-word" still carries a significant stigma and I'm unsure if it will ever be recuperated

wife concludes that it is merely a characterization, that this categorization denies Patty's full humanity.

Neither Maddie's (A8) parents nor Patty's (A12) parents said that their adult child with disabilities is definitively a mascot or "the r-word", but rather (as in Maddie's case) "sort of the team-mascot-type person" and (in Patty's case) "like the town retard." Both sets of parents share collective observances of how what they perceive is qualified acceptance, but by using the modifiers of "sort of" and "like," they are also signifying that their adult child's acceptance or status is still somewhat ambiguous. On the one hand, it is a sign of those outside of the close network of people with disabilities recognizing and acknowledging (and for Maddie, actually giving her hugs) a person with IDD, but on the other hand, these characterizations signify that they are perhaps not fully realized.

These parents' perceptions also reveal differing perspectives about closeness of networks and the investment people have in engaging with different people in their community. Maddie has more potential of being recognized and embraced because the boys relate to her brothers as teammates and have become familiar with her over the years, since she has accompanied her parents to many of her brothers' sporting events. Patty is the oldest and has two younger sisters, which is not the same dynamic as being the younger sister of two athletic brothers. Also, the frame of the Memorial Day parade is not necessarily an occasion where people engage in lengthy interaction, and while it could be that this is an example of Rick's expectations not matching the usual type of engagement in this type of contact zone, it does serve to elucidate his point that she is an outsider in the community and not seen for her full potential.

Part of the movement for inclusion that I addressed earlier focuses on early interaction between students with and without disabilities, so I was eager to hear more on a topic from one of the coaches who has first-hand knowledge of these interactions. I spoke with one of the coaches who is also a special education teacher and he told me how he used stories of kids acting kind to people with disabilities to inspire and motivate students without disabilities to be better people and more accepting of those with disabilities. As a teacher in special education and a coach for the OSHO, Nick (C1) has worked with both middle and high school students and has seen the differences in acceptance among the different ages, school cultures, and genders. He noticed that the gap between students with and without disabilities is not as wide in elementary school when they are able to learn basic skills together, but once they reach middle school, some of the concepts are more difficult for others to grasp, so the gap widens. In high school, the gap is even wider, but Nick believes that there is an added dimension of maturity and empathy in high school that enables some to become more accepting and understanding. Nick also admitted that it has a lot to do with the culture of the school and their parents; in addition to what he's noticed is a gender divide in terms of the majority of peer volunteers who help in his classroom have been girls.

In an attempt to spur more attention and appreciation for acceptance, Nick spoke to one of the middle school guidance counselors to organize a town-hall style of meeting for the sixth grade students. They decided to show two videos they found on the internet about a group of students who did something special for someone else. He explained:

In one case, the one video I found that I love is there's this little first grade boy and he's different, he's got a speech impediment and he dresses

different, he wears like a suit and tie, he's the manager of the fifth grade football team. So all these fifth-grade boys found out – there's like 45 of them – they found out that he was being picked on at school by the other first-graders, so the fifth-grade boys all decided to show their support for him, they were all going to dress like him, so they all wore suits and ties to school and it was just like – during the interview, a 10 or 11-year-old boy with the interview started breaking down crying, saying how much they loved him, and in that moment I'm just like, "if that's my son, I'm a super proud dad. He gets it."

Later on in the interview, Nick contemplated the change that he witnessed from seventh to eighth grade in the number of mainstream volunteers he had helping with his students with disabilities. He said had the most volunteers from seventh graders, and the number dropped once those students hit eighth grade, and he saw the largest decrease for boys.

He wondered what was causing this drop and if it wasn't, "cool" to help in his room, why were so many people doing it? He asked, "Who determines coolness? Now that one boy-that fifth grade team decided he was cool, but is that a good message? The football team thinks you are cool, so that's what makes you cool?"

Nick then went on to talk about the other examples he wanted to show and talk about with the town hall type of assembly he was planning:

Did you hear about the football game? I know a whole lot of them are, like, athletic related. I guess this team was about to score and this boy was running to score a touchdown and he stopped and went down right at the one-yard line on purpose. And the coaches have no idea what he's doing. There's a player on their team who has Down Syndrome and he never plays. And the kid went in and said, "He's going in in my spot and he's scoring the touchdown." And the adults had no idea of this. The kids all planned it. And they did it. It was pretty cool. And that's the thing – like these kids did this on their own. Be those kids. Being a kid takes the initiative, besides that you want to do good, you don't need to be told to do it, you don't need the award to do it, you do it because it's the right thing.

Nick begins by observing that many of the celebratory moments are “athletic related” and recounts the story of the boy with Down Syndrome who scored a touchdown at the high school game. Nick finds this story significantly poignant because “the kids all planned it,” which he repeats for emphasis when he adds, “these kids did on their own.” For Nick, the fact that the kids took the initiative is the most significant component to his narrative, and what he categorizes as doing “the right thing.” He then follows with a similar story about a person with disabilities who was elected to the high school prom court, but at the end of his story, he immediately turns to my question about whether these actions could also be considered part of the “mascot mentality”:

I want to tell them that I had a girl that I taught four years ago – two years ago – as recently as two years ago – and last year she was on the prom court – was it prom court or Homecoming court? In high school. And I had a kid two or three years ago when I was teaching and these were students from my class and he was prom King. And I just think those things in high school are popularity contests and again, why not give it to someone – where they should be the way it is in college when you apply for it and it’s based on your grades and your service and things like that – those aren’t the people who ever get recognized for those sorts of things, but someone else was. They didn’t do the most popular person, a group of students got together and said let’s nominate him, and he got on the court and they said were going to vote for him to win and he did and it was such a special moment. I mean it was so cool. I don’t even think he grasped what it meant to be that but it was really, really cool. He was happy. His parents couldn’t believe it. And the whole school loved it. I mean if he wouldn’t have won – it had to have been a landslide vote. I mean, it was so special for some kid who maybe thought, ‘Oh I was going to be that or whatever.’ Hopefully, they may have not have been the person that said let’s go ahead and nominate this person, but everybody who could have been otherwise stepped aside and gave that up to give it to someone else who maybe isn’t going to have that opportunity later. And I just think that that’s neat. I think it’s neat for the whole school to see that whoever it was that decided they wanted to try and get that to be done got it to happen. And it can happen. And it should be recognition for someone else to have that moment. I don’t know, I worry a little bit about things like that, like you said, like the mascot mentality thing and having them be like a caricature or something.

Stories of allowing the honorary team member with disabilities to score a goal or a touchdown are not uncommon, but what work do they do? What lessons did these stories teach, how were the people with disabilities portrayed, and how was the message of acceptance conveyed? Perhaps more importantly: what were the long-term effects for all of those participants involved? For Nick, it is clear that the back-story that concerns the planning and the kids' initiative is more important than the outcome being everyone's happiness. It is also important to recognize that these narratives do not exist on their own but have been created in an environment where news stories tell the horrors of bullying and teasing, where we all likely have memories of the poor treatment of ourselves and/or others who did not fit in with the popular crowd. With the widespread awareness of social media bullying, teen suicides, etc. is it any wonder that people are looking for feel-good stories that counter the image of high school being a scene from "Carrie" (1976; 2013)?

What are some of the obstacles facing individuals with IDD in terms of being included with their peers without disabilities? Tom Shakespeare moves beyond the social model of disability, which focuses solely on the barriers residing in society's stereotypes and stigmatizing practices, to look at some of the factors caused by some impairments that can make social relations more difficult. In addition to speech and hearing difficulties that can make communication difficult, Shakespeare mentions the following factors:

For example, people with learning difficulties may not behave conventionally or understand the subtleties of body language and ironic banter. People with mental health issues or cognitive impairment may lack insight, become anxious or suspicious, or otherwise interact in unusual ways. They may forget previous conversations or social contact. The lack of eye contact may be disconcerting for people unfamiliar with visually impaired people. In other cases, physical difference or deformity may be very distracting. As Erving Goffman (1968a) described, the effect of stigma

is to undermine the possibilities of interaction, at least at the outset. It is difficult always to attribute these impairment effects to oppression or discrimination, rather to social embarrassment or unfamiliarity. As Lenny and Sercombe (2002:16) observe, ‘the dynamics at work when people with disabilities interact with others are complex and contradictory’ (Shakespeare 2006:176–177).

Investigating such interactional dynamics further, special education author Richard Lavoie discusses expectations about friendship and how difficult it can be with people (he focuses specifically on children) with IDD to find and maintain friendship, which he defines as “a mutual relationship formed with affection and commitment between people who consider themselves equals” (2005, 307). Lavoie believes many problems occur when people expect children with IDD and social skills problems to become friends with their peers because children have different developmental levels when it comes to peer interaction and how they perceive others. While Lavoie is looking specifically at children, and I am interested in individuals with IDD who are 18 or older, I do not want to apply his analysis to my research with the implication that I am infantilizing the OHSO athletes, but I do want to consider the framework he provides as a way to think about different relational competencies and how this applies to inclusion. Citing the work of Dr. Robert Selman, professor at Harvard University’s Graduate School of Education, Lavoie explains that children with IDD can face obstacles progressing along five developmental levels of friendship:

- Level 0 (ages three to seven)¹⁶—relationships are based on proximity, adults are needed to initiate and maintain friendships, and child is unable to understand others interpret same situations in different ways

¹⁶ I am uncomfortable with developmental timeframes such as these because there are so many individual factors involved but I am including them as he cites them.

- Level 1 (ages four to nine)—child begins to understand perspectives of others, friendships are created out of mutual interests, and child begins to recognize unique skills of friends
- Level 2 (ages six to twelve)—child begins to understand how he is viewed by others, compromises occur, but relationships are still very fragile and minor offenses can end relationship
- Level 3 (ages nine to fifteen)—friendships become more mutually supportive, two-person cliques featuring jealousy and possessiveness can be formed, disagreements can occur without ending the friendship
- Level 4 (fifteen to adult)—relationships become more solid and benefit both parties, possessiveness decreases as both parties recognize need for other relationships, friendships occur at varying levels of intensity (343–345)

Lavoie uses this system to help explain to parents how difficult it might be for people with varying degrees of difficulties in social skills to be friends when individuals are on different levels. He also cites Mel Levine's (founder of All Kinds of Minds) list of social competencies for children to maintain friendships: relevance, affective matching, timing and staging, social memory, social prediction, recuperative strategies, awareness of image, and feedback cues (345–350). Based on my observations of many of the OHSO athletes, I would estimate that few of them possess all of these competencies and yet they would still likely believe they could call multiple people "friends." I am unsure to what extent those friends are more like kin because of extended ties, proximity, and shared status and experiences, but these frameworks are useful in a general sense when applied to the idea of inclusion and how the discourses surrounding the mascot as being included is more superficial because the reciprocity and depth require more competencies that many people with or without disabilities do not typically have. In his discussion on disability rights and the future of charity, Tom Shakespeare cites Jewish philosopher

Maimonides who reserved the highest rung on his “golden ladder of charity” for interventions that “removed the structural conditions which made people dependent on the generosity of others” (2006, 165). If we were to employ this philosophical standpoint to inclusive efforts—moving beyond the act of voting someone for Homecoming Queen or King or allowing the team player to make a touchdown when they normally would not have such an opportunity—I argue that the ultimate goal involves looking at the barriers preventing more meaningful and lasting interaction between disabled and non-disabled members of the community. Although I recognize that developing balanced friendships or relationships might be difficult because some supports might very well be necessary to establish and maintain working these relationships, I believe that increased interaction can challenge traditional conceptions of normalcy and provide contact zones where people can find ways to recognize and respect commonalities and differences.

Characterizations

For the final part of this chapter, I turn to some of the most difficult issues facing characterizations of people with disabilities. Somewhere between the extremes of being pitied and being exalted as inspirational, people with disabilities and their families strive to be seen as normal. This is difficult, especially because the conditions for acceptance are often limited to pity or inspiration. I will provide examples of some of the most problematic situations I discovered in my research, and although I cannot resolve them, I hope to demonstrate how folklore research, including approaches to ritual and performance, can be helpful. Characterizations of people with disabilities have evolved

from both a folklore and disability studies point of view. In his book *No Pity*, Joseph Shapiro argues, “no other symbol of disability is more beloved by Americans than the cute and courageous poster child—or more loathed by people with disabilities themselves” (1993, 12). The poster child, according to Cyndi Jones, publisher and editor of *Mainstream* (a disability rights magazine) points out that the poster child image oppresses, plays on fear, says it’s not okay to be disabled, and “if you just donate some money, the disabled children will go away” (14). Folklorist Marilynn Phillips has examined how the poster child campaign of the mid-1940s and 1950s evoked images of a cure, but that there were never poster adults because “disability was barely tolerable—and only to be pitied—when it struck cute and innocent children” (15). Soon afterwards, the polio vaccine was invented and the fear of polio decreased—but the vaccine was not a cure for those who had already been affected by the virus. This, according to Phillips, put the onus on the disabled children and adults to “‘try harder’ to prove themselves worthy of charity and society’s respect. If science could not cure disabled people, then society would expect them to cure themselves” (15). Beginning in the mid-1950s, the “valiant ‘crippled’ child on crutches, trying to walk” became the new face of the poster child campaigns (15). As a result of the societal expectations to try and overcome one’s physical impairments, those who tried to walk using heavy braces and crutches were praised for being the “best” polio patient, while those who used wheelchairs were viewed as being lazy (16). Ironically, in the 1980s a consequence of pushing oneself too hard became known as post-polio syndrome, where those who had exerted themselves the hardest had increased atrophy of their muscles (16).

The opposite end of the poster child that is intended to evoke pity is the “supercrip” who is deserving of respect only when proven “capable of overcoming a physical or mental limitation through extraordinary feats” (16). Rather than being accepted on one’s own terms, the supercrip and the poster child are obstacles preventing meaningful inclusion because they are based on extreme stereotypes that evoke strong emotions of either pity or inspiration, effectively making people into caricatures rather than opening opportunities for inclusion based on full personhood.

The Homecoming royalty with disabilities could also belong to the third visual rhetoric of the exotic because they are still removed from the ordinary, distanced from potential normalcy due to the sensationalism and entertainment capitalized upon through their differences, and temporarily elevated to a celebrity-like status. Garland-Thomson points to photos of fashion models with missing limbs and a hypermasculine tattooed man in a wheelchair as examples of how rather than concealing, normalizing, or erasing stigma, photos like these “use the hyperbole and stigma associated with disability to quench postmodernity’s perpetual search for the new and arresting image” (69). This is where the images and narratives of Homecoming Queens and kings with disabilities do not fully align with the exotic because overt sexuality is ignored or dismissed. Many parents and caregivers (and also disability studies scholars) are reluctant to discuss the idea of people with IDD actualizing their sexuality. Being affectionate and demonstrative is acceptable, but at what point is the line drawn before the affection turns sexual and who is allowed to access this aspect of full personhood? For example, in one video Alex Milan, a young woman with Down Syndrome who was elected Homecoming Queen, is

shown walking through the halls arm and arm with the Homecoming King and star quarterback, then interviewed while sitting next to her mainstream peers, again with her arm intertwined with the quarterback as she strokes his arm, rests her head against his shoulder, and blows kisses to someone off camera (Mack 2012). Her behavior is accepted because of her mascot status and the abundance of “love” that she expresses for everyone, which is something that was a common sentiment attributed to many other Homecoming Queens with intellectual disabilities. This was acceptable because expectations of appropriate behavior and boundaries are loosened when someone is a mascot. This type of behavior is worrisome because it does not translate well for people who often lack the cognitive skills to understand the differences in expectations, obligations, and behaviors among people who are friends, loved ones, acquaintances, or strangers. It also highlights the overly polite gestures offered by those without IDD to those with IDD but not how these acts of kindness can be both misleading, infantilizing, and potentially harmful because they do not acknowledge the possibility that affection can and does become sexual.

It is fascinating to note that the news stories that did not mention a Homecoming Queen’s generous loving nature and willingness to give hugs and smiles and instead focused on the young women earning their titles fairly and not because of sympathy votes were the individuals with physical and developmental—not intellectual—disabilities. In fact, the discourses threading through their stories were dialogic, situating themselves as counter-narratives to on the one hand, people being nominated as a cruel joke, and on the

other hand, people being elected Homecoming royalty because of their peers' good-willed charity.

Alison Kafer's work on the Values.com/Foundations for a Better Life (FBL) group is particularly useful for understanding the underlying messages that provide the subtext for inspirational billboards promoting the narrative of overcoming. Citing billboards featuring Whoopi Goldberg's ability to overcome dyslexia through hard work, Michael J. Fox's optimism and determination to combat Parkinson's, Christopher Reeve as "Super Man" because of his strength, to name a few, Kafer deftly unpacks FBL's portrayal of disability as "an individual physical problem that can best be overcome (and should be overcome) through strength of character and adherence to an established set of community values" (2013, 89). According to Kafer:

The focus on personal responsibility precludes any discussion of social, political, or collective responsibility. There are no billboards touting solidarity, or social change, or community development; none of the images celebrate disparate groups coming together to engage in coalition work. There is no recognition of ableism or discrimination or oppression in these materials, only an insistence that individuals take responsibility for their own successes and failures. As a result, disability is depoliticized, presented as a fact of life requiring determination and courage, not as a system marking some bodies, ways of thinking, and patterns of movement as deviant and unworthy (89).

Kafer does offer an oppositional reading towards the end of the chapter where she examines the image of a young baseball player, Justin Stokes, who is sitting in a wheelchair holding a baseball bat while being surrounded by his teammates who are also in wheelchairs. The words "a league of their own" followed by "OPPORTUNITY" invite the reader to believe that the baseball players are doing well because they have been afforded the opportunity to play in their own league (99). I visited the website to learn

more information about the story and the message supported by the website and read a caption written by his mother who explained that Justin and his teammates are part of the Miracle League, which is:

[A] league of kids with physical and mental challenges that have the opportunity, thanks to a specialized field provided by various donors, to play baseball. They have ‘angels’ that help push their wheelchairs along the bases, parents and families constantly cheering them on, and fans that come from miles around just to see them play. No one keeps score, everyone gets to bat and everyone wins. When Justin is on the baseball field, he is part of a team like all of his friends and is treated just like any other kid. Through his experience, he has been able to discover his unique talents instead of focusing on his disabilities. He has realized that his disease does not have to limit what he can accomplish. Justin is incredibly strong and he has taught me that life is a journey with endless opportunities to become more than what we are.

In Kafer’s oppositional reading that utilizes tools from feminist, queer, and disability studies scholars, she contrasts this image with the others in the Foundation for a Better Life series by highlighting the emphasis on community rather than focusing solely on one’s individual efforts and achievements. Kafer argues that this sign can be interpreted as both a recognition that people with and without disabilities need opportunities and resources to thrive and a call for increased social responsibility (99). Acknowledging her interpretation is not likely congruent with what most people take away from the billboard, Kafer recognizes that most will view this through a heavily sentimental lens in which “‘Opportunity’ reads not as part of a collective responsibility, as something tightly woven in structures of privilege and oppression, but as a personal obligation to those imagined as far less fortunate than oneself, a private gift completely divorced from ableism, discrimination, or inequality (99).

Applying this emphasis on community to the election of Homecoming Queens, we can ask whether this is a community's attempt to be collectively responsible? The forms through which collective responsibility are demonstrated and interpreted reflect the complicated histories of representations of individuals with disabilities and moments of visibility and inclusion. In two of the examples prominent in the media for Homecoming Queens with disabilities I observed some common patterns and tropes, and one of the most significant similarities between the two girls was that they were developmentally, but not intellectually, disabled.

The first example is Melissa, a teenager from California, who has been “confined to a wheelchair by cerebral palsy” and ran for Homecoming Queen to serve as an inspirational role model and to boost the self-esteem of kids like her.¹⁷ From the opening paragraph, cerebral palsy is portrayed as something that has a tragic component that sets up an adversarial framework of individual versus disability as it is described as something that confines one to a wheelchair, rather than portraying Melissa as an active agent who uses the wheelchair as an adaptive mechanism. The article's author then notes that Melissa campaigned “long and hard” by participating in skits, games, and contests, hanging up posters, and reaching out to others to “show off her personality to students who may not have known anything about her beyond her wheelchair.” Melissa's mother further emphasizes Melissa's meritorious victory by admitting that although she is heard of cases where people felt sorry and voted for the “disability kid,” her daughter “worked

¹⁷ <http://www.today.com/news/cerebral-palsy-student-crowned-Homecoming-Queen-1D80231088>. Accessed October 21, 2014.

her butt off” to win “fair and square.” The high school principal also acknowledges hearing about other schools where spots are reserved on Homecoming courts for students with special needs, but that this is not the case in his school, where she was nominated and won “legitimately”—that is something he interprets as being “really indicative of the type of kids and staff we have at this school...They’re an inclusive group that looks at people for who they are.”

While I am not questioning Melissa’s intentions to educate others about who she is beyond her disability, her competitive willingness to participate in the same competitions as the her rivals on the Homecoming court, nor the impact her outgoing personality that has had on those around her, I do feel the following items warrant further attention: (a) the portrayal of Melissa’s cerebral palsy and wheelchair as confinement (denoting a tragedy of sorts); (b) the counter-narrative that Melissa’ mother and principal allude to by making it very clear that Melissa was not chosen out of sympathy or pity and that her win is thus legitimized; and (c) that this legitimate win is a testimony to the inclusiveness of the students and staff at the high school.

The first issue sets up the frame that Melissa’s disability is somehow negative and tragic since it confines her to a wheelchair and she must fight hard to get people to look beyond her wheelchair to see her for who she really is. This coincides with the visual rhetorics of the sentimental and supercrip because it focuses on the narrative of hard work and effort that she must demonstrate in order to gain acceptance. However, it could be countered that Melissa’s mother’s statements supporting her daughter’s efforts could be viewed as legitimizing her inclusion as an equal among her peers because the rules of

competition were not altered to afford Melissa an unfair advantage (something we don't often see in other integrated activities such as Unified Sports where although it is based on normalcy and inclusion, the rules of competition are sometimes more flexible in order to give the lesser skilled athletes better chances at succeeding).

The second issue that demands exploration is the assertion by both Melissa's mother and the school principal that Melissa was *not* chosen out of sympathy or pity. In Goffman's (1967) terms, making a claim to be "not" something is a form of impression management as each person frames the event and the actors involved as playing a certain role (31, 44–45). Two things are occurring in these conversations: (a) there is a face-saving movement that protects the nominated person for being chosen out of pity or sympathy; and (b) the people who are saying the votes are not out of pity are claiming the choice as legitimate and warranting higher value. In *Frame Analysis*, Goffman also discusses the challenge faced by representing someone as both having diminished capacity and as a legitimate participant. His example refers to women who are treated differently as both as a matter of respect and acknowledgment of their limitations (1974, 196–197). In this case, Melissa's mother and principal speak as ones who have the knowledge and authority to represent the student body as collectively acting out of genuine respect and following a particular ethos of competition. For the mother, this is acceptance of her daughter's hard work and personality and, perhaps vicariously, successful parenting. For the principal, this is a reflection of his school and his successful leadership. It appears they are familiar with high school students voting for someone to be a Homecoming Queen or King out of sympathy, which can be read as an illegitimate

reason or inauthentic inclusion. It is possible that some nominations are examples of what Edgerton (1967) refers to as “benevolent conspiracy,” or when as Gerber explains, “a normal co-conspirator gives praise, moral support and practical instruction in acceptable social behavior to a retarded employee, tenant or neighbor, and thus helps sustain the masquerade” (1997, 17). It is better than bullying or nominating someone as a joke, which is also an inauthentic form of upending a social ritual, but it is still not the same as being the true goal: nominated for one’s “true” nature that goes beyond the disability and seems to tread into a category complicated by a desire for the extraordinary (Homecoming Queen/King) while still being ordinary (“normal”). This was alluded to in the case of Alejandrina Guzman that I will explore next, and is a positioning move that places some people with disabilities as “legitimate” winners and truly included, while simultaneously distancing themselves from other people with disabilities who might not have worked as hard and were awarded the vote out of sympathy or pity, and are therefore not really included. It also serves to mark the peers and community as people who are viewed as casting sympathy votes as not truly inclusive. The possibility that people either voted for the people with disabilities because it made them feel better about themselves for doing a charitable act or that they would have conversely felt badly about themselves if they had not voted for them and had chosen one of their competitors instead are two options that remain unsaid or untellable. Why is this narrative possibility silenced?

Stories about homecoming queens with disabilities generate several possible narratives, some of them more tellable than others. The stories are often promoted as

narratives about inclusion, but the protagonists of these stories are not the person with disabilities but instead the good-hearted students without disabilities who are portrayed as having genuine feelings toward their classmates with disabilities and whose acts are an example of their generosity. As a result of the election of people with IDD to the Homecoming court, the whole community benefits from feeling better about themselves. The question of charitable tolerance is a complicated issue that extends far beyond the scope of my research and cannot be fully addressed here.

In addition to the people who elected Melissa Homecoming Queen, the people supporting Melissa on a more familiar level are also important, evidenced by Melissa's expressions of gratitude to all of the great people in her life who support her. For Melissa and her mother, although Melissa fought hard for her position as Homecoming Queen, it was not a solitary battle and I argue that this highlights the tension between the individual and community responsibility. Kafer states that a reinterpretation of "opportunity" read from a critical feminist, queer, and crip perspective emphasizes a collective responsibility to ensure that people with disabilities have the opportunities to rise. Kafer cautions against reading opportunity through a sentimental lens that stems from a feeling of personal obligation to those imagined less fortunate, and I argue this sentimental rhetoric is the subtext that Melissa and her mother are arguing against, but I worry that they are not able to divorce it from the confines of ableist discourse or the possibility that there were those who did vote out of sympathy. The students who vote for the individuals with disabilities may very well have honorable intentions. They appear to want to be charitable without being seen as charitable, and while I am not necessarily saying that being

charitable is bad, I do believe it can have negative consequences. I believe this is why some of the Homecoming Queens are rejecting the possibility that there was a charitable element involved, but I am concerned that their responses incorporated the ableist discourse that can be just as damaging.

The ableist discourse and the distancing move away from those who might have won the Homecoming Queen due to sympathy votes is also apparent in the example of Alejandrina Guzman. Alejandrina Guzman, a senior from Azle High School, was surprised to learn that she was elected Homecoming Queen. She cried when her name was announced, thanked her classmates for enabling her to represent them, and said, “I just want to tell people never to give up. Keep trying and dreaming.”¹⁸ In the article, Alejandrina’s story is framed as extraordinary because when she was born, her doctors told her parents she would not live more than one day. She has a rare condition called diastrophic dysplasia that hinders her bone and cartilage development, she “is 2 feet 8 inches tall, with abnormally short arms and legs...has a cleft palate that gives her voice a high pitch and has clubfeet that turn inward. She cannot braid her own hair or drive a car.” While these aspects of her disability might be considered to be limitations or things that set her apart from others, for Alejandrina, “my disability is what makes me.” She rejects the possibility that she was nominated out of pity and that it is because of who she is and how hard she works that she won the title of Homecoming Queen. In addition to mentoring elementary school students, being a member of the high school’s spirit squad,

¹⁸ <http://www.star-telegram.com/2012/10/25/4365113/azle-Homecoming-Queen-nominee.html>. Accessed October 21, 2014.

serving as vice president of the National Honor Society and a Student Council representative, Alejandrina creates video blogs discussing her disability and encouraging others to be thankful for what they have. For example, Alejandrina asks her internet audience in a video, “Do you try to make the best out of every day? It’s hard. Everything is hard. Life is hard.” Her determination and strength of will are cited as some of the traits that make her stand out among her peers and this is by Alejandrina’s statement that “the only limits in life are the limits you place on yourself... I want people to understand they can accomplish whatever they want if they are willing to do the work.” This sentiment is supported by her teacher who says that Alejandrina “tries harder than everyone else in the room, and she shines...No matter what obstacles present themselves, she will overcome or just figure out a way to go around,” and her principal who states, “[s]he is always smiling, always working hard.”

I am concerned that these statements reflect an underlying ableist discourse that is critiqued by many in disability studies (Brueggemann 2009; Campbell 2008; Cherney 2011; Garland-Thomson 2002; Kafer 2013; Price 2007) because it is linked to society’s demands that the person with the disability be valued for their extraordinary abilities and determination to overcome the adversity created by their disability. Kafer (2013) refers to this in her coverage of Wehmeyer’s Everest climb and the supercrip, and the feats that garner attention and respect from the nondisabled toward the disabled. It is not inclusion based on normalcy or ordinariness; instead, I argue that these characteristics are unrealistic demands that few people, disabled or not, can meet in everyday life. Is trying harder than everyone else typically the standard of measure against which Homecoming

Queens and kings are judged? Does one need to “always” be smiling and overcoming obstacles? According to Goffman in his work on stigma, it is precisely what is demanded of the stigmatized in order to fulfill the requirements of out-group alignment with the “normals” so that the individual must not deny one’s difference, but should try to fulfill ordinary standards as fully as possible through hard work and persistent self-training (1963, 115). In addition, “a cheerful, outgoing manner should be cultivated” to demonstrate to the normals (who have their own problems, too) that the stigmatized individual does not possess bitterness, self-pity, or resentment about their stigmatized condition and status (116). Goffman states:

The stigmatized individual is asked to act so as to imply neither that his burden is heavy nor that bearing it has made him different from us; at the same time he must keep himself at that remove from us which ensures our painlessly being able to confirm this belief about him. Put differently, he is advised to reciprocate naturally with an acceptance of himself and us, an acceptance of him that have not quite extended him in the first place. A phantom acceptance is thus allowed to provide the base for a phantom normalcy (122).

Becoming a Homecoming King or Queen is not the same as being included as normal.

Although it is a legitimate ritual in which people perform normalcy, it does not necessarily provide acceptance of people with IDD as ordinary members of the community. Often the only option available to stigmatized individuals is a form of qualified acceptance. Along these lines, Jason Whitesel describes camp as one of the only options available to a group of gay fat men (their self-described identity) who want to participate in a gay pride parade

As many folklorists and anthropologists have observed, the ritual performance of identity is powerful and meaningful, whether or not it changes everyday status and

hierarchies. Most significantly, Victor Turner has discussed the role of outsiders and people who were on the margins of society as symbolic figures creating the possibility of *communitas* (1969, 111). I argue that Homecoming rituals are not typical in the sense that they follow the pattern of status elevation or reversal associated with liminality. They are rituals of induction involving an elevation of status, the act of voting someone King or Queen is legitimate practice (it is not symbolic) but it does shift to symbolic when you consider the role of that position. Does it change their power or accessibility? Maybe. Does it make people with disabilities more visible? Yes, for the person who is chosen. It cannot be invalidated by discourse—the win is legitimate because it is part of a practice and ritual. The motivation is something else. A disability studies perspective questions what is gained by temporary (or even permanent) celebratory status and who benefits. As celebrities, individuals with IDD are often described as working harder than everyone else or as making everyone smile, and these are true observations with potentially actual consequences. A person who works harder could potentially then get a job, and people who smile could potentially change their perspectives. In other words, the feel-good consequences of charitable acts are real, and disability studies scholars have often failed to take account of the reality of the temporary benefits of celebrity status. Nick's argument provides an alternative to the pity motive. The election of a person with a disability to the position of Homecoming Queen or King or honorary team captain requires further complication. I will explain how within Rosemarie Garland-Thomson's framework, a person with a disability becoming a Homecoming Queen would fall into the category of the sentimental, but I want to explore this in more detail to question how this

becomes complicated when it is also considered humanizing and a point of connection or good spirit for many involved.

According to Rosemarie Garland-Thomson, there are four primary visual rhetorics of disability: the wondrous, the sentimental, the exotic, and the realistic. She argues, “not only do these representational modes configure public perception of disability, but all images of disabled people either inadvertently or deliberately summon these visual rhetorics and their accompanying cultural narratives” (2002, 59). More importantly, however, is the function of these rhetorical modes since none of them operate for the benefit of the disabled person but rather “almost all of them appropriate the disabled body for the purposes of constructing, instructing, or assuring some aspect of putatively nondisabled viewer” (59). The wondrous is the oldest genre that can be traced back to “the monsters of antiquity, who inspired awe, foretold the future, or bore divine signs, and freaks, who were the celebrities in nineteenth-century dime museums and sideshows” (59). Folklorists would recognize these in tales of changelings and others whose marks could represent either good or evil. Presently, the wondrous has come to represent admiration and awe rather than amazement, often in the form of the supercrip, but the gap between the disabled figure and the nondisabled spectator is still vast because the pendulum has swung too far, further isolating the disabled figure as “exceptional rather than ordinary” and minimizing any possibility for parity or equality (61).

The poster child phenomenon belongs to the second type of visual rhetoric, that of the sentimental, which “produces the sympathetic victim or helpless sufferer needing protection or succor and invoking pity, inspiration, and frequent contributions” (63).

Garland-Thomson claims that the sentimental rhetoric has transformed from the world of charity to retail as people consume products associated with companies promoting tolerance (64–65), thereby making themselves feel like responsible shoppers as well as citizens. I argue that this encapsulates the majority of portrayals featuring people with disabilities as Homecoming royalty or mascots because of the strength and frequency of emotions evoked. This becomes problematic for several reasons. Whereas the poster child and other images appear to truly make the contributor or consumer feel better, there is little doubt that being elected to a Homecoming court or the honorary team manager for a high school athletic team boosts one's visibility, confidence, and self-esteem. It is also interesting to note that it seems the public is becoming wiser and more aware of the negative connotations associated with good-natured gestures spawned from sympathy or pity and now offer a counternarrative that says, "we are not doing it because of this person's disability, but because of who they are." What does it mean to be truly who you are and is that a rejection of the disability? Is it to look beyond the disability? Is it negatively valued to have your experiences shaped, in part, by your experiences learned from having a disability? Here we can recall the example of Disabled Theatre/Theatre Hora and the idea that people with disabilities are merely being themselves, which implies that they are not capable of acting, performing their disability, or perhaps of manipulation?

What points of contact and connection are required for inclusion? Rick (P13) talks about how people will say hi to his daughter but do not know how to interact with her beyond that. Her speech impairments might increase this divide because it requires a

level of patience and understanding that some do not have. Coach Nick (C1) speaks about how he sees people in his multi-handicapped classes being categorized and accepted based on their social skills, which people assume translate into functioning levels and potential for connection.

Coach Nick explains:

I think the kids come in and assume that all the kids that are in here are this group of kids. They all have different personalities and I think a lot of times some of them – the kids were more verbal – have a little higher social skills, get grouped, they are perceived as being higher functioning and yet they are not necessarily always higher functioning. I mean, I have nonverbal students who have a better grasp of money and numbers and things and reading and writing than kids who are super social, but the peers don't see that because they don't have a way to connect with them really. I've got a lot of kids who really interested in sign language though because they know one of my kids signs and so they love that. There a lot of sweet kids, but it's hard to connect with certain kids.

The tellable and visible narratives are the ones of the Homecoming Queen with disabilities that are shared through social media, featured on the local news, and highlighted in newspapers. There is a widely-distributed and televised PSA from The Foundation for a Better Life (FBL) featuring the true story of Shellie Eyre, portrayed by Becca Winegar (an actress with Down Syndrome), that reenacts the moment when Shellie was crowned Homecoming Queen by her high school in 1997. According to the website (www.values.com), her inspirational story is of:

A life lived with courage, determination and unrestricted love for everyone she meets. She was born in 1979 with Down syndrome and is the second child of a family of four children. At three years of age she experienced a major setback in the form of a stroke that left her paralyzed on her left side. But her optimistic outlook and her boundless perseverance made it obvious

to all who knew her that she would succeed in overcoming whatever obstacles would be presented to her.¹⁹

She was selected the 1997 Homecoming Queen due to her popularity and “easy smile and loving heart.” According to the website, Shellie’s “landslide victory was due in part to a wonderfully accepting student body that embraced unselfish inclusion, and to Shellie’s attitude towards all her classmates. When asked why everyone liked Shellie so much, one of the students said, ‘It’s hard not to love Shellie when you know how much she loves you.’” In accordance with many of the other FBL’s messages, citing Shellie’s life is a source of inspiration, “an example of what true beauty can be, and where love, acceptance, and inclusion can triumph over any disabilities.” I followed up on this story to see what Shellie was doing today. A Google search located Shellie at a non-profit organization called Murray’s Greenhouse where people with disabilities are offered a “safe” environment at a cost of a little over \$20 a day to attend and learn life skills and enjoy social opportunities with their peers (Manson 2011).

Patterns in stories about Homecoming royalty and other mascot stories about being brought to tears, one expression signaling a triggering of the sentimental. Harilyn Rousso, disability rights activist, author, psychotherapist, artist, does not want to be the object of people’s pity or tears. According to Rousso (2013):

There is little about my life that merits crying, other than my constant exposure to people who insist on crying about me; they infuriate me more than those who are overtly hostile...I tell myself that being cried at is better than being rendered invisible, although I am not entirely convinced (160).

¹⁹ <http://www.values.com/inspirational-stories-tv-spots/96-homecoming>

Rousso might say that the crying Jerome Bel experienced when he saw Theatre Hora is a distancing move; it reasserts the distance between the able and disabled person. The distance may be undeniable. The greater problem is that the person who cries might think that they do share the experience. As Shuman points out, putting oneself in another's shoes only goes so far; critical empathy requires a recognition of the limitations of understanding across difference (2005). At the same time, experiences like the election of a person with IDD to the Homecoming court and Theatre Hora can be humanizing moments.

Disability studies scholars have offered insightful criticism of they call "inspiration porn" and have argued that it prevents rather than promotes inclusion. For Alison Kafer, being perceived as inspirational implies that disability is a tragedy and that just the sheer fact of living and getting out in the world is worthy of inspiration. As she mentions in her book, people have expressed such sentiments to her with the addition that they would have killed themselves if they were in her position. In her book, *Don't Call Me Inspirational*, Harilyn Rousso (2013) tackles the problem of being viewed as inspirational with a similar sentiment to that of Kafer. Like Kafer, she has also had to face the cruel and insensitive remarks of those who applaud her for not giving up due to her supposed tragic circumstances. On one hand, disability studies scholars such as Kafer and Rousso persuasively point out that regarding others as inspirations is inevitably a distancing move. On the other hand, people do look to the experiences of others for guidance and motivation, and the line between these and inspiration is not necessarily clear.

To return to the questions raised by Theater Hora, I argue that the problem is not a simple one of whether people are represented accurately or realistically or whether the representation perpetuates stigma. I have asserted that the people with IDD are not necessarily innocent, but that they are often deployed as romanticized, pure characters in a drama through which people without disabilities are made to feel good about themselves and then perhaps cry. Are these moments humanizing to the extent that they allow inclusion? If so, at what cost? Or do they perpetuate a pitying and distancing relationship? Perhaps both are true. As Harilyn Rousso suggests (Rousso 2015, personal communication), we probably do not know what is motivating everyone involved and it would be useful to interview those who voted to see what compelled them to make these votes. What makes these ritual performances so compelling is not just their politics, but also the complexity of meanings and the ramifications that extend (or not) beyond the moment for all of those involved.

Chapter Seven

Employment Opportunities

In the previous chapter on characterizations of people with disabilities, the possibilities of acceptance and inclusion revolved around the tropes of hard work, motivation, and positive attitude. These three components, in addition to innocence and asexuality, point to a promise of recuperability for those with intellectual disabilities. While innocence and asexuality are the more presumed, less likely to be discussed, and consequently more invisible aspects of the stigmatized vernacular surrounding intellectual disabilities, hard work, motivation, and a positive attitude are the most publicly lauded in terms of marketing an attitude of diversity and inclusion. These motifs appear in both public and private discourses, evident in the instances of the previously-discussed mascots and the following examples from campaigns promoting employment for people with IDD. Apart from my concern that one of the only paths to being considered a valuable member of society is through working, I argue that the tropes that are championed throughout Special Olympics, Best Buddies, and the public discourses celebrating the merits of some people with IDD do not, in actuality, work. One of my concerns is that the motifs of hard work and trying to achieve one's personal best map almost too easily onto the government initiative that pushes for community integration through employment and that this is an example of a discursive entanglement. The discourses celebrating hard work and doing one's best do not take into account societal prejudices and the struggles to find a place in a competitive work environment. If someone tries their best but their best is not good enough, for a variety of reasons, they might be perceived and labeled as "unemployable." This is one way of describing how

the stigmatized vernacular creates entanglements, or “messy” categorizations, that in turn become new discourses based on false binaries. Stigma (Goffman 1963; Coleman 1997) is a way of connecting behavior to a category-bound activity (Sacks and Jefferson 1995) and I argue that the taken-for-granted assumptions relating a person’s value to their perceived motivation to work and earn wages can slip dangerously into marking someone’s behavior as a naturalized category representing their identity. In this chapter, I explore the public discourses disseminated through the media and then compare and contrast them to the personal experience narratives and case studies compiled through my research to demonstrate that although there is a growing awareness and push to include people with IDD in the workplace, there is a disconnect between what is promoted theoretically and what is actually occurring in people’s lived experiences. Until we understand the points of disconnect, we are not going to see the changes we desire.

Before proceeding into an in-depth analysis of the issues relating to employment opportunities and experiences for people with IDD, I would like to address how these topics are best addressed through the framework of discourse analysis and personal experience narratives rather than what might be considered more traditional occupational folklore approaches. Occupational folklore has often looked at close-knit assemblages of members in professions or groups (firefighters, longshoreman, mushroom hunters, etc.) that are considered insular, dangerous, and/or possessing a high amount of esoteric knowledge and a strong sense of solidarity (McCarl 1985, Green 1993, Fine 1998). My research does not necessarily fit into the traditional models because many of the people with whom I have conducted interviews do not, in fact, have jobs—their stories reflect

the processes of seeking, trying to maintain, and sometimes losing employment. The lack of a sense of group solidarity results from the various individuals' differing levels of awareness about the one thing that they all have in common—the shared identity of having an IDD. Another issue is the problem of the hierarchy of technique that McCarl references in his chapter on occupational folklore in Elliott Oring's *Folk Groups and Folklore Genres: An Introduction* (1986). What might be considered common sense or taken-for-granted movements, skills, and techniques that a person without IDD could acquire is not necessarily the same for someone with IDD. Furthermore, someone's ability to gain proficiency might not correlate with a typical timeline and for some with IDD, it is not about being adept or masterful, but merely about trying to achieve the acceptable. In light of these differences, the work that bears the most commonalities with my research is Jack Santino's study of Pullman Porters and flight attendants. As he notes in his 1986 article, "A Servant and a Man, A Hostess or a Woman: A Study of Expressive Culture in Two Transportation Occupations," Santino compares narratives dealing with job duties, stereotypification, and subordination (305). Unlike Santino, I did not come across any particular mentioning of class or race, particularly when interviewing with people with IDD, but I did encounter stories of stereotypical assumptions, unfeasible expectations, and a frustrating sense of helplessness in the face of subordination and discrimination.

There are over 200 million people with intellectual disabilities in the world. In an attempt to promote inclusion for people with ID, the Special Olympics hopes to bring a greater understanding of our common humanity to every individual and community. By

providing year-round sports training and athletic competition for people with ID, the Special Olympics' mission reflects the belief that that this training will give them "continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community." These rewards are intended to translate beyond the field into everyday life because it is hoped that through the successful experiences in sports, people with ID will "gain confidence and build a positive self-image which carries over into the classroom, home, job, and community." As I discussed in previous chapters, the focus has been on trying to achieve one's personal best, as evidenced by the motto of the Special Olympics that says, "Let me win, but if I cannot win, let me be brave in the attempt" (Special Olympics 2016). Hard work, motivation, and a positive attitude aimed at achieving one's personal best are also considered important assets when seeking employment in the community, but I have concerns that barriers to success are not sufficiently addressed. While possessing these soft skills might make someone more employable than a person who does not demonstrate these attributes, are they enough? What is occurring in the space between the discourses promoted by the government and organizations seeking more employment opportunities for individuals with ID and the experiences of those job seekers with ID and their caregivers who cite numerous obstacles and hardships when it comes to actually finding and maintaining a job?

According to the Disability Employment Initiative (DEI) website, "Since 2010, the United States Department of Labor (DOL) has awarded over \$95 million to thirty-

seven projects within twenty-six states under the Disability Employment Initiative (DEI) to improve education, training, and employment outcomes of youth and adults with disabilities by refining and expanding already successful workforce strategies” (U.S. Department of Labor 2015). In 2011, Ohio was one of seven states to receive \$2.9 million to “support collaboration across multiple workforce and disability service systems in each state” and to “expand the workforce development system’s participation in the Social Security Administration’s Ticket to Work Program by requiring participating state workforce agencies or local workforce investment boards to become employment networks.” Ohio Governor John Kasich signed the Employment First Executive Order in 2012 to establish statewide collaboration and coordination, created the Employment First Taskforce and Advisory Committee, and “made community employment the preferred outcome for individuals with developmental disabilities” (U.S. Department of Labor 2015). According to the Employment First website, the taskforce is responsible for “expanding community employment opportunities by reducing barriers and aligning state policy” (Ohio Employment First 2016). Folklorists can help to identify the barriers that are preventing people from gaining employment by collecting personal experience narratives; it is through these types of stories that patterns and disjuncture between policy and practice emerge. It is my intention to act as a scribe documenting the different cultural viewpoints that are circulating around the issue of employment for people with IDD because I am interested in the presuppositions that enable or prevent people from meeting expectations since these are often rooted in cultural assumptions.

In a video posted on the Ohio Employment First website, Ohio Governor Kasich states:

We want people who are disabled to have a full place in our society and our Employment First is giving people a lot of opportunity to get jobs—outside of, for example, a sheltered workshop. You might see them working in Lowe’s, you might see them working at Kroger’s. This is making families happier. It’s allowing these people with disabilities to be treated with respect and giving them a position where they can find fulfillment. What could be more important than that? I mean, why we never paid attention to this, I don’t understand... So for the community of those who have disabled [sic], we’re doing everything we can to train you, to get you placed in a normal setting. It’s what we all should be striving to do. (Ohio Employment First 2016)

Moving away from a time thirty to fifty years ago when institutionalization and segregation for people with IDD were cultural norms in the United States, Employment First is a policy intent on “shifting expectations for a cultural transformation” so every individual of a legal working age has an opportunity to seek employment. This is started with a shift in expectations so rather than assuming that individuals with IDD are unable or unwilling to work and their only options are to be segregated in sheltered workshops or day programs, Employment First believes that each person has the abilities, skills, and talents to enrich the community and people around them. They want to ensure that young people with IDD are educated about employment options and planning while in school and that adults with IDD have “support teams that assist in learning more about how abilities and interests can match opportunities in with workplace.” In summary, Employment First argues the following:

Every person should expect that community employment is the preferred outcome for working-age adults with developmental disabilities. Every agency, school organization and individual within Ohio’s developmental disabilities system plays a role by focusing on what everyone can do and

providing the best supports and services to enable people to choose and succeed in community employment. We're transforming to a system culture that creates opportunities and pathways for integration, independence and full community participation. (Ohio Employment First 2016)

Part of the cultural shift to which Employment First is referring is one where people recognize that community employment brings about the benefits of greater independence, self-esteem, and wealth-building potential to the individuals with disabilities, but also benefits employers and co-workers by creating a more diverse work environment.

The Best Buddies "I'm In To Hire" movement is another one that, like Employment First, seeks to create a cultural shift in attitudes toward people with IDD finding meaningful employment in the community. Founded in 1989 by Anthony Shriver, Best Buddies is a non-profit organization whose mission is to "establish a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities (IDD)," and whose goal is to "put Best Buddies out of business." Like Special Olympics, Best Buddies is an organization that has inclusion as its goal but that has practices that bring together people with intellectual disabilities rather than folding them into ordinary social life. The "I'm In To Hire" campaign is aimed at raising awareness about the benefits of people with IDD being a part of the work force because the current employment statistics are unacceptable—"a staggering 85% of adults with developmental disabilities supported by state developmental agencies do not have a paid job in the community (National Core Indicators, 2012–2013)." In an international holiday message distributed to those on the Best Buddies email list, Anthony Shriver, Founder and Chairman of Best Buddies International, states that his organization hopes to raise one

million dollars in 2015 to launch the employment campaign because “there is nothing more important for our special friends.”²⁰ The video’s message is supported by images of people with disabilities in the workplace in addition to statements made by employers, co-workers, and individuals with disabilities.

Everybody should have the same sort of joy and fun and experience of getting up every day, having some place to go that you care about, and that you do important work, and I feel that we all do that at Eaton Vance and now Billy does, too.—Jeff Beale, Vice President/Chief Administration Officer, Eaton Vance

It’s really important that we continue to raise more funds. The opportunity to put hundreds of potential Buddies into meaningful work, not just putting screws into envelopes, but actually having meaningful employment that changes the lives of both them as participants but also the employees at these firms. That’s enormous.—Mike Beaudet, Vice President Client Relations & Programs, ESG

It really changed my life because I have never worked with anybody like Aaron and to see the potential that he has and the ability and the motivation —Angela Strickland, Lead Chef, Whole Foods Market

I’m the kind of person who likes to help out everybody. It’s like a family to me.
—Aaron, Whole Foods Market

These statements support what the government’s and non-profit organization’s initiatives are claiming—employing people with IDD in the community benefits all of those involved. First, there is the assumption that everybody finds meaning in work. While that might be the case for many people, it is a sentiment that is based on an ethos that could be considered culturally specific and historically located. Not all countries and societies expect everyone to work in a competitive environment, nor does everyone in the world equate getting a paycheck as a marker of being a valuable member of society. Therefore,

²⁰ <http://www.imintohire.org/about/>

when Anthony Shriver says, “There is nothing more important for our special friends,” I question whether he is referring specifically to meaningful employment in the community or if he is referring to an overarching theme of inclusion.

Second, not everyone is on the same path to employment and it is important to note the different interpretations and accompanying significance of the term “meaningful employment.” Meaningful employment, according to the Employment First web-based, is when people with IDD work in the community setting where at least half of the employees are people without disabilities, earn at least minimum wage, and receive a paycheck.²¹ When Mike Beaudet from ESG (featured in the “I’m In To Hire” video) refers to meaningful employment being something that is not putting screws in envelopes, he is referring to what is commonly referred to as piecework or assembly work that often takes place in sheltered workshops, where people with IDD perform repetitive tasks and the only people without disabilities are those employees in charge of the other workers. In most states, it is legal to pay individuals a percentage of minimum wage based on a percentage of the work they are able to produce. The consequence has been that people can work all day and make as little as \$0.10. According to the local newspaper in an article about the recent changes in government funding moving away from sheltered workshops and into community employment, sheltered workshops were considered innovative in the 1960s and a welcomed change from the institutionalization and isolation from the past. For many parents of adult children with IDD, sheltered workshops were ideal because they were considered safer and more stable than

²¹ <http://jobguide.ohioemploymentfirst.org/>

integration in the community. For those individuals with IDD who wanted a less protective but still supported environment, enclaves were offered as an alternative. Enclaves were considered the next step in job placement for people with IDD because the enclaves allow people with disabilities to work together as a group, sometimes in a community setting, but they are often not paid at the same rate as people without disabilities. Enclaves sometimes operate through the local county boards of developmental disabilities and the workers might perform janitorial, manufacturing, or lawn maintenance tasks, and while the groups might work out in the community more than those who are in sheltered workshops, they are still not considered to be part of integrated employment. Supported employment is another option and entails people with disabilities receiving assistance and supervision as needed (often gradually tapering off to promote more independence as job skills are acquired). Where an individual with disabilities fits within the framework depends on a multitude of factors (abilities, type and severity of disabilities, level of independence and decision-making capabilities, location, transportation, support, job availability, etc.) and this is a topic of much-heated debate.

In the introduction to this thesis, I mentioned a 2014 local newspaper article that featured some of the opposing attitudes centering on employment possibilities and the push against sheltered workshops. The article begins with the story of Cathy Ticknor who had always wanted a job running a cash register and was delighted when she finally obtained one, but then almost heartbroken when she lost her job because she was told she wasn't fast enough. After searching, finding, and then leaving jobs in the general

workforce, Cathy went to ARC Industries and found employment in a warehouse where she is now an assistant, “helping others in the warehouse where all workers have some type of developmental disability, bosses remain patient and no one gets fired.” For Cathy, the sheltered workshop’s existence is greatly important. Acknowledging the current public policy movement that is pushing for alternatives to sheltered workshops being prioritized as one of the first or only options, supporters (often parents of adult children with disabilities) of sheltered workshops believe it is “unfair and unrealistic to assume that most everyone with developmental disabilities will be able to find, enjoy and keep community jobs.” Judy Rotolo, parent of Tony, a 41-year-old ARC attendee, disagrees with those who say that sheltered workshops are segregated and that the workshops offer alternative activities, training, and care for those who do not want to work or who feel unable. Anne Matteis, whose 42-year old son Jimmy, has had several internships and jobs but has experienced a great deal of stress from not being able to secure and maintain the job positions he desired. Matteis explained that although she was initially against the idea of placing Jimmy in the workshop, she now feels it was a “lifesaver” because, “Just pushing your child out there because you say he deserves it, even if he doesn’t have the skills, might do more harm...In the workshop, he never stresses.” Kyle Fleshman, a 26-year old man who has been at the sheltered workshop for seven years, stated that he did have a training opportunity in merchandise stocking in the community but that he did not like it, but that he loves his workshop. Some of the sheltered workshop employees have been there over forty years, and although one of the workshop managers admits, “I don’t know if that’s a good thing or not...I know that in the 34 years I’ve been here, I’ve never

known them not to be happy.” These statements support sheltered workshops as viable and necessary options for people with IDD on the grounds that they offer stability, security, happiness, and protection from the precarity of community employment, but in whose best interest does the sheltered workshop serve? Based on these interviews, it would seem that some of the individuals with IDD and parents would choose a sheltered workshop over the chance that they could experience more stress and instability were they to try to find work in the community again. It would be naïve to assume this is the case for everyone involved, but it also leads me to ask: (a) are some people “happy” because they simply have not been allowed to pursue any other choices? and (b) is this reflective of the past and present situation and possibilities and perhaps indicative of the lack of options available now, but is it shortsighted in thinking this is the way things have to be in the future?

Ethnographic observation can be enormously useful for answering these questions. In what follows, I attempt to offer detailed observation based on my participant observations of and interviews with the OHSO community. As I have mentioned in my methodology section, I did not interview everyone on the OHSO team and because many of the athletes are in transitional phases, it is unclear how their circumstances regarding employment opportunities have changed since I conducted the formal interviews. I have continued to speak informally to several of the parents and word spreads quickly since it is such a close group, so in terms of permanent integrated employment in the community at the end of 2014, I have heard that at least three of the athletes work at a local grocery stores bagging and moving carts, one athlete works at a

movie theatre, and one athlete works at a zoo taking tickets. Next, I will provide case studies for each of the individuals and their family members I interviewed in order to provide more in-depth analysis of the patterns that emerged as each struggled to transition from high school into adulthood, particularly in terms of employment.

Patty (A12)

Patty went to a high school where she was one of several students with IDD who spent much of the day in a resource room with intervention specialists while joining her mainstream peers for activities like choir. Patty's parents, Rick and Beth, expressed their disappointment and frustration with the school system's treatment of Patty, which they believe has done more harm than good about Patty's social and academic developments. Her parents feel betrayed that they trusted the school system to do the best to their ability teaching Patty and believe that because she was segregated in a resource room, the standards expected from her were set too low and she was unable to develop the social skills and aspirations to achieve more that could have come from being surrounded by peers without disabilities. Rick and Beth cited Patty's reading abilities and that they had growing concerns because the school was reporting that Patty was reading at a 3rd grade level at school and that she was reading very well, but when she was at home and her parents were trying to help her with her homework, she had significant difficulties and when she was tested in the spring of this year, she was at a 1.5 grade reading level. They did not want to be perceived as overbearing parents, but they do not believe that Patty

was adequately exposed to a mainstream experience and that the transition planning was not as thorough or extensive as it should have been.

While in high school, Patty volunteered at local businesses and libraries under the direction of the transition specialist from her high school and during the summers, she volunteered at a daycare and spent time in a career camp, which was meant to give her exposure to multiple settings and jobs and help her learn more job and living skills. After high school, Patty attended a transition program at a community college where individuals with IDD took classes and also tried different job experiences. Patty blossomed, according to her parents, during the first year of the transition program because she was around students who had higher functioning skills and Patty aspired to be like them, she developed more friendships, and as a result, gained more self-confidence. She is currently attending another transition program that serves people who receive state Medicaid funding through the Individual Options (I/O) Waiver or the Level One Waiver. This program functions as a day program and an enclave and Rick and Beth are concerned because based on what they have seen from their visit, Patty might be surrounded by people who are at a lower functioning level than her (although they admitted that the attendees were not all present and that this was just their first impression) and that this could cause her to not try as hard or continue to develop as she had demonstrated over the past year.

I attended multiple transition meetings with Patty, her family, transition specialists, and local government agency representatives and was able to witness firsthand some of the confusion and lack of assuredness her parents described about the

transition process in addition to the common themes the service professionals cited as potential barriers to Patty's success. It was through these meetings that I learned more about the disparities between what everyone thought was best for Patty and how Patty's lack of voice and/or understanding of the transition process made it more difficult for her to advocate for herself and her interests. It is also important to remember that not many 19-year olds know what they want to be or how they are going to achieve their goals. When I spoke with Patty one-on-one, I asked her what was most important to her and she answered her friends and family. I asked her if she wanted to get a job and she said, "yeah," but when I asked her what she wanted to do, she replied, "To be honest, I don't even know." Her parents are concerned with how she occupies her time, they do not want her to sit around the house all day, and they want her to be social because they know that she is happiest when she is being social. They believe that Patty does not care about the monetary reward that comes from a paycheck, but that she enjoys the social aspect, she wants to say that she has done a good job, and she wants to make people happy. One year ago, their biggest concern was that Patty did not have any friends and when they read her Facebook post, "If anybody wants to talk, let me know" and saw that no one responded, they were devastated. Now that Patty has made more friends through the transition program, they hope that this will spur her social development and maturity and she will be able to be more employable with each passing year. However, there are deadlines and timelines for services that can aid Patty and if she does not meet the criteria for showing a particular amount of progression, there are concerns that she would miss opportunities and services.

Several issues relating to Patty's performance in work training programs have arisen in various transition meetings. At the transition meetings with local agency representatives, one of the agents said that their concern is the lack of progression they have seen in the transition program and during the schoolwork experience because according to her teachers and the state employment social workers, she appears to "lack motivation" and gets "easily distracted." They were not concerned with her skill set—they believed she could perform various job duties—but that she is not at a stage in her life where she is ready for competitive employment because she has focus issues and would likely need paid and natural supports (the term used for co-workers who are not paid to help but still provide instruction and support as needed) to help her stay on task. Unfortunately, as the social worker reminded Rick and Beth, it is the nature of business for things to change and while Patty could have a manager or natural support person who would agree to check in every half hour or hour to make sure she's following instructions, that person could change shifts or jobs and their replacement might not be as accommodating. A second issue that is correlated with Patty's "lack of motivation" is that she does not try to find other work when she is finished with a particular task. To expect that to be an intrinsic value and behavior for most teenagers, let alone someone with IDD, reflects a lack of understanding about what motivates people. This can be interpreted as disappointment that Patty does not perform the category of not just a good worker, but a worker who goes beyond what is required of him or her. Patty has also fared poorly when assessed for being able to work by herself. Is this a true reflection of Patty's capabilities as a laborer or is it perhaps a reflection of a poor job match because she might perform

better in a more social occupation—particularly since friendship and being around people are what motivates her more than monetary rewards? A third criticism of Patty’s work performance is that she does not do a good job when she does not enjoy it. Again, is this something that could be remedied through a better job match or is this something that is now attached to Patty and marks her as a person who is not a good worker?

In these transition meetings, the service professionals reported their assessments in order to determine what services Patty might need over the next couple of years and to plan her options in preparation for graduating in 2016. Both Patty’s parents and service professionals expressed concern that they were setting Patty up for failure by expecting too much from her too soon but also worried that they were not providing her with the right tools to motivate her and prepare her to become a better worker. Patty’s challenges were primarily described in general terms, such as “lacking motivation,” rather than in concrete terms, such as “not finding additional work to do when she completed a task.” It appeared that everyone agreed that the goal was to help Patty become eligible for competitive employment, which meant that she would need to be able to work independently, but it was not clear how quickly this development was likely to occur and whether or not it would develop within the necessary timeframe for Patty to receive the services she needed to thrive. At one point in a transition meeting, Beth began to cry, saying that Patty was brighter than you might think, that staying focused was a huge struggle for her, but that she can do more than wipe tables if people would just take the time to get to know her and see more of her strengths and abilities. Beth explained that she was crying because she had never had a special needs kid before and felt like she has

been relying on professionals for information and advice, but that she feels like she's hearing that there are no other options. One of the service professionals explained that his/her area of expertise was competitive employment and that if Patty was not able to reach the level that she needed within the necessary timeframe, it did not mean that there would be no other options for employment, but that they might involve ongoing supports. Rick said he felt like he was in a state of "quiet panic" and that he wanted to make sure that they are doing the right thing because he didn't want to screw it up by overestimating Patty's abilities or placing her in a job that she hated. Patty enjoys working with children and animals and Rick and Beth wondered if she could get a job at a daycare or a local animal shelter walking dogs or playing with the animals. Unfortunately, as the service professional explained, those are usually volunteer-based positions and the jobs that actually get paid at places like animal shelters involve more janitorial or clerical work. Beth said that she would like to see Patty in an office working as a greeter because she enjoys being around people, but would not be able to work as an administrative assistant answering phones because of her speech impairments. The service professional again pointed out that unfortunately, there are not a lot of available jobs for someone to merely act as a greeter in an office, and that office jobs generally require phone and clerical skills.

In one interview with Beth and Rick, Beth reiterated the feeling that there were no options at all once Patty graduated high school and Rick said that their small community would be perfect to integrate people with IDD because it is safe and people tend to know each other more than they might in a larger community, but that the culture wasn't one

where integration was valued or prioritized. Rick would like to create a business for his daughter and others like her with IDD, but they do not have the time or money to quit their current jobs and fund the creation of a new business. He said that he would like to develop a comeback to the argument that it's too expensive to fund services to employ people with IDD and he said that with some people with autism who are extremely productive, "you can take advantage of their obsessiveness," but with somebody like Patty, "it's harder to demonstrate productivity." Beth agreed and cited Patty's distractibility and difficulties focusing and staying on task as some of the limitations that make it difficult for her to find employment, and thus greater inclusion in the community.

Nicki (A10)

Nicki is a 21-year old young woman with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), obsessive compulsions, Attention Deficit Disorder (ADD), and anxiety issues. She is currently in her second year of a transitional program after graduating from high school and has had a series of difficulties with the changes that have occurred since she graduated. Nicki's parents recounted the struggles they have faced negotiating Nicki's transition from high school into adulthood and their concerns with Nicki's ability to perform tasks consistently in order to gain employment and finding a place in the community where she feels like she belongs. Based on her job training experiences in high school, her parents and teachers had expected that Nicki would have been able to transition successfully into some type of job experience where

she could perform similar tasks to the ones she had engaged in during her high school years.

When Nicki was in high school, she stocked shelves at a local drug store and a store that sold nuts. She generally performed these tasks well, with some need for redirection to be reminded to stay on task and refrain from being distracted by her classmates, and it appeared that her co-workers and employers were kind, patient, and supportive to her needs. Nicki would say that she liked her bosses and stocking shelves because it was easy and she has to do the same thing every day. As to whether or not this was Nicki's ideal job or whether she wanted to do something different, it was hard to tell. At one transition meeting, Nicki said that she wanted to be a lifeguard because she could swim well, but because of her disabilities, this would not be possible. It is unclear whether Nicki truly does enjoy doing repetitive tasks or would prefer to try new things because she has mentioned to me that she enjoys making the same things every day and work that is "not too hard" but when I tried to learn more about what she liked or disliked about her jobs, the narrative became confusing. At one of her internships, she had worked in a lunchroom cafeteria making sandwiches and had told me she enjoyed it because it was easy doing the same thing each day, so I attempted to see if she had similar or different feelings toward her current work:

O: what's the hardest job at [place of internship where she does janitorial services]?

N: um, cleaning stuff off the floor-with the broom-I sweep sometimes. It gets stuck on the floor.

O: do you like doing new things every day or do you—

N: —not really

O: —like the same thing?

N: not the same thing every day

O: you don't like to do the same thing every day or you do?
 N: I do sometimes
 O: what kinds of things do you like to do over and over again?
 N: I like doing gum every day.
 O: what do you mean "doing gum?"
 N: picking it up off the floor [long pause]
 O: why do you like doing that every day?
 N: because people don't put it in the trashcan. I have to do everything for them probably [laughs]. I don't like doing stuff for other people though. It's because they don't do it themselves.
 O: so you do like doing that or you don't like doing things for other people?
 N: I don't really like doing other stuff for people.

Looking back on this exchange, I can see how it can be confusing and my intentions to clarify whether she preferred routine work or changes in routine did not go as I had hoped. One of the reasons I focused on this area of work experience and preferences is because I have heard from some parents that changes in routine, particularly for those with autism spectrum disorder, can make transitioning into a job more difficult than if things were to remain as consistent as possible. I have also heard from some of the individuals with IDD that they enjoy trying new things every day and they get bored if things remain the same, so I was interested in focusing on this particular aspect whenever possible during the interviews.

Based on this excerpt, it could be interpreted that Nicki finds picking up things that are stuck on the floor difficult but still gains satisfaction from the task, particularly since she is very cognizant of rules and is not pleased when she perceives people are breaking rules (with littering being one of her top pet peeves). Nicki enjoys order and routine and it is possible that this activity provides Nicki with a feeling of accomplishment and elevated status because she is correcting a wrong. On the other hand, I could be misinterpreting Nicki's narrative and focusing on the wrong section of

the dialogue, thereby missing the significant moment when she interrupted me by saying “not really” when I asked her if she liked doing the same thing every day. When I tried to understand her position more explicitly and asked for clarification as to whether she did or did not like doing the same thing every day, she answered, “I do sometimes.” This dialogue between myself and Nicki is further complicated by my knowledge that Nicki does not generally like to say anything negative about people, places, or activities because she perceives it to be “rude” or “judging.” Based on my interviews, I am unable to determine whether the difficulty or diversity of tasks directly correlate to Nicki’s level of enjoyment, but this points to the importance of job exploration and observation with individuals with IDD and to pay attention to her expressive behaviors as tools to understand her better.

Henry and Greta, Nicki’s father and mother, expressed concern and confusion about Nicki’s preferences, motivations, how much was too much of a challenge, and what they could do to help her be happier and fulfilled. Nicki seemed to be saddened by the transition accompanying graduating from high school because it meant she was leaving familiar people, places, and routines behind her. Her parents recounted that Nicki had expressed that college was hard and that she did not want to go to college, but any adjustment relating to transition was going to be a challenge for Nicki. Her parents explained:

- H: Once the adjustment’s made...it’s part of a loving group of some kind-it’s part of a loving group of some kind-she feels welcome-and that’s what’s important to Nicki.
- G: She likes succeeding at her jobs.

After she graduated, Nicki seemed to “unravel a little bit,” according to her mother, she began to experience more seizures, was emotional about not being in the high school building anymore, one of her direct support professionals moved away, and her favorite teacher retired. Her father thought that she might be coping better as time progressed from that initial transition:

H: I think she’s overcome it. Like the little story that illustrates it-when we go on our bike rides, every time she wants to go past the school. She has-at the end of the ride we go past the high school, right? Well, recently that isn’t as important to her when we’re on our bike rides-she wants to past St. X, the church we go to, that has the special issues’ focus on the congregation-that’s why we’re going there. And when we go past Y, she’ll say, ‘Hello, Y’ like she does to St. X—indicates her connection to it but her connection to-just as it was in school-to a place where she can go, where she feels safe, where people know her, she’s part of a—

G: —a place where she belongs.

Henry and Greta had hoped that in addition to the high school and church, she would also find the post-high school transition programs places where she could thrive and belong.

At the end of high school, according to Greta, Nicki looked like she could have done any number of jobs but ended up doing the same job of making turkey sandwiches every day. The grade of C+ that she received at the beginning of the year progressed to a B by the end of the year, but she still had difficulties with obsessive behaviors (like squeezing the sandwiches too hard or tearing at her gloves) or zoning out and not knowing what to do next (she would drop a piece of meat on the floor, which is understandable, but would stand there and not pick it up or move to the next task). Her parents said that it was difficult because Nicki has had this issue her entire life and so when she is having an “on” day, she can do a lot, vacuum at home, behave appropriately,

demonstrate a certain “savoir faire,” as Greta called it, but when Nicki is having an “off” day, she seems unable to do the things she had done before. Greta gave an example of a cafeteria task where instructors were trying to teach Nicki to make sure there was clean silverware and divide it between the forks, spoons, and knives, but Nicki wasn’t able to complete the task according to the instructions. Greta expressed some of her confusion and frustration by adding:

G: So those were things that anyone would’ve thought she would’ve been able to do and Clara [the transition specialist] was trying to get her to do it independently-although Clara-I wish I’d understood and I think if she [Nicki] had understood this, she might’ve tried harder-to the extent that she was able-because sometimes she’s not invested in it. If she’s getting other satisfaction in it. But it did sort of bother her when she saw that and said, “Well, I can do that now.”

This seems to imply that Nicki was not aware of the significance of her performance in these situations and how they would relate to her future possibilities. Perhaps she was more interested in the social element, or maybe she was overwhelmed by the sensory stimulation and her anxiety caused her to tune out the distractions and focus on the tactile elements of the sandwich or latex gloves. Regardless of the cause, the effect was that these moments where Nicki was unable to perform the job tasks competently translated into her not being considered eligible for competitive employment. Greta explained, “that’s their goal to be able to say, ‘No, this person can do this’ and they’re [the workers] supposed to be able to be alone for twenty to thirty minutes at a time and they [job coaches] would come back and she’d just be standing there. Or some days she would do well and she’d put the tray in the place where they go in the cooler and it might be in crooked and just not—definitely zoned out or something.”

Contemplating Nicki's future in terms of employment, Henry says he does not have a lot of hope other than an environment like a local business where Nicki could stock shelves. Her mother says, "I do have an expectation that Nicki will achieve paid employment if she can get back to that place where she was. I think it would be better if it's a place where there can be a relationship that's developed that would make someone have a stake in why to help her achieve that." Referring to the efforts of parents who create small businesses to provide a place for their children to work, she adds, "If we were farmers, she'd have a job on the farm." Greta remembers a health professional once telling her that many of these issues are problems relating to a modern age and that if we lived in an agricultural economy, people with disabilities would have roles on farms and be with their families. Greta believes Nicki would excel in that type of lifestyle because of her physicality:

G: She's as strong as an ox. She'd be perfect for any setting like that where you have a family business where you just need two pairs of hands and strong legs to do actual work that's straightforward work...I think she has-what's going for her I'm told is not all that common, at least in some of the people that tell me this, is her work ethic being so strong. That's not always the case. Sometimes there more of the 'I don't want to do it' or more of a laziness or lack of—

H: —yeah, she doesn't ever—

G: —investment.

H: —hardly express that. She might want to say she doesn't want to vacuum right now if she's on Facebook or something.

G: Even now, with the little things around here, she'll turn around and unload the dishwasher...I've thought about this, too, because of the need for the sort of ongoing direction if it's not going to be a totally repetitive thing-or even if it's repetitive and it's a reminder, "Okay, you're done with this shelf and you need to move to Aisle 10"-there's a lot of work that can get done by this person with direction. If I created a house painting service-there's no doubt that she'd be an able and energetic partner in cleaning house-if someone wanted to create a business like that or certain types of activities. So I'm somewhat

optimistic about her ability to earn money. I wish that she-sometimes it just seems like an increment more would get her into a place.

Her father takes the discussion about possible employment to the next step and asks, “What’s she going to do with the money?” Earning money, as Henry points out, is a means to many other ends and it is difficult for him to imagine Nicki “getting the satisfaction out of living that we all get from earning money.” He refers to Nicki’s apparent disconnect to the process of shopping and how she will say she wants to go and buy a CD but then never play the CD because she already listens to it on her computer.

H: I’m just not optimistic at this point that she can find satisfaction in her earning money and-so in other words, the question really isn’t ultimately will she be able to earn money. It’s the whole transition to having a productive-well, and it’s not even this, when these questions are asked in academia, it’s kind of all about the productive life. It’s almost asked from an economist’s point of view. But really, being a parent, that’s really not what the relevant question is. It’s transitioning not to a productive life but to a—

G: —engaged—

H: —satisfying life, right? Having money is an element of that, but satisfaction and also some of the other things we’ve been talking about, being part of a family, being part of a work—

G: —but it’s especially a part of it if you-you know, we have money, but for families that don’t, they’ve got a child who can work and actually bring home money to help the family—

K: —defray their expenses. Or to many families to kids-they’re just glad they’re 21 and out the door and there are families like that, right? Maybe those kids needed to have money.

In addition to questions about the importance of earning money and its lack of relevance or significance in Nicki’s particular case based on her family’s income level and her own lack of understanding of the value of money, her parents expressed concerns about Nicki’s safety if she becomes employed out in the community. Her mother worries about keeping her safe from molestation that could occur in a work setting, “or any setting that

she's in that's corporate, as Henry put it-not that that couldn't happen in a more personalized setting, but where you don't have the personal sense of trust or might not mistrust but you just might not know everyone you'd come into contact with." When asked if she thinks Nicki would be able to identify that something inappropriate was occurring and if so, would she be able to communicate that something happened, Greta says it is difficult to say, particularly if the perpetrator is manipulative and aggressive. She thinks that maybe a more public setting would provide more protection than a setting where someone could be more isolated into a space, a building, a basement, but that even hospitals are worrisome because they could be places where someone could be taken advantage of in a stairwell. Nicki has a difficult time differentiating between strangers, acquaintances, and friends, and believes that someone can become a friend merely by saying "Hi" to her.

Because of Nicki's openness and willingness to trust people, it is understandable that her parents have concerns about her ability to safely navigate a world in which she is exposed to many different kinds of people, including those with ill intentions. Based on the difficulties Nicki has experienced with what her father refers to as "the trauma of transition," her inconsistent work performances at the different job sites, and her trusting nature, it is understandable that her parents have considerable worries and concerns about Nicki's future. Will employment be something that gives Nicki a greater connection to the community, a sense of accomplishment in a job well done, or will she continue to find a sense of community in the Special Olympics and her local church and places where she feels she belongs?

Tori (A14)

Tori is 23 years old, graduated from high school two years ago, lives with her parents, and has autism spectrum disorder. Tori currently attends an enclave for people with autism and although she has some experience in a bakery setting, she has not been hired permanently and is still filling out applications at the enclave that she attends every day. Her mother, Maggie (P11), had hoped that the family would simply look towards the county and someone would be able to find a job for Tori, but that did not work and so she found out about the enclave from another OHSO parent whose son attends the program. Maggie had also heard nightmarish stories from some of the other OHSO parents whose adult children were unemployed, such as “the kids not getting jobs, getting jobs [and] getting fired, job coaches that don’t show up...” She said she heard of one OHSO athlete who gained then lost two or three different jobs and was fired from one of the jobs because, according to Maggie:

M: They said he instigated things. I think he was a dishwasher somewhere, that was one of the jobs, and I don’t find him to be that type of person but I think if other people take him on and I think that’s the worry that you have is other people doing the job think it’s funny or, you know, don’t understand the quirks and things that some of our kids have and then they aggravate it and I think that’s what happened with him.

She knew of another boy who worked at Walmart and was fired and she was not sure if he accidentally ran a cart into someone or something else happened, but she did not know if his parents even knew the reason for his termination. Maggie said that one of her biggest fears is the lack of communication between the employers, job coaches, employees, and parents/guardians. She said that when nobody tells the parents anything, “you can’t make it better...I need to know if she gets a job, if she’s showing up on time

or if she's not and whose fault is that? Whether the job coach is coming, if the job coach is any good." Maggie related a story of when Tori was attending a summer program through a local agency and how it was not a good experience for Tori:

M: They moved her around like every week in the program or every couple of days and I said to the woman, 'Nobody ever called me. No one ever said she's acting up.' I could kind of tell just by the way she was acting at home. And she said, 'When she has a real job, no one will—nobody will be contacting you.' And that really worries me. I mean as long as I'm here or somebody is, you know, a guardian, that you want people to communicate because I think there are ways for us to make it better – we know our kids. I think that's what I've heard from some of these other kids that have been let go from jobs, it's – they did one thing wrong or maybe they did more than one thing wrong, but no one knew until it was already—well, you know, they're fired.

Maggie told me of another story where one of the OHSO athletes was not getting the proper training he needed from his job coach because his job coach was dying from cancer and was not able to make it to the job site to help the young man learn the job. No one told the parents until it was too late and the young man was unable to benefit from the more intensive and consistent job training that is supposed to be provided through job coaching.

Privacy and rights appear to be the underlying issues here, but it seems that there is some vital channel of communication that is missing between the various parties and, particularly if the adult is not his or her own guardian, it appears that this might be one of the places where more attention is needed. Even among parents and service agencies, the lack of clear information causes frustration and misunderstandings. Maggie said that she had heard from other OHSO parents that if she pursued jobs for Tori on her own, this could prevent some agencies from helping out in the process. "I need to know how all

that works,” said Maggie, “and if I contact someone, what can I tell them? Yes, she will have a job coach or that kind of thing?” Maggie routinely went through the local newspaper to see who was hiring and when she found an ad for a local drug company in need of workers to pick and sort, she wrote them an email and said the following: her daughter has autism, this kind of job might be really good for her, she might be really good at it, she’s never sick, she won’t be texting all day, there might be a job coach available to help her transition into the job, and that she and Tori would be willing to meet with them. She never received a reply. Maggie added that she has even thought of writing a letter to the paper saying, “I’ve got my daughter here. Give her a job. Somebody in this community—let’s see what we can do.”

Maggie said that this was what she was hoping the school would take responsibility for and that although Tori did have the opportunity to volunteer at different places through the help of the school, the businesses did not reject the free help but did not hire anyone after the volunteering came to a close. Maggie asked the school if it would be possible to send invitations to the various businesses to bring them into the school, bring the kids in, and let them start seeing these kids.” She said that no one ever tried this approach, but something needed to change. To continue to use the same businesses for transition training, all the while knowing that they are not hiring people with disabilities once they finish their volunteering work, is a recipe for continued failure.

Transportation and reliable people to help with the job training and transition process are some of the key factors that Maggie considers vital to Tori gaining employment in the community. She believes that Tori would excel at highly-structured

jobs where she is assigned repetitive tasks, but is also very concerned with safety and does not want Tori to be out in parking lots or working by herself in a back room.

Although Tori is healthy (she never missed a day of high school) and can read and talk, she does have difficulties with social interaction and changes in routine. When Tori has been in transition programs where the students are moving around from job site to job site each week, Tori does not cope well and her anxiety greatly increases. Tori also performs better when she is with a small group because she tends to get overstimulated and lost in the crowd when she is placed with large groups of people. This became very apparent when she was training in a campus cafeteria surrounded by many people and loud noises. She began constantly talking to herself and her job coaches said she was swearing, which was something Tori rarely does. Maggie felt that the aides didn't have any patience with Tori and that they didn't seem to understand her disability and once Tori seemed to settle down into a routine, she would be moved to a new location. Maggie asked them to leave her in one place so she could develop some self-esteem and security in one location, but the program directors said the program was set up so everyone had to try different areas. Maggie also discovered index cards written by Tori that would say, "No rocking" and to stop talking to herself, which led Maggie to conclude that they had little understanding of autism. Maggie asked the teacher, "'what does that [rocking] hurt?' 'Well, maybe she's rocking and not doing her work.' That was the teacher's answer." For Maggie, it seemed that the program was developed so everyone could fit into its parameters, that "they really only wanted people in there that really had very little disability" and "they were not going to adapt anything to a particular person's needs

because this was supposed to be comparing them to a ‘typical’ person—that they could do work in a ‘competitive,’ as they refer to it, environment.”

Because Tori does not generally communicate in speech patterns that reflect a linear narrative or use words to express her emotions, people around her often rely on Tori’s behaviors, vocalizations, speech patterns, and energy level as indicators of her emotional state and preferences. When I asked Maggie what motivates Tori, she said she was not sure, but that Tori seems to enjoy being busy and pleasing people. Maggie said Tori does like sitting and watching television or playing with her iPad, but that she also appears to enjoy her routine social outings with her book club, Special Olympics, running with her father, going to church, and attending a camp for people with IDD. While Tori might not be able or willing to express what motivates her or what type of job she would like to do, she does respond well to structure and routine so it is understandable that her mother sees this as part of her personality preferences and something that could be worked with as a strength and is concerned that those responsible for helping Tori find a job seem to be ignoring this preference and trying to change Tori to be more adaptable.

Chris (A2)

When I interviewed Laura (P9), Chris’s mother, Chris was in his last year of high school and was getting ready to graduate. Laura said that when people have asked her what her goals are for Chris, she has always said that she wants him to be as independent and happy as possible. While she originally thought a large part of that would be Chris living on his own, she has put that off in favor of whatever is fulfilling for him and makes

him happy. I asked Laura if Chris wanted to work and, if so, what did he want to do for a job. She said that although Chris does not vocalize it very much, he does want to work. He had done job training through his high school for five or six years, participated in transition programs the previous two summers, helped out at a camp for people with IDD where he had been a camper himself, and had some job experience at grocery stores and a health club. Laura said that Chris did not seem to be too interested in janitorial work at one grocery store (“he doesn’t turn his nose up at that but you could tell he just wasn’t into it”). He really enjoyed working at the health club because although he was still doing janitorial work, he enjoyed the atmosphere of the fitness center because working out is very important to him and being around people made him happy.

Out of the options that Chris had tried, Laura was leaning more towards a job in a grocery store because it is highly transportable since there are grocery stores all over the world and he really liked it. She told me one story that epitomized his passion for his job:

L: He would come home and he would talk about it and he would just really – you’d have to ask him, but then he would start talking about it, what he’d been doing, what he liked to do, and you to ask him and I think – when I knew for certain how much he liked to do it was when I went up to his room and I said, “okay, enough TV, enough computer, whatever” and I went to his room and he was drawing. I went and looked at what he was drawing and he was drawing a map of the store and all of the aisles and he had a map of his own, labelled where everything was, and it was really cool. It was like, you really like this job, don’t you? And he was like, “yes.”

Laura attributed Chris’s passion for his job because he had opportunities to interact with many people who were nice to him and spoke with him. She would have liked to have seen him do more bagging and carts because she feels that is more employable, but he only had a couple of weeks’ training in those areas when he was in school. Laura

established a savings account with the money Chris earned at the different jobs with the intention of using that money to help him find a job coach since that is a model she has seen other parents resort to and have had positive results for other OHSO athletes. She cited the example of Ryan, another OHSO athlete, and his parents, who ended up paying out of pocket for a job coach:

L: He [Ryan] got through everything in the system and there was nothing he was good enough at and had enough intensive training in to be employable, so—we see that—I mean, I don't think anybody gets out of the high school system really employable even though I give those teachers a lot of credit, you know, trying to give them lots of different experiences and they survey them and do questions, really give them different jobs and opportunities so that they understood what it was like to work and what you had to do, conform, fit certain molds, you know. But we never get enough training in a skill that they're really quite employable yet.

Laura added that she was aware that there were “follow-on” programs that were supposed to aid in the transition out of high school, but she had seen a lot of mixed feedback on those. I asked her what she thought Chris would gain from being employed and she answered:

L: Well, he likes to work. He's a good worker. All of his teachers said that, they said that at his transition program—they gave him a job to do and he does it. He likes that and he takes pride in that. And I think it's fulfilling for him, just like any of them—us. It'll give him some income and that will be good. I don't want him to rely on Disability all of his life. It's not that much. So it gives him some income that he can use to take care of himself and also there's a social thing, too, for him—it's fulfilling. It's kind of like what anybody would want from their job is to do something that makes them happy and is fulfilling. You know, it's work, they call it work for a reason, but—so it's a mix of good and bad but it's part of being human, a contributing member to society, and it's good for him. It's also good for other people, you know, to see that here's somebody that doesn't have everything that all of us are gifted with and they still are contributing member of society and not only that, they're a great person, too, you get to know them.

Maddie (A8)

Maddie attended the same school as James, although she was a year younger than him, and because their school belonged to one of the smallest school districts and there were no other students with IDD in their cohort, they received a lot of individualized attention from their teachers and were able to access programs outside of their district that those in larger districts were unable to access. Maddie's parents, Cathy and Robert, focused on intensive intervention programs from the time Maddie was 4 months old throughout her entire school career. They networked with parents they met through those programs, the Down Syndrome Association, school, and the Special Olympics, and they learned that they could not rely on service coordinators to know what's going on or what services were available in the community, but instead turned to the parents as a source of information in order to learn from other people's experiences. Cathy and Robert have felt a lot of frustration and concern because they realized that in spite of their hopes that service professionals would direct them to the appropriate services and programs, the parents were ultimately responsible for attaining resources. As I discussed in the chapter on esoteric/exoteric, Cathy and Robert are no strangers to navigating complicated networks of agencies and services—both have had careers as social workers, and yet they still were having difficulties. After all she and her husband had done, and with all their knowledge and resources, they still were not able to fulfill their original goal of finding employment in the community for their daughter. They said they had services as early as it was possible to get them, but that those responsible for educating parents about those services, the service coordinators themselves, did not really know what was going on or

what resources were available in the community and the only way they found out about things was through other parents.

Once Maddie entered the school system, her parents relied on the parents and the school system for direction. There seemed to be a greater disconnect with the county service agencies during this period—no one from the county was coming to see Maddie and the county closed her case because she had not been utilizing the services although Cathy and Robert had not been contacted by them. At one point, a county agent asked Cathy if they could send her Maddie's records and close the case, to which Cathy responded, "Well, you can do that, but make sure she stays on the waiting list." Cathy was referring to the Individual Option (IO) waiver for those eligible for Medicaid funding and it has an infamously long waitlist, so it is incredibly important for people to apply as soon as possible since the wait can be years. The service professionals did not follow Cathy's request, but Cathy followed other parents' directions and ensured her daughter got on the waitlist.

When Cathy and Robert activated her case again as they were preparing to enter the transition out of high school, they found a similar lack of assistance from the service coordinators. Cathy explained, "They're very nice people, but they're just not well informed and they seem to be in a box of terms of what they are familiar with—and maybe that's just the individuals that I've had, but I don't know of that many other people who are saying different things." Once they entered the transition phased, they were confronted by dashed hopes and failed expectations because, as Cathy noted:

C: Well, you get to this transition and you have no clue what's out there, what's available. You were told all these things when they were little

like, “if you start this infant stim [stimulation], they’ll be able to go and work in sheltered employment” and all these bright things of what’s available and how they could be independent, or at least somewhat independent in terms of living and working. And you had all these bright pictures and you go through and you do everything you were told to do, you know, all the services plugged in through the school and whatever and then you get to that phase and it’s like, “I’m sorry, there’s nothing out here for ya” and I mean, there is, but of course your kid never qualifies for it. It’s limited. And a lot of programs they start up and they don’t continue...so the training programs to get people to actually work in a work setting or at least some kinds of employment type things—they just kind of fizzle on you. And what you’re left is some of the services that have been around for years, like [the day program and sheltered workshop], which is where Maddie is now.

Currently, Maddie attends the sheltered workshop three days a week and does piecework or whatever work they have available for her, but this was not what they had in mind when Maddie was preparing for transition.

Cathy said transition was “the most difficult part of our lives” because Maddie had always had so many work opportunities—even working in the cafeteria during middle school—from working in various libraries to working in the high school cafeteria, a grocery store, retail stores, a hospital, thrift stores, and a drug store. She worked at a career center and in a production environment where she learned more job skills like assembly work, showing up on time, how to dress appropriately, among other things. After high school, she went to a transition program where she had eight different job possibilities, but when it came time to discuss what to do afterwards, according to Cathy, “we kind of heard them changing their tune, particularly with the county people coming in, because they have nothing and had two work coordinators for the entire county.” Maddie was not able to move fast enough to bag groceries like James, who is employed at a grocery store, but she has other skills and strengths, particularly in libraries and

bookstores. One of the job placement finders told Cathy that Maddie would have a hard time working in the library because library funding has been cut so they would not likely be hiring. Cathy told him that she didn't care if Maddie got an actual paid position and perhaps she could volunteer in libraries and bookstores, but he countered that Maddie could not work in those types of places because she was too short and wouldn't be able to put things on the tall bookshelves. In spite of how well Maddie had done in her different internships and job tryouts, it did not matter in the end because, as Cathy said, "they all just basically said, 'She's just not going to be able to work anywhere with placements we have.'" When Cathy asked them what placements they were referring to, they said they had an enclave janitorial service that cleaned buildings downtown from 3:00 to 11:00 and a machine shop that required workers to move very quickly. "Of course," said Cathy, "we were really discouraged. He [Robert] had to hold me back at these meetings because I was just like-I was just losing it. And my friends who have gone through it have been the same way."

It was around this time, when Maddie was attending a post-high school transition program, that Maddie had the opportunity to volunteer two days a week for a couple of hours at a time at a motor scooter/coffee shop. The shop had just opened and could not afford to pay Maddie for her services, but appreciated her help nonetheless, and it was a win-win situation because Maddie liked the people and work, they liked her, and Maddie's parents felt that there were few alternatives for Maddie. Maddie's options were limited to the sheltered workshop or post-secondary job training programs that hoped to provide jobs for people once they completed the program, but people were not getting

jobs and the programs were rapidly becoming defunct. Around this time, Cathy heard that if you did not get a placement in the workshop, you might be able to get on a waiting list but there were no other options for Maddie's day activities once the transition programs ended.

C: So what we decided to do was pursue this community experience and then we just bit our tongues and marched her into that warehouse like she was-like our whole-she's been going to school since she was 4 months of age and ran her all over the city until she got into [the high school] and then we thought we did everything we possibly could and she still ends up in the same place that she would have ended up had we done nothing.

The coffee shop closed, so Maddie is now only working at the sheltered workshop, and although they had felt like their world was coming to an end and they felt frustrated and hopeless, Cathy and Robert believe that it has actually worked out okay. The workshop has a history and provides a sense of stability and permanence for Cathy and Robert. Maddie appreciates the routine and she gets to see some of her friends from her infant stim classes and teammates from the OHSO team.

Cathy and Robert are aware of the rupture between their past hopes and current reality and how they perceive the workshop versus how Maddie feels about it. Robert said that his issue with the workshop was that he had envisioned Maddie "growing up and being able to, at least in some fashion, contribute out in the community with some type of job skill, if not independent, at least supervised at something." Cathy explained that when the workshop was first created, it was considered novel and innovative, but as Maddie grew up and inclusion became the predominant theme, "there seemed to be the possibilities were endless with kids with disabilities-that there were going to be so many

more opportunities out there and so you get a different picture that you're not going to end up in the same place that the previous generation had ended up and were happy with because they were coming out of the institutions and whatever." She acknowledges that it is a warehouse but the staff are wonderful, there are movies if there is not any work available, they have Wii games, fashion shows, holiday parties, and various leisure activities. However, Cathy also said that many of her friends, including other parents from OHSO would say things like, "my kid will never go to [the workshop]." Both she and her husband had reservations of their own when their first took Maddie to the workshop. Robert recalled the experience of the initial visit:

R: a certain amount of fear and anxiety that we were leaving her in an environment where she was going to be exposed to a lot of things that she, for her entire life, had never been exposed to—people who were more severely delayed or disabled than she was. And it's sort of like, if she's around that enough, she's going to regress. That was basically it for me. But I don't know that that's really occurred. I mean, I think she's been challenged there to a certain degree. I don't think my fears have been realized, to a great extent. It hasn't turned out as bad as I thought it would be, basically.

For Cathy, the workshop is a much better alternative to her sitting at home and doing nothing all day. Cathy believes that Maddie is happy and because Maddie does not do well with a lot of transitions and disruptions to her routines, Cathy is not sure anymore if she even wants her to have employment in the community because jobs fall through and bosses change. Maddie's parents are aware that there is a growing anti-piecework sentiment, but they said that Maddie seems to love piecework and seems very excited and proud when she comes home and shows them how many pieces she made that day. Ultimately, Cathy said it is important to recognize this tenet with not just Maddie, but

with all of her children—that “what you expect them to have, or what you want from them, is not necessarily what they want.” This does not prevent her from wondering if she and her husband are failures because they were not able to get her to a point where she could go out and get employment. However, when she continues to see other young adults with IDD and OHSO athletes who are much higher functioning than Maddie but still have not been able to get employment, she realizes that a lot of it is about opportunities, or lack thereof.

Cathy also mentioned gender as a possible factor that makes it more difficult for Maddie to find job opportunities when compared to her male counterparts. She believes that because some of the young men with IDD are more physically adept and stronger than some of the young women, they have more access to more physically-oriented jobs and activities, such as working in grocery stores. In addition to issues of strength and physicality, there is the fact that Maddie is 26 but looks much younger and people base their impressions and react to Maddie on an assumption that she is younger than she is. As it stands now, Cathy said that she believes that the workshop is trying to move out in new directions and find more opportunities to get out in the community, even if it is on a volunteer rather than paid basis. She would like to see Maddie out in the community doing something, but adds:

C: If that doesn't work out or a job falls through and she can't come back to [the workshop], then I have a problem with it. And that's kind of the way it's always been—if you go out there, you get something, you lose your place at [the workshop]. Now there may not be a waiting list and you may be able to get back in but there's no guarantees, and I think that's what bothers me. I think that the people at [the workshop] are a little bit more nervous because they know things are going on, they know they're kind of becoming dinosaurs, but there's still a need to have

places like that for a lot of folks that can't make it in competitive employment.

Cathy and Robert continue to contemplate the paths that Maddie has explored and those that might open up for her in the future, but at this moment, they are most concerned with what makes Maddie happy and secure in a stable environment. For their family, the sheltered workshop is one of the only viable options that they have seen that meets their needs and although they are not closed to considering other opportunities should they arise—right now, there really doesn't seem to be anything else for Maddie.

Matt (A9)

Matt is a young man with Down Syndrome who lives at home with his parents, Evelyn (P6) and Keith (P16). When I interviewed 26-year old Matt with his family, he was temporarily employed in a customer service position at a hospital, but the position was precarious and he was anxiously trying to find a more stable and permanent job. Like some of the other OHSO athletes, Matt was going through a transition program and had experienced various job-training opportunities but did not have a permanent position. It was apparent from Matt's words and his parents' observations that his employment situation was causing him anxiety but that he was developing coping strategies to help him manage the stress. I asked for an update on his current job situation and any future job prospects since I had learned in my last interview with his parents that he was still looking for other opportunities, but his family said that they had a possible job opening in progress but were unable to discuss it at that point.

Matt enjoys helping people and his dream job is one involving customer service, but unfortunately, his current customer service job at the hospital has not gone the way he and his family or job coaches had intended. As we were discussing what people might not know about Matt but what they should know, Matt's parents said they wanted people to know how hard and exhausting it is for him to be appropriate and typical. Matt then asked his father, Keith, "What do you say when I get home after work?" Keith asked if it was that he was waiting for a hug or for Matt to clean his room, but that was not it—Matt said it was that he was outgoing and that he is "making the world a better place." Evelyn, his mother, said that it has gotten very tough in his current work environment because he knows he is not going to have a permanent job there and that some people were actively trying to prevent him from gaining permanent employment. In the following brief exchange, Matt's mother reassures Matt that he is making a difference and he admits that it is still a struggle:

K: you are making the world a better place

M: I try to be, but it's not easy

K: it isn't easy, is it?

O: what's hard?

M: everything. Getting a job is hard.

When I asked about the situation at Matt's work, Evelyn said that things have gotten very tough because "they have taken away privileges from him that would make him a good candidate for the position that he has, so he used to be able to get on the computer and find room numbers for everyone-you know, for all the patients and that-but they've taken all that and the computer privileges away from him now" (P6:7/13). She said she was not sure if they were afraid that Matt might compromise patients' personal information, but

that she did not think that he would do that because he had gone through the annual training. Rather than looking further into the issue or clarifying their position, his boss has taken away his computer privileges, so Matt's tasks and abilities are limited to greeting and delivering things to rooms. She also mentioned that even though they had invested in years of speech therapy for Matt to help him with articulation, he was never given the opportunity to answer the phone, which would have been another tool he could have used to further develop his communication and interaction skills. It was not always this rocky—Matt was originally given the position because the head of the department was very helpful, encouraging, and opened the doors for him. I am not sure if there was a change in staffing or if some other complications had occurred, but Matt said, “They don't want me there.”

When discussing how people treat Matt at work, Evelyn said that some people at work said that Matt did not move and work fast enough and were even timing him to see how long it takes him to deliver newspapers to the rooms on different floors. Matt said it's “very stressful,” but he has developed two responses. The first one is to tell them that he had a bathroom emergency and the second one, Matt said, “was realistic...I was helping a patient.” Evelyn added that at one point, his supervisor was telling him to take the stairs to deliver newspapers to the 4th, 5th, and 6th floors because the elevators were too slow. I asked if anyone else was timed while they were delivering items to rooms and Matt said no, he was the only one. Because this job is not leading to a permanent position, I was interested in learning more about Matt's job preferences. I know that piecework and repetitive tasks in janitorial, grocery, and clerical work are some of the

limited options available for people with IDD, so I was curious how Matt would react to me suggesting those types of jobs.

O: would you ever do a job where you have to do something over and over again but maybe it's not with a lot of other people? Like mail?

M: no, I'm more, like, with people

O: being social

M: yeah

O: would you do a job where you had to be on the computer or filing if it was only for a certain amount of time or do you only want to be around people all of the time?

M: with people all of the time

Matt emphasized that he cares about people and added, “well, I actually—well, I ask myself being at home with my mom and dad and help them out when they get old.” Matt already helps out at home because his father had a stroke and sometimes needs Matt to assist Evelyn with moving him. It is unclear how long he will remain at his current job, what his future looks like in terms of employment in the community, and how his hopes and expectations for employment will align with available opportunities.

Derek (A3)

Derek is a 28-year old man who, like Matt, is in a post-secondary transition program, but does not have permanent paid employment. He has had job training opportunities in multiple areas such as libraries, restaurants, and college settings, and wants to work; he currently has a seasonal job at the zoo. Eileen (P5), his mother, told me of some of the difficulties they have faced while trying to secure a position for Derek—from issues with service professionals to tragic circumstances leading to personnel changes resulting in Derek losing his position. Eileen said that in one of Derek's

transition meetings, his job coach who had seemed adversarial during the meeting spun around in his chair and asked Derek a question. He asked Derek if he wanted to see his friends every day, hang out, do fun things, play games, watch movies, go places, or would he rather work? Derek looked at him and answered, “Work.” This is a testament to Derek’s motivation to work, but it is not an answer that one could imagine many people answering in that manner when presented with a question framed in such a way to positively load the first option compared to the second. While I was not at the meeting and did not interview the job coach, I can’t help but wonder what would motivate someone whose job it is to help people with disabilities find and learn how to keep a job as a question in that manner? The story does confirm the experiences reported by other parents who suggested that some service professionals only want to help those who are minimally disabled and can more easily be placed in jobs. The parents suspect that many of the service professionals are under pressure to provide statistics of success in placing clients.

Eileen told me of some of the difficulties they had faced while trying to secure a position for Derek—from issues with service professionals to losses of natural supports—that made it difficult for Derek to maintain steady employment. When Derek had a job at a college library, Jack, one of his supervisors connected with him and became a natural support, appreciating the unique skills and talents Derek brought to the job. However, not everyone was as helpful or positive, which was apparent through his relationship with Steve, one of Derek’s job coaches, who said that Derek was not motivated because he did not ask for more work when he completed a task. As I discuss in the sections on Patty

(A12) and Tori (A14), equating an individual's lack of requesting for additional work after completing a task with a lack of motivation is something that continues to emerge in my research, requiring a more thorough exploration.

Steve said that Derek was not fit for the job at the library because he misfiled the oversized books by putting them on the wrong shelves. In actuality, Derek did not put them on the wrong shelves but instead asked his supervisor where to put the books. Although Derek could be faulted for asking too many questions and potentially disrupting his supervisor, he could not be faulted for misfiling because that would require him to guess about something's proper location and Derek did not have the capacity to guess. The college students temporarily employed in the library did guess and were sometimes correct, but when wrong, the books were often lost. Jack recognized this and appreciated that Derek was the only worker who did not guess—and subsequently found more misfiled books than had ever been located in the library.

Maria, a different supervisor, came to Eileen, said that Derek was diffident, and had a bad attitude because although she had told him every day that if there were too many trays on the first floor, he was to move them upstairs, but he did not. Eileen suggested that it might not be a matter of attitude but that Derek did not understand the concept of “too many.” When Jessica, Derek's job coach, pointed out the wainscoting on the wall to demonstrate that trays above the line needed to be moved upstairs, Derek moved them. Maria came back to Eileen and complimented her on whatever she had done to change Derek's attitude because it had worked—not understanding that it was an issue of comprehension and sign systems, not attitude.

When independent with a natural support like Jack, but this time at a local restaurant, Derek had similar success when the manager, who had volunteered with the Special Olympics and knew Derek from high school, recognized Derek's strengths and needs. Bussing fit well with some of Derek's strengths because he has an excellent memory and quickly memorized where all of the tables were in the restaurant so he did not need to look at a map when a table needed to be cleaned. The restaurant manager saw that his work ethic, speed, and determination affected the other employees and made them work more effectively because they did not want to appear as if they were not working as hard. When Derek would get distracted because he wanted to be more social and talk with the other workers, the manager would simply tell him that it was time to work and the time to be social came after work, and Derek would promptly return to his tasks. Sadly, a tragic incident occurred and a new person, who was not as understanding, replaced the restaurant manager, and when Derek started talking to his co-workers, the new manager said that Derek was no longer needed at the restaurant.

Lewis (A7)

Lewis is a 28-year old man with IDD and has faced considerable difficulties obtaining services and employment. He spoke with me on multiple occasions but did not feel comfortable being recorded. Lewis lives with relatives and is his own guardian, which has its benefits and drawbacks. When he was younger, he moved to Ohio from another state but he and his family were unaware of the extensive processes involved in obtaining services so when he was asked to take an assessment to determine what types

of services he could qualify for, he answered them from an optimistic viewpoint and with imagined support when necessary. Unfortunately, because he was not familiar with this type of assessment and that its goal is to determine what the individual with IDD can do completely independently and without support, he was denied services and funding.

Lewis's relative, Linda, said that it has been a struggle to help Lewis find support and promote his independence because they began the process of trying to navigate the government service agencies too late. Because Lewis is unable to drive and does not receive Waiver services, he does not qualify for transportation assistance and this adds another complication to his employment opportunities. Lewis has also faced difficulties when it comes to having service professionals understand and assist him with his goals. He was uncomfortable discussing some of the issues with me because the memories were still upsetting to him, but Lori relayed a story about when they were meeting with someone from a county agency and this person was dismissive to Lewis and said she could not understand him (Lewis has speech impairments) so directed all of her communication with Lori while simultaneously ignoring Lewis. The agent then said that she did not think Lewis was employable, which significantly upset Lewis. Lori said she wanted Lewis to attend a post-secondary transitional program to give him a college-like experience and more job opportunities, but the agent said that no one had been placed in a permanent job after completing the program. Lewis then got an internship at a local pet store and then a paying job at the zoo. The agent again said that she was not hopeful that Lewis would find permanent employment with the zoo because, as far as she knew, only one person with IDD had gained a permanent position at the zoo in 22 years. After Lewis

was working at the zoo for a short while, the agent contacted Lori and said that Lewis was not working out and that he would need to find another job. Lewis's job coach spoke with the zoo and, contrary to what the agent predicted, Lewis now has a permanent part-time job at the zoo.

As of December 2015, Lewis had been working at the zoo for three years. He began working four hours per day with the assistance of a job coach and he learned to take tickets and stock the maps. Lewis said that after his third month of working, he no longer needed a job coach and has gone from being part-time seasonal work to part-time permanent. When I asked him what he liked about his job, he said he loves the people and the kids. Lewis gets along well with his co-workers and is particularly fond of a retired school principal who acts as a natural support and friend. His biggest struggle is communication, his "talking voice," but he has learned to adapt by speaking slowly and if someone is unable to understand him, he asks him or her to go to one of his co-workers. Lewis said that he is very proud of his work and that he has never missed a day of work and even received an award for always being on time. He told me that his bosses appreciate him because he always has a good attitude and is honest and that one day he hopes they will put him in the window to help people buy tickets. Lewis still relies on his family and his neighbors for transportation because the bus does not have a route to the zoo. This makes it difficult because sometimes his family have to drop him off on the way to their jobs, which means he arrives at the zoo hours before his shift starts. Lewis does not complain, but he does wish there was a way for him to have transportation that

would allow him to be more independent and would not inconvenience his family and neighbors.

Although sheltered workshops are being closed, few opportunities exist for individuals with IDD to find employment in the community. The young adults and their parents often mention their frustration at many of the obstacles they encounter, such as the difficulty of finding a good fit with a job description, the difficulty of getting natural supports on the job, and the lack of appreciation of the abilities of a person who has disabilities. Complex issues—namely, how to accurately measure an athlete’s strengths and limitations, motivate athletes to strive for their personal best, and underestimating athletes’ capabilities due to lowered expectations—mentioned as problematic in the Special Olympics also appear in the employment world. The obvious difference is that Special Olympics endeavors to identify each athlete’s strengths and build on them. What is less obvious, and I would argue, equally important, is the question of expectations, a subject that requires greater elaboration of the role of the “natural supports.”

As I discussed earlier, the best natural supports have high expectations of an employee with disabilities. Someone who tolerates inadequate work actually does the employee with disabilities no favors. There is a fine line between setting high expectations and creating stress for an individual who will have a meltdown. To use just one example, motivation is certainly an obstacle for many individuals with IDD, especially when it is measured by the ability to identify a new task upon completion of a task. This is actually something that can often be solved without ever-increasing

“motivation” by, for example, making lists or having a natural support to go to when a task is completed.

Similarly, the problem of socializing inappropriately is a major obstacle for employment, and it is very difficult for many people with IDD to navigate the social world of a workplace (not that it is easy for people without disabilities). It is often difficult for the natural supports to refuse social interaction—such a refusal would be rude if directed at someone without a disability. This is one of the trickiest areas to address because having high expectations can be in conflict with ordinary social interaction. Sensitivity to sensory stimulation might also be a factor that needs to be considered. Rather than assuming that someone is not capable of competitive employment because he or she is constantly distracted by tight-fitting items and clothing (such as a hat or hairnet and rubber gloves) but is working in an environment where those are required, the job developers and coaches should look at the environment and match it to the individual.

In many of these cases, the explanations of difficulties the individuals with IDD faced in employment situations pointed were discordant in some way with the situation. They were not inaccurate, but neither were they entirely salient. Moreover, instead of pointing to a lack of fit between a particular job and a particular employee, the individuals’ inadequacies were taken as categorical signs that marked them as “unemployable” generally. Given the State of Ohio’s interest in employing individuals with IDD, it is surprising that the discourse does not address the lack of appropriate employment sites. Instead, the focus is on the individuals’ inadequacies. The discursive

entanglement, then, is the misapplication of the binary oppositions between employable/unemployable; motivated/unmotivated; needing natural supports/working independently. In this discursive entanglement, inappropriate job sites are discursively translated into unemployability.

These stories, in addition to the media examples and government initiatives, call attention to some of the fundamental dimensions of transition into the workforce and ask us to consider if the motifs of hard work, positive attitude, and striving to achieve one's personal best translate from the sports context into the community context to help people become more included in society. Implicit in this question is the assumption that someone's value as a citizen and our willingness to consider them as normal is based on their ability to work and earn money. Another undercurrent is the notion that sports and competition are one of the best methods to building character, developing social skills, and fostering employment opportunities and successes. Obviously, the Special Olympics is a sports-based program; what does the eclipse of other types of programs (i.e. arts) by the Special Olympics suggest about this idea? Are there other routes to these outcomes? Are sports really the "best" for everyone? Many of the athletes participate in other programs as well. For example, there are several programs and spaces that encourage artistic production among people with disabilities. I am not arguing that sports provides a singular mode for building character or developing social skills, nor that my intention was to look no further beyond sports, but that my focus for this thesis was to observe how some of the athletes were, or were not, able to translate the skills they acquired in Special Olympics to employment, some were no.

The discursive entanglements surrounding motivation, (un)employability, and (in)competence, as well as the lack of attention given to the potential benefits to the workplace when people with disabilities and natural supports suggest more work is required to begin chipping away at the systemic issues preventing so many people from truly being included.

Chapter Eight

Conclusion

In my work, I have attempted to navigate the difficult terrain of the creation of a folk group, its relations with outsiders, and the ways that in the process of countering stigma and seeking the "regular," often, the stigma is nonetheless perpetuated. This is one way to understand the controversy about Special Olympics that began my discussion in the introduction. Here, in the conclusion, I discuss some of the murky unresolved dimensions of a folk group's efforts to counter stigma. In addition to the creation of a group with members who understand each other and serve as networks and resources for each other, the interactions and gatherings that are based on belonging to a category rooted in a diagnosis of intellectual and developmental disability can reproduce stigma. This is particularly apparent when considering the lens of spectacle, invisibility, and hypervisibility as evident in representations of people with IDD in the media, Special Olympics, and in everyday community interactions.

Rapp and Ginsburg do an excellent job of observing that groups of parents, allies, and people with disabilities constitute a kinship group. When we add a folklore perspective, shifting the focus to folk group rather than kinship group, we can additionally observe the performances and rituals that help to sustain the group's sense of itself, its relations with outsiders, and how the group thinks it is perceived by outsiders. In other words, the concepts of folk group, performance, and ritual help us to understand the complex negotiations of presentation of self for a stigmatized group.

Folklore offers disability studies a framework to better understand the diversity of experiences, particularly through ethnography with people with IDD and different ways

they express their worldviews and experiences. It also provides a lens through which we can explore stigma and untellability—especially in areas that might be problematic, such as individuals who want to remain in sheltered workshops or be an inspirational mascot and have narratives that are politically opposed to the movement towards inclusion. Folklore provides the possibility of examining different performances, as I have done through sports, and invites us to examine group formation and identity, rituals, expectations of performance, and how narrative in everyday life sustains stigma or provides new paradigms.

In every dimension of my research, from family interactions to Special Olympics, to employment, I encountered the difficulties coaches, parents, educators, and employers faced in their efforts to create reasonable expectations for people with intellectual and developmental disabilities. What are the causes and effects of having too high or too low of expectations for people with IDD? At Special Olympics events, whether practices, games, or social interactions, I was able to observe how the coaches assessed capabilities, tailored their expectations of the athletes, selected the task(s) most necessary and manageable at the time, and then persuaded the athletes to try to achieve their personal best. Obviously an incredibly complex and difficult process, this requires the coaching staff to learn, process, and prove their own capabilities and competencies as leaders. The coaching staff must engage in a massive amount of observation, and display keen insight, wisdom, patience, encouragement, and flexibility. As I have mentioned before, the goal of the Special Olympics is to “provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities,

giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community” (Special Olympics 2015). The Special Olympics groups athletes by age, gender, and ability, in an effort to give everyone an equal opportunity to win. Ideally, the Special Olympics hopes the groupings and divisioning create a level-playing field that is foundational for competition in the Special Olympics. However, noting that the only requirement to be a member of the Special Olympics is to have a disability requiring an Individualized Education Plan (IEP), it is almost impossible to account for the multitudes and varieties of intellectual and developmental disabilities and truly provide equal groupings at all times. The athletes have a great range of abilities, not only physical abilities, but intellectual and emotional abilities, such as the ability to take direction, to remember the rules, to pay attention, and to demonstrate simple and complex skills. Some of the athletes do not want to run, some do not want to run in their designated lanes or in the required direction, some do not want to pass the ball and would rather take a shot at scoring every time they get the ball, some act as peer supports by helping their teammates practice difficult skills and shouting encouragement, and others go too far in offering guidance (perhaps confusing the role of athlete and coach) and risk being perceived as bossy and overbearing.

Special Olympics provides a place where individuals with IDD can participate in physical activities, learn about sportsmanship and appropriate boundaries, improve their self-esteem, and have different people (coaches, volunteers, family, and caregivers) assist in recognizing the necessary steps to achieve a goal. Nonetheless, some of Storey’s

criticisms ring true and warrant further attention, such as the paternalistic attitudes exhibited by some coaches and volunteers towards the athletes when the adult athletes are referred to as “kids,” a lack of leadership involving people with IDD, and the potential for athletes to be further stigmatized by representations based on sympathy and pity. Additionally, sometimes coaches and volunteers do not know how to assist someone in achieving a greater goal because they are afraid of upsetting athletes and pushing them beyond their comfort level, which results in lowered expectations and missed opportunities for athletes to actualize their full potential. My concern is that by glossing over behaviors and not setting high enough expectations, some coaches, volunteers, and parents might be perpetuating a stigma that those with IDD do not have the abilities to learn appropriate boundaries and behaviors—a mindset that borders on pity. I have seen volunteers hug the athletes, in spite of the coach’s rules against hugging, and not correct certain actions and behaviors because the volunteers (as well as some of the parents) view the Special Olympics as a place where the goal is to make the athletes happy, at whatever cost, even if that means allowing behaviors that could potentially further stigmatize those with IDD. Happiness and greater self-confidence are not bad goals, but by only focusing on these objectives and not asking whether the athlete is capable of more, volunteers and coaching staff can do a disservice to the athletes because they are missing opportunities to help those with IDD to be more successful, whether as athletes or as social interlocutors.

Several scholars are beginning to study modes of interaction between individuals with and without IDD (Ochs et al. 2001); a few have offered models that move beyond

the restrictive pairing of caregiver and dependent. Val Williams' (2011) work is helpful for understanding how caregivers and people with IDD can communicate across their different competencies; Grigal and Hart (2010) provide models for how people working in postsecondary programs can raise their expectations of people with IDD. If the bar is set too low, we run the risk of never knowing a person's potential. If the bar is set too high, we might needlessly frustrate someone by asking him or her to do something that they are incapable of doing, which could likely harm an individual's self-esteem. The problem is that when people without IDD do not offer correction because of sentiments rooted in kindness or pity, they are assuming that those with IDD cannot do more, which then makes it even harder for those with IDD to develop skills necessary to live and work in an inclusive environment. To summarize, by not setting high enough expectations, we risk being paternalistic and not enabling people with IDD to become adults.

Limiting mindsets such as these can be detrimental and create a series of concussive waves that affect not just the future and possibilities for individuals with IDD to become as independent as possible, but also the perceptions, attitudes, and behaviors of those without IDD. For example, I have been working in an integrative environment over the past year that employs both individuals with and without disabilities, and I have had the opportunity to see what works and what does not. In that time period, two individuals with IDD have either quit their jobs or have been dismissed because of gaps in communication, unmet expectations, and a lack of job carving for the individuals, which essentially means tweaking the job description to best suit the individual rather than utilizing a one-size-fits-all approach. In one case, Emily, an employee with IDD who was

responsible for assisting other staff with bussing tables and polishing and cleaning silverware, was not able to understand and appropriately respond to social cues and this created conflict and misunderstandings between herself and her co-workers. Emily asked other employees for their cell phone numbers and would text too frequently; she contacted one of the older staff members and asked him if he loved her when he called her “hon” or “darling”; told other male co-workers that she liked them or had crushes on them; and she would get upset and start to cry if she felt other employees were being rude to her by giving her tasks without asking nicely (often when the business was at its busiest and social niceties were replaced by barking orders and commands). Emily preferred to socialize with other staff members and customers rather than attend to her job duties that did not involve as much social interaction, which contributed to her being reprimanded by management to focus on her tasks rather than socializing. Finally, after numerous occurrences of Emily becoming upset by what she perceived as people being mean to her, she quit, and as far as I am aware, no attempts to educate, repair, or resolve the issues were provided. I doubt this was out of any ill will on the part of the management or staff but rather a lack of education and resources to help both Emily and her co-workers understand the appropriate rituals and rules necessary in that environment.

In another instance, Alice, an employee with IDD who was responsible for cutting fruits and vegetables in the food preparation station, lost her job as a result of a combination of factors. Alice’s employers felt that she had started to regress and rather than continuing to improve on her speed and quality of work, Alice was becoming less

productive and more distracted. Additionally, the one co-worker who had helped train Alice, knew Alice's strengths and limitations, could provide oversight and offer verbal cues to remind Alice of her tasks while still doing her own work, and acted as a natural support, was going away for an indefinite amount of time. The managing staff asked for job coaching assistance from Alice's service provider agency, who was supposed to provide the necessary support to ensure Alice is taught the skills she needs, but the provider agency either did not respond or would send staff who would arrive when Alice was not working or they would stay for an hour at most, which was not a sufficient amount of time to help Alice with her tasks. Alice's other co-workers were afraid to correct her (because she might respond with an unpredictable and heightened degree of emotion) and did not want to spend their time helping her stay on task when they had their own duties to accomplish. Alice then began to eat too much of the food that was provided for employee meals and only a few people would correct her so she could learn when and how much was appropriate to eat (a similar issue is featured in the British television show "The Specials" in which one of the members is in danger of losing her job because she is eating too much). Ultimately, Alice was let go and her parents, employers, and provider agency decided that she was not capable of working around food. However, Alice had worked in a bakery for over a year and did not exhibit these issues, but she also had a staff member with her the majority of the time and that environment was designed specifically for those with IDD.

These are not isolated incidents, and one of the most striking commonalities between these two examples is that the employees were not trained to interact with

someone with IDD. When the individuals with IDD acted or behaved in a manner that was out of alignment with what was expected of the staff without IDD, their co-workers responded by either ignoring the inappropriate behavior, defaulting to a position of extreme politeness or, more often than not, avoiding interactions with the young women with IDD altogether. As a folklorist, I recognize this as a breakdown in communication and expectations, which are locally situated and ritually practiced.

Many of the disjunctures, misunderstandings, and misrepresentations of individuals with IDD by those without IDD can be described through the lens of ritual practice and conventions for interaction. From my research, I identified countless examples of ritual interactions where I was quite sure that although a ritual might have been used appropriately, the individual was not necessarily competent in using it correctly. From sports talk, small talk, to face-to-face interactions in the community, there were many instances where a person with IDD was able to perform ritual interactions that seemed to fit the situation but, in fact, did not and thus marked the individual as different. For example, Tori (A14) has a phobia of dogs but recognizes the pattern of people often making favorable remarks when they encounter strangers walking their dogs in public places. When Tori sees someone walking a dog, she will often smile and say, “Oh, what a pretty puppy!” with enthusiasm and apparent good cheer. However, as soon as the dog comes closer, Tori will veer in an extreme arc to avoid any possible contact with the dog, to the extent that she will endanger herself by running off the sidewalk and into the street to avoid a leashed dog. She competently performed the ritual of greeting a puppy, but at the same time put herself in danger. Many of the athletes were

able to perform ritual competence of this kind but not utilize the kind of judgement needed in many circumstances.

Many of the athletes have cell phones, Facebook accounts, and use technological devices frequently to aid in their communication. With increased means of communication and opportunities for social interaction that move far beyond the face-to-face interaction in a smaller community, there is also a greater opportunity for competent ritual practice at one level to be misunderstood or result in social gaffes and awkwardness because an individual with IDD might lack the social awareness and judgement capabilities necessary to conform to complex (and often unstated) rules for social interaction. Derek's (A3) mother often describes his appropriate and inappropriate interactions as what might be seen as ritual interactions. Derek has difficulty recognizing the boundaries between co-workers and family, and because he is so friendly, some co-workers respond to his requests with kindness. At one of his jobs, he asked his co-workers for their wedding pictures and this made them very uncomfortable. Fortunately, they reported it to the job coaches (sometimes fellow employees do not know what to do with this discomfort and it results in a dismissal from the job). In Derek's case, the job coaches were able to explain that it is not acceptable to ask for photos; and at an end of the year party, the employees thoughtfully took pictures of themselves and presented them on a mug to Derek as a present. Instead of either ignoring his request, placating him, or dismissing him, these co-workers were willing to help him to understand that it was unacceptable, and as a result, it became a learning experience for Derek. By giving him the photo mug, they offered an acceptable substitute through the ritual of gift giving.

In another example, Derek was interested in looking at YouTube clips and pictures of people kissing on his computer, but he would often end up on pornographic websites. His mother, Eileen, set a rule that said that the people had to be happy and wearing clothes. These parameters did not have the desired effect because Derek was still finding pornographic sites. Eileen realized that Derek had really been interested in kissing, so she discovered that weddings and engagement proposals were safer material for Derek and he has viewed hundreds of weddings on YouTube. There was then an issue because Derek wanted to make still images from these video clips and hang them in picture frames on his bedroom wall and also wanted to make a photo book with some of his favorite pictures. His care provider realized that Derek was making a photo album that was supposed to be pictures of Derek and his friends and family, but was instead choosing images of people he did not know. His mother and support workers are using his interest in photos and videos to teach him the difference between people he knows and has interactions with and people he sees on the television or computer with whom he does not have any relationship. This concept is additionally confusing because he has posters of sports figures and celebrities on his walls. Some parents would not bother teaching these different concepts because they are indeed confusing categories. Some parents might not care because he is not hurting anyone and it makes him happy. However, Derek's mother sees this as an area where he is already motivated and the photos capture his interest, so she is using this as an opportunity to teach him valuable lessons. She believes he is capable of having a more sophisticated understanding of social networks and who is and is not a friend, and that understanding this will help him learn

skills that he will need in the future to recognize other people's boundaries. As in the example of the photo gift, Derek does not necessarily understand the rationale, but he does understand the rule. He is given an opportunity to meet higher expectations for more acceptable behavior.

The boundaries between family, friend, co-worker is difficult for many adults with IDD. Some of them see a care worker as a best friend and some parents have no trouble with this; as long as the person with IDD perceives this person as a friend and is happy, their parents do not want to disrupt what they see as a healthy connection. The relationship can boost self-esteem, even if it is not actually a reciprocal friendship. Derek's mother, Eileen, also reports that Derek sees his care workers as companions and eagerly waits for every interaction with them. Nevertheless, she insists that he differentiate between care worker, friend, teammate, social worker, therapist, and co-worker, and tries to help him to understand the rules for each kind of interaction.

Greetings, gift exchanges, and photo collecting are all ritual practices governed by conventions, and regarding the practices as rituals rather than as complex categories is one way to assess and modify expectations. In the discussion that follows, I review the controversy about Special Olympics through the lens of ritual acts of hugging.

Like Keith Storey, I find the continued connection between Special Olympics and hugging problematic. Although the coaches for OHSO have made it a rule that people are to use handshakes and high-fives instead of hugging, hugging continues to be a common practice with other Special Olympics teams. Storey argues hugging reinforces negative stereotypes, infantilizes adult athletes, blurs boundaries of (in)appropriate

behavior, and teaches people it is okay to hug strangers. Hugging is a potentially dangerous behavior when generalized as acceptable and then applied to different settings and situations, particularly in the work environment (Storey 2008, 137–138).

Teaching appropriate social boundaries extends beyond hugging, and sometimes people without IDD are uncomfortable to set limits because they do not want to upset someone with IDD, and they do not think the person with IDD is capable of understanding how to differentiate among various social circles. Saying “I love you” is another tricky example of how boundaries can be blurred. The connotations behind these words carry different weight and significance depending on the person and context. Sometimes parents do not mind when a person from outside of the family, such as a care worker, says “I love you” to their adult child with IDD because: (a) they do not think the individual with IDD knows better; (b) they believe the individual’s ego is so fragile that to not have someone say “I love you” back would be a devastating blow; (c) they believe that the most important thing is that their adult child is happy; and (d) it can take a lot of effort to explain abstract concepts such as love and friendship and what is and is not appropriate behavior when interacting in a variety of settings.

Another area of boundary challenges requiring an assessment of the expectations of people with IDD is their use of technology and communicating platforms (i.e. Facebook, cell phones, etc.). I have witnessed several examples where people without IDD get irritated and frustrated when a person with IDD calls, texts, or messages them too frequently. One approach would be to ignore the contact attempts (or block the individual) and only respond when available, which is one of the paths of least resistance

and effort. Assuming people with IDD cannot be taught appropriate boundaries does them a disservice because they could continue to contact other people too frequently. An alternative approach is to teach boundaries and social norms by setting specific limits on the frequency and times a person call/text/message.

All of the examples I have described about expectations, both failed and met, reference conventions for appropriate behavior. As folklorists, we know that those conventions are always locally defined and enacted. The groups that determine what is acceptable and what is not are folk groups and sometimes kinship groups. Special Olympics provides an opportunity for people stigmatized for their failure to conform to expectations to reconsider both how they might assess expectations, what should be expected, what's too much, etc.

Although I was able to collect some instances of challenges in setting and meeting expectations in workplaces and in social interactions from participant observation and interviews, my primary area of observation was at Special Olympics practices and events, and I am particularly interested in how Special Olympics can serve as a site for enhancing social skills. By expecting everyone to eventually follow all of the rules, the coaches maintain a practice that includes everyone and permits great variation for each individual's ability. Some might never get to the final point of success, but everyone is somewhere on the continuum, which can include mastering all of the skills and then learning to teach them to someone else. Having a limited amount of coaching and volunteering staff impacts how much attention can be paid to the various athletes and their particular needs. I have witnessed the complexity of this in practice when a group of

athletes was supposed to line up on the track to prepare to run the 50-meter dash. One athlete was talking to another athlete and not paying attention and getting in the correct starting position. A second athlete was having difficulty with her balance and finding the right line to stay behind. A third athlete was so excited that he kept starting too early. The other athletes were ready and waiting, but the coach had to decide at what point he had to move on from continuously regrouping everyone to start at the same point and when to ignore some of the infractions for the sake of time and keeping the majority on schedule. On the one hand, it could be argued that the athletes who were more competent in this particular activity were not able to work on more advanced skills because more focus was spent on bringing the others to the starting line (see 0 regarding inclusion in education for a similar argument). On the other hand, it could also be argued that this moment taught patience and good sportsmanship. For the coaching staff and volunteers, it was an example of a time when they chose to accept a certain level of insufficient behavior, but knew what they would like to see in the future and create a plan on how to get there. This kind of patience does not necessarily work in the workplace. However, with the proper supports, a person with IDD can know that more is expected of him or her, and the support people can continue to provide new goals. Some of the adaptations that are made in the workplace help everyone. Even the attitude of constant incremental improvement helps everyone, especially in doing menial tasks.

As discussed in 0, portrayals of individuals with IDD can have a variety of implications based on expectations and presumed (in)capabilities. At one extreme, some individuals with IDD are portrayed as “supercrrips,” always smiling and happy, working

harder than everyone else to achieve many taken-for-granted milestones, which is a move that does lend a sense of “hypervisibility” (Shuman and Goldstein 2012). Additionally, someone with IDD is portrayed as another form of supercrip, a type of mascot exemplifying innocence, for whom expectations are lowered because he or she is believed to be incapable of becoming more complex. The poster child, the homecoming queen/king with disabilities, and the honorary team captain who is allowed to make a touchdown in the last moments of the game are all examples of mascots—one-dimensional characterizations (often created by those without disabilities) to evoke sentimentalism and offer little in terms of long-lasting benefits or relationships. Both forms of hypervisibility create distance—distance from others with disabilities, obscuring those who do not fit the unrealistic molds required for recognition and acceptance; and distance from those without disabilities, who then fail to recognize them as fully human, multi-dimensional, and capable of growth. At the other extreme, individuals with IDD are ostracized, segregated, and ignored because people without IDD either: a) do not know how to interact with people with differing cognitive capabilities; or b) do not want to be contaminated in some way by the stigma. Hypervisibility and invisibility are two ends of a spectrum that offer little hope for inclusion for those with IDD.

Diane Goldstein says that “understanding narrative might mean understanding regular folks [referring to non-elite medical and legal participants], and that understanding regular folks might be a good thing” (2015, 127). Many people with IDD and their families want to be understood as “regular folks.” They are so rarely seen as regular. Some parents of children with IDD and individuals with IDD have chosen not to

participate in Special Olympics precisely because they do not want to do anything “special,” particularly special education or special sports. Others, including those I studied, describe Special Olympics occasions as opportunities to be regular. They get to cheer on their children just as other parents do, and the athletes get to be athletes, as if that were the most “regular” thing possible.

Within this community, people experience disability as ordinary, everyday, integrated into life experience. However, the families in the group have had their share of extraordinary events that they mark at their edges of their ability to cope, sometimes including grief and loss, and they might be the first to say that not everything is experienced as ordinary. Shuman argues that when one person’s ordinary becomes someone else’s extraordinary, it creates a misalignment that sets people with disabilities and their families apart from others (Shuman 2011). As Cathy (P3:5/13) described, the OSHO group has provided a network of support and understanding that she did not find elsewhere. It is an example of what Rapp and Ginsburg offer as a new kind of kinship, often rooted in the experience of shared isolation that is a product of stigma. The community encompasses a wide range of interactions, from moments of celebration to mourning, including a yearly eulogy for a team member who died when he was a teenager, in addition to the multiple medical situations that range from difficult to critical. It is therefore necessary to broaden the notions of ordinary, regular, or normal (Davis 1996). I also recognize the tension that exists among several strains of normalcy, including: (a) striving to attain a sense of normal as a mode of inclusion; (b) redefining and expanding ideas of normalcy; and (c) rejecting normalization altogether and instead

encouraging a level of acceptance that accepts people for who they are. As I have argued, I believe that having high expectations does not translate into a lack of acceptance of people. Additionally, this research has taught me to be cautious about minimizing genuine moments of extraordinary accomplishments and suffering. Along with many of the parents, I share moments where I cannot help but feel awed and inspired. I also am aware that these emotional responses can venture into dangerous areas bordering on inspiration porn. I continue to check myself and consider specific contexts, individuals, and performances to gain a deeper understanding of connection and distance, ordinary and extraordinary, and how romanticizing people with IDD potentially removes their place at the figurative table. In these spaces, I also continue to learn how our dependence, frailty, and idiosyncrasies are shared aspects of the human condition, signifying the importance (and often overlooked need) to recognize and respect interdependence.

I continue to work as a direct care provider; I frequently have daily interactions with people with IDD; I go to Special Olympics-related events; I enjoy having lunch, a walk, coffee, or a couple of drinks with some of the OHSO athletes; I communicate through phone, email, text, and social media with some of the athletes and sometimes I have to reestablish boundaries and expectations, just as I might with someone without disabilities. Sometimes I am amazed at the depth of perception and social awareness exhibited by my friends who have been considered too intellectually and developmentally disabled to work in the community. There are also times when I take certain competencies for granted; for example, I sometimes forget that one of my friends is not able to tie his shoes and sometimes needs reminding which end of the knife to use when

cutting food, but this is because I am so familiar with his competencies that often greatly exceed my own. He has a better memory than I do, he keeps better track of time, and he is much more adept at using an iPad than I am. I am reminded that everyone has unique competencies, but sometimes not the ones that are counted.

In recounting these stories, I am reminded of Diane Goldstein's and Susan Ritchie's attention to the problem of ventriloquizing others; I have made every effort not to do that here. I would like to push this point further to consider the conditions in which people make excuses for people with IDD when they speak on their behalf (one form of ventriloquizing). When people speak on behalf of those who are less articulate, even in order to celebrate them, they fail to accord them personhood. Whether they romanticize people with IDD, for example as innocent, they do not recognize a person's subjectivity. When disability is associated with stigma, the reactions or perceptions about it waffle among shame, pity, or charity; if the pendulum swings in the opposite direction, we are offered the compromised option of disability pride. This is problematic because it offers a false "promise" (Shuman 2005) of acceptance, and also assumes that individuals with IDD have the necessary level of self-awareness to embrace an entity that recognizes and values membership in a group based on disabilities, and it also requires a particularly slippery concept and use of "voice." Through daily encounters and everyday experiences, I continue to shape my ever-growing ideas about disability, identity, and competency. I am challenged every day to not take someone for granted by projecting my impressions of what it means to be disabled on to another person.

The larger goal of disability studies and folklore is to understand and foster our interdependence as humans, but we are far from reaching these goals. Through my research and every day interactions and observations with Special Olympics athletes, their caregivers, and strangers, I have learned that these goals of expanding our expectations and recognizing each other's humanity do require patience and a recognition of our interdependence. As Judith Butler states, "Precarity exposes our sociality, the fragile and necessary dimensions of our interdependency" (2012, 148).

Appendix
Informant Name Codes

Informant	Interview Date	Interview Date 2	Code*
Beth	7/28/2013		P1
Brenda	4/20/2015		A1
Bruce			P2
Cathy	3/11/2013	5/26/2013	P3
Chris			A2
Coach Nick	11/8/2013		C1
Coach Pete	6/16/2013	9/21/2015	C2
Derek	9/12/2013		A3
Dorothy	4/20/2013		P4
Eileen	9/7/2013	10/9/2015	P5
Evelyn	7/27/2013		P6
Gary			A4
Greta	6/1/2013		P7
Hank			A5
Henry	6/1/2013		P8
James			P17
Keith	7/27/2013		P16
Laura	7/28/2013		P9
Lewis	2/6/2015		A7
Lori	2/6/2015		P10
Maddie	1/19/2014		A8
Maggie	1/19/2014		P11
Matt	10/24/2013		A9
Mitch	7/28/2013		P12
Nicki	10/28/2013		A10
Nina	9/13/2014		A11
Patty	11/7/2013		A12
Rick	7/28/2013		P13
Robert	3/11/2013	5/26/2013	P14
Ruby			A13
Ryan	6/18/2014		A16
Todd	4/20/2015		P15

Informant	Interview Date	Interview Date 2	Code*
Tori	1/19/2014		A14
Victor			A15
Will			A16

* A – Athlete, P — Parent, C — Coach

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