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FROM CORPOREAL BANTUSTANS TO ABAKHUBAZEKILE:
DISABILITY AND IDENTITY IN SOUTH AFRICA FROM A
HUMAN RIGHTS PERSPECTIVE

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of the requirements for the

Doctoral degree in Medical Anthropology

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FROM CORPOREAL BANTUSTANS TO ABAKHUBAZEKILE: DISABILITY AND IDENTITY IN SOUTH AFRICA FROM A HUMAN RIGHTS PERSPECTIVE

By

Martha Mary Laclave

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY IN MEDICAL ANTHROPOLOGY

Department of Anthropology

2005

ABSTRACT

FROM CORPOREAL BANTUSTANS TO ABAKHUBAZEKILE: DISABILITY AND IDENTITY IN SOUTH AFRICA FROM A HUMAN RIGHTS PERSPECTIVE

By

Martha Mary Laclave

This dissertation uses a human rights perspective to investigate the multiple realities of disabled South Africans active in the disability rights movement in the context of rapid social change. Specifically, this dissertation investigates: (1) How disability is defined and organized in the context of democratization and human rights in South Africa; and (2) The multiple ways disabled South Africans identify with their disability toward an understanding of difference or political identity. The research on which it is based departs from the more characteristic approaches to the study of disability in that it includes people with multiple disability types (i.e., blindness, deafness, mobility disabilities, mental disabilities, and other disabilities), and people with various ages of disability onset. Although there are studies from the social sciences on disability, the approaches used have not been able to critically pose how the disabled have become marginalized in relation to a wider context nor have they considered the diversity and tensions within the wider disability community outside of their specific disability type. Trends in anthropological theory are assessed in terms of appropriateness to the research sample. Theories of the body, embodiment, and social suffering are appraised against the backdrop of semiotics, new social movements, and social justice. The struggle against apartheid provided a revolutionary context for the disabled to mobilize, and during negotiations and reconciliation in the early 1990s they were able to articulate and elevate disability as a social issue rather than as an under-theorized or apolitical group to be managed by charity, and the health and welfare sectors. Therefore, the treatment and placement of the disabled in post-apartheid South Africa becomes critical in the context of the country's attempts at democratization and the metaphorical link of overcoming difference.

Keywords: disability, identity, social movements, human rights and social justice, lifecourse, social change, critical-interpretive anthropology, social suffering, semiotics

DEDICATION

This dissertation is dedicated to my mother and father, Christine and Thomas Laclave. Without their emotional, intellectual, and financial support, this dissertation would not have been possible.

ACKNOWLEDGMENTS

Thank you to all participants. This work belongs to you and all disabled South Africans.

The South African Blind Workers Organization provided Braille services for informed consent forms and contact cards. Their prompt response to my inquiries eased my budget and made life easier while in the field.

The National Archives of South Africa in Pretoria and the South African History Archive (at the University of the Witwatersrand in Johannesburg) aided in the access and retrieval of documents important to Chapter Two in particular.

The Office on the Status of Disabled Persons was instrumental in seeing my arrival in South Africa. Their availability is a quality of good government. Thank you to Colleen Howell for sharing drafts of the disability history project.

Thank you to Jacob Climo, my friend and advisor. You provided me an accessible space that allowed me to grow according to my needs and thought processes. You are missed. I am thankful for my committee, Judy Pugh, Rita Gallin, Susan Peters, and John Davis, Jr. Rita, you have made me a better writer.

A special thank you to Shuaib Chalklen, Dominique Souchon, Naomi Janse Van Vuuren, and Mark Beare. Your intellectual support and friendships have been sustaining. Ben Williams and family, you are my township ambassadors and extended family.

Lastly, I am deeply grateful for the love, patience, and support of Oliver Giancola.

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PART II

CHAPTER FOUR

KEY TO ABBREVIATIONS

ANC	African National Congress
CODESA	Convention for a Democratic South Africa
DEAFSA	Deaf Federation of South Africa
DICAG	Disabled Children's Action Group
DPI	Disabled People's International
DPO	disabled people's organization
DPSA	Disabled People South Africa
INDS	White Paper on an Integrated National Disability Strategy
NP	National Party
NSM	New Social Movement theory
OSDP	Office on the Status of Disabled Persons
PADI	People for Awareness on Disability Issues
RDP	Reconstruction and Development Program
RI	Rehabilitation International
RM	Resource Mobilization theory
SANCB	South African National Council for the Blind
SASL	South African Sign Language
SHAP	Self Help Association of Paraplegics of Soweto
TABBA	Transvaal Association for Black Blind Adults

PART I

CHAPTER ONE

INTRODUCTION

Only recently, and among a small group of scholars, has disability been included in the discourse on race, gender, ethnicity, nationalism, and other identities. "This failure to link the relationship of the disabled community to larger cultural patterns is analogous to a failure to link such relationships as gender and ethnicity to contemporary structures of power" (Raphael, Salovesh, Laclave 2001:154). This dissertation uses a human rights perspective to investigate the multiple realities of disabled South Africans active in the disability rights movement in the context of rapid social change. Specifically, this dissertation investigates: (1) How disability is defined and organized in the context of democratization and human rights in South Africa; and (2) The multiple ways disabled South Africans identify with their disability toward an understanding of difference or political identity. The struggle against apartheid provided a revolutionary context for the disabled to mobilize, and during negotiations and reconciliation in the early 1990s they were able to articulate and elevate disability as a social issue rather than an under-theorized or apolitical group to be managed by charity, and the health and welfare sectors. Therefore, the treatment and placement of the disabled in the new South Africa becomes critical in the context of post-apartheid South Africa's attempts at democratization.

Since its first free and democratic elections in April 1994, South Africa's repressed majority has gained legitimacy and power, fostering and expanding its discourse of change, empowerment, and non-discrimination. The transition to democracy is a critical time for restructuring society and its institutions, where core concepts such as racial identity and citizenship become redefined. Though disabled people had begun to organize themselves in the late 1980s, it was not until the early 1990s that they, and the organization Disabled People South Africa specifically, identified with the larger struggle against apartheid. This was during proposed negotiations for a transition from authoritarian rule to democracy, the process of democratization, and disabled people worked to position disability on the national agenda. The strategic input of disabled people during this time contributed to the rights-based and democratic goals of the "new" South Africa. Components of democracy include universal franchise for all adult citizens; local, provincial, and national elections; a constitution with a justiciable bill of rights that guarantees the basic human rights of all citizens; free press; and revival of civil society, to name a few (see Cherry 2000:4; Diamond 1992; Huntington 1991; Phillips 1991). These components of democracy need to be accountable to the pervasive methods of coercion, hegemony, and control that exist in tension with these goals. The disabled must continue to be absorbed in the discourse and practice of democracy as an issue of identity rather than individual tragedy. In other words, disability needs to be understood as a political identity rather than as a number of affected patients. Structures and services that have worked in such a way as to perpetuate inequality during apartheid – for example, policy, education, health and welfare, and employment – must now recognize disability as difference. Understanding disability socially is a conceptual shift and had to be included in the process of democratization in order to work toward human rights for all.

The South African model of disability is a social model. Essential and critical structures and official government mechanisms have been established largely by pressure from disabled activists. As a result, disability is specifically mentioned in Chapter Two of the Bill of Rights of the 1996 Constitution of South Africa. Disability also is addressed nationally and officially through an office in the Presidency (known as the Office on the Status of Disabled Persons, or, OSDP) and in an outstanding document (White Paper on an Integrated National Disability Strategy, or, INDS), both of which work toward the inclusion and integration of the needs and participation of the disabled in all government departments. This exemplary model of inclusion, how disability became a social and political issue, is examined through the lives of activists past and present in the South African disability rights movement. Their experiences are compounded by elements of competing beliefs of disability (as charity objects, as needing to be "'fixed," as somewhat in an awkward social category), race (in the effectiveness of mobilization for disability rights), and larger social change (the end of apartheid and the legitimization of the oppressed majority). Despite these hard-won rights, activists have a variety of interpretations about their own disabilities ranging from rejection of their disability to the embrace of it that positively defines them. A uniting element in these interpretations is accessibility. Accessibility is a common term in disability circles and generally refers to the physical environment (e.g., ensuring entrance to buildings by building a ramp for wheelchairs, providing sign language interpreters). However, accessibility to these participants also means acceptance, inclusion, and fulfillment of rights. This theme has been defining on an individual level in the creation of self and identity, and collectively in the articulation of movement goals. This dissertation explores these interrelationships.

NOMENCLATURE

The Disabled, Disabled People, and People with Disabilities

This dissertation follows the American Anthropological Association's (AAA) Manual of Style. It is based on the *Chicago Manual of Style*, 14th edition, 1993 (Grossman). Where a concern is not covered in the AAA guide, the Chicago guide is the next reference for consultation. While other style manuals now advocate person first language, that is, a *person* with a disability or *people with* disabilities (as in the *American Psychological Associations Guidelines for Non-Handicapping Language*), neither the *AAA Manual of Style* nor the *Chicago Manual of Style* explicitly clarify or even mention disability. Person first language has been favored by disability activists, emphasizing the person rather than the disability in an attempt to underscore their humanity. Nevertheless, people with disabilities are gaining understanding and control of identity and definition issues, they have begun to reject person first language. The disabled have entered the identity politics arena and argue that just as it is ridiculous to refer to a woman as a "person who is a woman," for example, it is equally so to say a "person who is disabled." Person first language emphasizes the individual and his or her malady rather than a political identity and public issue. Titchkosky (2001:135-136) identifies two interpretive moves with person first language in relation to how the disabled have used the term: "first, it separates the individual from disability and, second, it circumscribes disability as some-thing (bad) that is only understood in relation to its attachment to individuals. While ironic, this is also political and, while political, its politics are hidden." Hence, *disabled* and *disability* have become common terms used by disability rights activists and are making their way into the discourse of policy makers and healthcare professionals.[1] I agree with the above arguments. However, people in this study use both "disabled people" and "people with disabilities" as well as a number of other terms, described in depth in Chapter Five. I use *the disabled* and *people with disabilities* according to the above conditions.

"Participants"

The people interviewed, who shared their lives and allowed me to observe and talk with them, provided the data for this study and deserve to be called "participants" rather than "informants." While "informants" is the usual term used in anthropology, it connotes a disengaged source of information. This study concerns activists in a movement that is currently in a process of redefinition. The material of this study is useful to them and will potentially evolve into a movement discussion document. They deserve to be called "participants" and I will use that term in this dissertation.

Black and White

In the South African context, "community" has been used interchangeably with "race," "ethnic group," "nation," or "peoples" to maintain that "communities" must also develop "separately" (Thornton and Ramphele 1988:30). These terms are appropriately qualified with quotations because they must be approached as interpretations rather than as descriptions of reality. The history and usage of "ethnic group," "race," "tradition," "tribe," and other terms contribute to the discourse of domination in South Africa. The portrayal of South Africans by missionaries, explorers, colonists, early historians, and anthropologists gave the impression of bounded, static, unchanging social entities, often reinforcing "tradition" and "inherited culture." "Tribes," for example, even during the pre-colonial period, never existed with observable linguistic, cultural, political and

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[1] See Linton (1998:8-33) for further discussion on the political uses of these terms.

economic boundaries (Skalníc 1988:72; see also Marks 1992:128 and Kuper 1969:479-480 and 1975). Many of these terms are still debated in the social sciences. If primordialism – "the idea that phenomena can be explained by reference to 'ultimate' causes, typically 'race' and 'culture'" (Hammond-Tooke 1997:5) – was challenged by postmodern theories surrounding the Other and identity, why do anthropologists continue to refer to *the* Zulu, *the* Tsonga, *the* Ndebele, and other seemingly identifiable groupings (Skalník 1988:77-78)? While people may have an ethnic consciousness, an awareness of being Zulu or Xhosa, or Sotho or Tswana, as Marks (1992:128) explains, "the reinforcement, manipulation and construction of ethnic identities have been at the heart of segregationist policies of the state before 1948 as they have been central to its apartheid policies since." Hence, borrowing from Cherry (2000:63), I will use the term "black" to include all "people of color," meaning those considered Colored, Indian, or African in South Africa (see also Boonzaier 1988:64-65). Thornton (1996:150) accurately states, "South Africans have multiple identities in common contexts and common identities in multiple contexts." This statement will be used throughout this dissertation because it is a cogent reminder of the situation, aiding in the understanding of portions of analysis.

HISTORICAL CHRONOLOGY

South Africa's colonial history essentially begins with the establishment of a refreshment station in Table Bay by the Dutch East India Company, commonly known as the VOC or *Verenigde Oost-Indische Compagnie*. Founded in 1602 to coordinate Dutch trading expeditions to the East Indies, the VOC controlled all Dutch trade east of the Cape of Good Hope (Saunders and Southey 2001:60). The Dutch-Khoikhoi wars (1659 –

1660 and 1673 – 1677) in the south-western Cape ended with the Khoikhoi failing to expel the Dutch from the area and Dutch expansion beyond the peninsula. Between 1795 and 1806, the British occupied the Cape partly due to bankruptcy of the Dutch colonial administration. The Dutch formally ceded the Cape to Britain in 1814, providing opportunity for the British to develop a colonial state and dominant power for the remainder of the 19th century (Saunders and Southey 2001:31).

Diamond and gold discovery in the late eighteenth century spurred further interest in control. Wars between settlers and African peoples as well as between British and Dutch and Afrikaner settlers ensued, forging deep political fissures with very human consequences. For example, the British military established concentration camps for Boer women, children, families of surrendered Boers, and Africans who could or provided assistance to Boer guerrillas beginning in 1900 during the South African War (1899 – 1902) (also known as the Boer War).[2] Tens of thousands died in these camps from unsanitary and overcrowded conditions (Saunders and Southey 2001:49; see also Spies 1977).

The Union of South Africa came into being in 1910 and racial segregation developed on a more comprehensive scale shortly thereafter, even before the election of the National Party in 1948. An example of such actions is the Natives (Urban Areas) Act of 1923 that established locations for Africans in urban areas. The thinking and theorizing involved in devising or implementing racial segregation is also highlighted

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[2] *Boer* is Afrikaans for 'farmer.' As per Saunders and Southey, the term referred to white farmers in the 18th century, but in the 19th century was used to refer to Afrikaners in general, or the white inhabitants of the Voortrekker republics and those fighting on the republican side of the South African War (2001:27). Further, "The term came to have derogatory connotations when used by non-Afrikaners. When used by English-speakers, it suggested backwardness and lack of culture, and many blacks used it for any white person associated with racism and apartheid" (Saunders and Southey 2001:27).

through the early history of anthropology in South Africa. There has been a relationship between anthropologists and anthropological thinking of culture and society and the creation and legitimization of apartheid (Gordon 1991). The early practice of anthropology in South Africa from the 1920s – 1940s was divided between two approaches, *volkekunde* (or cultural anthropology as per West 1988; or ethnology as per Gordon and Spiegel 1993:84) and social anthropology. *Volk* is derived from ethnos theory, which developed among German anthropologists of the pre-war period (Sharp 1988b:19; Gordon 1991:79-80). Ethnos theory conceives mankind as divided into *volke* (nations, peoples), each *volk* having its own culture where people are ascribed to *volk* and acquire *volkspersoonlikheid* or *volk*-personality (Sharp 1988b:19). P. J. Coertze and Werner Eiselen relied heavily on this theory in their vision for *volkekunde* in South African universities, ultimately forming *volkekunde* as an indigenous South African anthropology (Gordon 1991; Sharp 1981). All *volkekunde* professors were ardent Nationalists and participated in formulating Broederbond "Native Policy" that later became government policy (Gordon 1991:82). The Afrikaner Broederbond was a secret fraternity and under D. F. Malan supported the Purified National Party, mobilizing Afrikaner votes for the National Party in 1948. Afrikaner nationalism, as a political philosophy with a specific history, precedes the concept or idea of *volk* (Sharp 1988a:82-84). As explained above, the portrayal of Africans by missionaries, explorers, colonists, early historians, and anthropologists gave the impression of bounded and static groups. The *volk* concept's contribution to Afrikaner nationalism masks class and other power relations (see Nagengast 1994:118-119). *Volk* and ethnicity have conceptual and effectual similarities. Alonso (1994:391) cogently explains:

> In contrast to nationalism, ethnicity is partly an effect of the particularizing projects of state formation, projects that produce hierarchized forms of imagining peoplehood that are assigned varying degrees of social esteem and differential privileges and prerogatives within a political community (see also Dominguez 1986; Norton 1984; Smith 1993; Williams 1991; Comaroff 1992).

The National Party could capitalize on *volk* as a conceptual component of Afrikaner nationalism. Indeed, the words of Nelson Mandela (1961:15) from underground remain accurate:

> To the Afrikaners the proclamation of a republican form of government represented the final triumph of their rancorous struggles against British domination. It meant that the final link with the British Crown had at last been broken, that the sovereignty of the "volk" had at last been realized and could now be enjoyed. But to the 10,000,000 Africans, and to the other non-white sections of the population, the Republic was a form of government based only upon force and fraud. Under it white supremacy, the savage suppression of the rights and aspirations of the non-white peoples, would be practiced. To them, such a society was totally unacceptable, and a campaign to give concrete expression to this opposition was immediately started.

South Africa's legacy of apartheid is evident in almost every page of this dissertation. The gravity and extent of apartheid has seared deep scars in the country and people. In Afrikaans, 'apartheid' means 'apartness.' The term refers to the policy adopted by the National Party (NP) in the early 1940s and its broader application (Saunders and Southey 2001:12). 'Separate development,' in this instance is structural violence. It is institutionalized oppression and dehumanization.

Apartheid legislation was implemented in an ad hoc manner (Saunders and Southey2001:12). With a patchwork of laws established in the 1950s, apartheid was at its most developed stage in the 1960s. Such legislation included the Prohibition of Mixed Marriages Act (1949), Suppression of Communism Act (1950), Population Registration Act (1950), Group Areas Act (1950), Bantu Authorities Act (1951), Bantu Education Act (1953), Public Safety Act (1953), Separate Amenities Act (1953), and Criminal Law

Amendment Act (1953). Apartheid underwent reformulation in the late 1970s due to international pressure and strong internal resistance (Saunders and Southey 2001:13), and economic hardships created more violence. Administering the network of apartheid laws was becoming very costly during this time of recession (Thompson 1990:221). Contributing to this changed state of affairs was a shortage in skilled labor, inflation, a growing white poor, emigration of professional white people from South Africa, a growing black population (Thompson 1990:221-222). In another respect, Afrikaner solidarity, key to electoral success of the National Party in the 1960s, was becoming divided (Thompson 1990:223).

The 1980s were a decade of "reform" in South Africa where "development" and upliftment were stressed for the "backward" sectors of the population (Sharp 1988b:9). The dramatic nature of these changes was capped by the emergency years (1985 through 1990), which was essentially a civil war. One such "reform" enacted by the National Party (NP) was their approval of a tricameral parliament as an integral part of the new constitution proposed in 1984. In addition, a proposed tricameral parliament separated government affairs into houses for whites, coloreds, and Indians. These developments amplified unrest, especially in the townships, where people were still ignited from the 1976 riots. Violence related to the struggle was high, with 2,987 deaths and 45,000 detained during 1984 and 1987 (Manganyi and du Toit 1990:1-2). The ideas and concepts of black consciousness, rising in the mid-to-late 1970s and growing in the 1980s, became instrumental in freeing Africans from negative self-opinion. People in the townships during the mid-1980s used civic organizations as a form of popular control and direct democracy, reclaiming authority with the loss of state control (Cherry 2000;

Chabedi 2003:361). It is under these conditions of the township environment and struggle for liberation that the Self Help Association of Paraplegics of Soweto (SHAP) and the emerging disability rights movement is rooted.

SETTING

Research took place from November 2002 to October 2003, with two preliminary exploratory field trips in 1998 and 2000. A total of 15 months was spent in South Africa. Research activities were focused in Johannesburg and Soweto in Gauteng province, because they were segregated areas during apartheid. Johannesburg is the largest metropolitan area in South Africa (City of Johannesburg 2003:9), growing from the discovery of gold on the Witwatersrand in the 1880s. During and after World War II, tens of thousands of Africans searched for work in Johannesburg and lived in shanties outside of the city (Saunders and Southey 2001:160). Adequate accommodation was not provided because the government did not want to encourage permanent residence of Africans so close to Johannesburg.[3] Soweto is an acronym for South West Township, depicting its coordinates in relation to Johannesburg, and not a name with "indigenous" roots. Soweto is a product of segregationist planning and has been the grounds of struggles for influence between the different tendencies in the African opposition to colonialism and apartheid. In the mid-to-late 1980s it was a political hotbed for defiance campaigns. In this context, participation in disability-related organizations can reflect or mediate such tensions, and indeed the South African disability rights movement has its roots in Soweto. Organizations for the disabled in Johannesburg and Pretoria did not

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[3] Johannesburg and Soweto are approximately 15 kilometers away from each other.

reach Soweto and provided a spark for the disabled in the townships to mobilize in the late 1970s and early 1980s.[4]

Gauteng is the smallest in area of South Africa's nine provinces, but the most populated. In the year 2001, Gauteng included 8,837,178 residents, or 19.7 percent of South Africa's population (Statistics South Africa 2003:6-7). The total population in South Africa for that year was 44,819,778 (Statistics South Africa 2003:6). "Black Africans" comprise 73.8 percent and 79 percent of the province and country, respectively (Statistics South Africa 2003:10, 12). Similarly, "Colored" are 3.8 percent and 8.9 percent; Indian or Asian 2.5 percent and 2.5 percent; and "White" 19.9 and 9.6 percent (Statistics South Africa 2003:10, 12).[5] Five percent, or 2,255,982 people, of South Africa's population is disabled according to the 2001 South African census (Statistics South Africa 2003:39). Of that number, 331,611 people in Gauteng are disabled, visual disabilities being the most common (91,304), followed closely by physical disabilities (84,917), then hearing (39,318), emotional (37,847), multiple (35,067), intellectual (32,970), and communication disabilities (10,188) (Statistics South Africa 2003:38-39). Of South Africa's disabled people, 1.3 percent have visual disabilities; 1.2 physical disabilities; 0.7 hearing disabilities; 0.6 emotional; 0.6 multiple; 0.5 intellectual; 0.2 communication (Statistics South Africa 2003:39).

THEORETICAL FRAMEWORK:
A HUMAN RIGHTS PERSPECTIVE VIA SOCIAL SUFFERING AND CRITIAL-INTRERPRETIVE APPROACHES IN ANTHROPOLOGY

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[4] "Township" is a colloquial term used in South Africa to describe the urban residential areas designated under apartheid for Africans and these areas are still referred to as "townships."

[5] For the 2001 Census, Statistics South Africa classified people by population group to monitor progress in the move from apartheid-based descrimination. They note that "membership of a population group is now based on self-perception and self-classification, not a legal definition" (Statistics South Africa 2003:vii).

> Human rights are internationally agreed values, standards or rules regulating the conduct of states towards their own citizens and towards non-citizens. [Baehr 1999:1]

According to Messer, anthropologists have contributed to the efforts of human rights in two critical ways (1993:221). First, anthropologists provide cross-cultural research about what rights are and to whom they apply (Messer 1993:221). Second, anthropologists have monitored compliance with human rights standards, and identified and expanded on the incidences of human rights violations and abuses (Messer 1993:221). In his essay "On Torture, or Cruel, Inhuman, and Degrading Treatment," Asad analyzes Article 5 of the Universal Declaration of Human Rights and finds that new ways of conceptualizing suffering are "universal in scope but particular in prescriptive content" (Asad 1997:285). To illustrate, Asad cites Scarry in saying that war is "the most obvious analogue to torture" (Scarry 1985:61), but furthers the argument by saying "that the general concept of 'cruel, inhuman or degrading treatment or punishment' is not applied to the *normal* conduct of war even though modern technological warfare involves forms of suffering that are, in scope and kind, without precedent" (Asad 1997:297). Anthropologists recognize how states use violence as a means of social control, reshaping or maintaining social boundaries, creating or manipulating meaning, and silencing resistance. These areas of investigation are broadened by a growing number of anthropologists using a critical-interpretive approach to investigate social suffering. Critical-interpretive anthropology attempts to bridge the impasse between the two approaches. Interpretive approaches are meaning-centered and able to locate the social significance of suffering as related to experience at the individual or micro level of analysis. Critical perspectives are often informed by Marxist theories, political economy, or world systems theory, and address more macro levels of analysis. Social suffering concerns what political, economic, and institutional power does to people and, in so doing, issues of human rights become more lucid (Kleinman, Das, Lock 1997:ix-xxvii). Social suffering is the result of "the devastating injuries that social force inflicts on human experience" (Kleinman, Das, and Lock 1996: ix-xxvii). It is the effect of social violence that social orders, be they local, national, or global, inflict on people (Kleinman 1997:226). Kleinman expands this description to include "the responses to human problems by the institutions of social policy and programs that are in principle organized to ameliorate the problem" (1997:226). Investigating social suffering with the strengths of the two approaches, critical and interpretive, upholds or buttresses a human rights perspective.

Studying disability provides an opportunity to explore human rights. Violent conflict, though not unique to South Africa, has been central to its modern history (Beinart 1992:455). But political violence can be expressed indirectly, as through the perpetuation of poverty. These are hidden violences of apartheid (Coovadia and Jinabhai 1990:98) manifested in deaths, illnesses, depressed quality of life, and *disability*. It should not be too far of a stretch to say that control can be aided through the creation of disabled bodies. Mechanisms of disablement are varied: poverty leads to disability; "accidents" such as road violence; riots and participation in political activity, especially during the 1980s in South Africa; sports injuries; mining and other labor-related activity are a few examples. All of these mechanisms are political. Disease from lack of medical attention, malnutrition, lack of resources (such as clean water), and the diseases of poverty all contribute to disability. An injury is not an accident, for "accident" connotes a neutral event without respect to causation, intentionality, and predictability (Bijur 1995:9). Sports injuries can be differently applied to class. Mining and other industries have killed and disabled thousands of workers. All of these examples have social impacts.

I find that disability in South Africa, as social suffering, is contested in terms of identity. The disability rights movement and the transition to democracy in South Africa reformed disability identity through a redefined concept of accessibility. Disability identity, in South Africa, is both informed by and contributes to the current discourse of change in South Africa. Disability identity in this context embraces accessibility and empowerment. Accessibility to these disabled participants means acceptance, inclusion, and fulfillment of rights. Accessibility, in another sense, is what other identities demand: the right to participate in a socially meaningful way, equality, non-discrimination, access to education and employment, and other fundamental components of democracy. A comparison with ethnicity helps illustrate these goals. Ethnicity, as defined by Sharp (1988a:80), "is the pursuit of political goals – the acquisition or maintenance of power, the mobilization of a following – through the idiom of cultural common-ness and difference." Adam (1995:473) follows a similar definition and writes that ethnicity also has been used to designate "a historical community of cultural similarities with a shared sense of solidarity and belonging, memories and symbols or methods of descent" (see also Smith 1986:22). Identities, of course, can be created, used, or responded to in political ways by those in power. For example, there was a shift in the early 1960s in South Africa from racial to cultural rhetoric, from race to ethnicity (Boonzaier 1988:65). While this was simply a change in terminology for some people, there was a gradual conceptual shift (Boonzaier 1988:65). Adam (1995:462) further explains that ethnicity became more "saleable" and useful for the maintenance of apartheid (Bekker 1993:26). Opposition groups or movements interpreted and used ethnicity in various ways to further their cause and philosophy (e.g., the Inkatha Freedom Party attempts to mobilize Zulu nationalism by harnessing various symbols and "traditions"). Identity can be used by individuals, too, toward more accurate representation, as with the use of the term "black" that I discussed above in "Nomenclature." Identity has also been used to better one's economic status, but at a price. "Pass-whites" or "play-whites" in South Africa were light skinned people living in white areas, but by birth considered "colored" (i.e., "mixed race") generally, but were "passing for white" or "trying for white" officially according to the Population Registration Act. Being considered white had advantages for employment, access to better housing, and other resources. In this way, pass-whites were located on the "remote boundary of the white race in constant danger of being expelled from it" (Teppo 2004:94). Conversely, Teppo (2004:94) explains, "it was dangerous for a dubious-looking white to be seen as a pass-white". A pass-white could be uncovered at any time by existing in such a fuzzy area. "Sometimes white-looking parents had darker children, called 'throwbacks' who revealed a coloured family history" (Teppo 2004:95). Identity, therefore, can be understood as a politically motivated, socio-emotional need and is applicable to disability identity as a response to the forces that oppress and repress the disabled.

Disability identity, like other identities such as race and gender, pursues political goals, and is based on an expanded definition of accessibility that includes the removal of physical, social, economic, political, and other barriers for meaningful participation in society. This is made more complex because as Thornton accurately and simply describes, "South Africans have multiple identities in common contexts, and common identities in multiple contexts" (1996:150). Disabled people began to understand the nature of being disabled in broader and more political ways with the disability rights movement. They began questioning and rejecting the individual perspective of disability as tragedy, and engaged with the larger struggle for human rights, most prominently in the revolutionary context of the early 1990s. Disabled people have learned to manage their disability socially in ways similar to that of other identities, but can often fight with, resist, or embrace the meanings of disability to their existence. Their self or selves shift in response to context, and can exist in tension or fusion, from one conveyed memory or experience to another. In one sense, the struggle for disability identity is explained as no different from, is similar to, has nothing to do with, or is informed by the struggle against apartheid. In another sense, a disabled identity is accepted into the shuffle of selves, rejecting a dominant discourse of disability as Othering. Hence, identity can also be a dialectical and discursive relationship of the self and situated experience.

Given this, research design, method, and theory deviate from the more typical works on social suffering. My perspective on human rights is influenced by the participants' views and by spending time in South Africa. Duties to uphold human rights are not only the responsibility of state parties, but individuals as well. This statement is also what lends the African Charter on Human and Peoples' Rights (the Charter of Banjul) its specific character (see Baehr 2001:80-82). To implement the Charter, the African Commission on Human and Peoples' Rights serves to promote, rather than protect, human rights (Baehr 2001:81; Welch 1992:44, 49). Baehr (2001:17) explains that the differences between East and West were in their emphasis on the rights of society as a whole versus a strengthening of international supervision. The differences between the South and the North, however, is in the South's emphasis on the importance of the right of self-determination, peoples' rights, and the duty toward society next to individual rights (Baehr 2001:17). Social suffering, although an attractive approach, is limited in ways related to my perspective on human rights. While social suffering is the result of social force on human experience (Kleinman, Das, and Lock 1996:ix-xxvii), the perspective detracts from participants' efforts at collective struggle. The following two subsections outline my modifications to a social suffering perspective that is more accountable to the realities and histories of the participants in this study.

Searches for Meaning: Selves and Identity

Identity as a politically motivated, socio-emotional need is applicable to disability identity as a response to the forces that oppress and repress the disabled. But identity is also a dialectical and discursive relationship of the self and situated experience. Identity used to refer to ‘sameness’ and in psychology meant ‘selfsameness’ (Sökefeld 1999: 417). Csordas (1994:331) notes a trend in social psychology to isolate aspects of the self, as in self-concept, self-image, self-awareness, self-esteem, for analytical purposes (Gecas 1982). In terms of semiotics, self means self-representations while self-experience refers to the pre-cognitive; but the self in any of these distinctions remains culturally organized (Ewing 1990). Cultural anthropologists, though, argue that 'selves' are culturally shaped and infinitely variable, hence the idea of 'shifting selves' (Ewing 1990:253-254). Ewing argues:

> . . . that in all cultures people can be observed to project multiple, inconsistent self-representations that are context-dependent and may shift rapidly. At any

> particular moment a person usually experiences his or her articulated self as a symbolic, timeless whole, but this self may quickly be displaced by another, quite different "self," which is based on a different definition of the situation. The person will often be unaware of these shifts and inconsistencies and may experience wholeness and continuity despite their presence. [1990:251]

In light of this, she proposes that people manage inconsistency through semiotic processes, through the construction of a series of self-representations based on "selected cultural concepts of person and selected 'chains' of personal memories" (Ewing 1990:253). Further, "Each self-concept is experienced as whole and continuous, with its own history and memories that emerge in a specific context, to be replaced by another self-representation when the context changes" (Ewing 1990:253). This is counter to the claim anthropologists make that the "experience of wholeness, continuity, and autonomy that we normally associate with the 'self' is a culture-bound, Western notion that is not applicable to most non-Western cultures, where the self is experienced contextually and rationally (Ewing 1990:253; see also Shweder and Bourne 1984)."

There is a connection between anthropologists seeking selves and semiotics. Rosaldo (1984:140-141) finds connections with self and identity, and further detaches from a perceived bounded Western notion of self:

> If culturally organized views of possibility and sense must figure centrally in the acquisition of a sense of self – providing images in terms of which we unselfconsciously connect ideas and actions – then culture makes a difference that concerns not simply *what* we think but how we feel about and live our lives. Affects, then, are no less cultural and no more private than beliefs. They are instead, cognitions – or more aptly, perhaps, interpretations – always culturally informed, in which the actor finds that body, self, and identity are immediately involved.

In her ethnography, *Crafting Selves: Power, Gender, and Discourses of Identity in a Japanese Workplace*, Kondo's general impression is of the self as register of the spatial and aesthetic, finding tensions and contradictions between external constraint and internal reality – both within the community she studied as well as within herself. Many of the chapters in Devish's (1993) account of Yaka healing and ontology are descriptions aimed at sensory perception and emotional states, locating the signifieds that contribute to multiple levels of expression and expanding knowledge that account for affective and bodily experience in therapeutic processes.

Further, I find that anthropologists with a variety of foci discuss "meanings," be they fields of meanings, locations or layers of meanings, bodily meanings, or hidden meanings. The body produces meaning for use in understanding reality (DiGiacomo 1992; Sheper-Hughes and Lock 1987:19). But there are other ways anthropologists use "meanings." Escobar (1992:408) finds that work on contemporary social movements look to fields of meaning to find dominant codes, and argues that conflict takes place in meanings (see Melucci 1988). It is in fields of meaning where the movement takes place (Burdick 1995:369), or even to unearth tropes of nationalism (Alonso 1994:386). In all of these "locations" it seems that "meanings" have come to be the redefinition of "culture" without using or owning up to using the word as it is assumed that anthropologists know what it is or can define it in a concrete, useful, or "meaningful" way. Anthropologists do not rely on "public rituals, codified belief systems, and sanctioned familial or communal structures" anymore for "capturing the distinctiveness of a culture," as Marcus and Fischer argue (1986:45). One avenue anthropologists have taken is personhood as a unit of analysis (Marcus and Fischer 1986:45) and I have done that in Chapter 4 through an examination of the lifecourse and everyday life. Anthropologists are concerned with meaning from the very beginning and are continuing to develop and look toward meaning as empirical data. I pay close attention to the ways people come to understand disability in their own lives and what it means to them, and how or if these explanations are utilized to forward disability rights. The spaces to find such data are in rapidly shifting, context-dependent, and inconsistent narratives and observations.

Semiotics examines how signs come to mean and have meaning (Tomaselli 1996:30). The catalyst or vehicle for meaning is in signifying practices. While a sign stands for something else, it signifies meaning. In other words, "Signs elicit other signs in necklaces of signification" (Tomaselli 1996:35). Semiotics offers conceptual tools, and is not a theory in itself. Anthropologists have been using some of the tools, such as metaphor and discourse. They acknowledge that discourse is the locus of power and knowledge and therefore must be viewed as discontinuous and fragmented, the uses of which are neither uniform nor stable (Foucault 1978). Semiotic tools enable understanding of the pushes and expanding of discourse in a different way by not separating the performative aspects from discourse, and recognizing that discourse includes the unsaid, silenced, and emotionally unavailable. These signs and codes are what "make sense" to the people involved through the construction of counter ideology. A disability identity, developed through participation in the movement, provided some of the vision needed to break from an embodied social suffering.

Social Movements

Because this research involves the disability rights movement, contemporary social movement theory is a logical direction. Two theoretical paradigms, the new social movement approach and research mobilization perspective, dominates the study of social movements (Canel 1997; Cohen 1984; Klandermans 1986; Melucci 1984; Salman 1990).

Both approaches examine social movements differently yet are compatible due to attention to different levels of analysis. While a new social movement approach is concerned with the "why" of social movements, resource mobilization is concerned with the "how," the contextual and strategic of social movements. Social scientists have called for an integration of the two approaches to better explain the logic that moves social movements (Canel 1997; Escobar and Alvarez 1992).

New social movement theory emphasizes shared meanings and identity politics rather than the politics of distribution and structure that characterize resource mobilization theory (Zugman 2003:154). Beginning in the early 1980s, social movement theorists postulated that new movements and organizations deal primarily with issues of identity and meaning rather than traditional class-based organizations like unions or political parties (Zugman 2003:154). Moving beyond economic and class-based sources of conflict, emphasis is shifted to the constitution of new identities (Canel 1997:201). While new social movement theory has opened the reasoning of why people mobilize, it does not sufficiently interrogate the strategies involved in mobilization. A major critique of new social movement theory is its flawed assumption that group identity is developed prior to strategy (Canel 1997:202). "Identity develops only in the process of interaction with other social forces, and organizational and strategic concerns are an integral part of it" (Canel 1997:202).

While new social movement theory is good at developing general theoretical postulates, it is weak in analyzing micro-contexts, a void accommodated by resource mobilization theory. A critical distinction between social movements and social movement organizations, or, preference for change and organized action for change (see

McCarthy and Zald 1977; Canel 1997:211) contributes to the analysis of South Africa's disability rights movement. This analytical distinction is accountable to the currently reported loss of movement momentum. While a powerful organization became the voice of the movement at the time of transformation to democracy in South Africa, its current reputation suffers. More importantly, when participants assessed the current state of the movement, they referred to the umbrella organization specifically. This transposition of the movement to organization is explainable considering that a social movement organization carries the movement message. Meaning is again addressed with regard to social movements in this dissertation because social movements are one way to foster identity.

RESEARCH DESIGN AND METHODS

This research departs from more characteristic approaches in medical anthropology and disability studies in that it includes (1) people with multiple disability types, (e.g., blindness, deafness, mobility, and other disabilities); and (2) people with various ages of disability onset. Although I do not particularly like using the term "type" with disability, disability type has been critical in maintaining and directing services, and participants speak of disability type in relation to mobilizing. Ethnographic studies on disability have examined disability in several ways. First, they have examined disability qualitatively by cultural immersion; second, they have included international contexts, filling in the void from the body of work that tends to focus on North American and European contexts. International settings for disability research are needed because, according to the United Nations (1986), approximately 80 percent of the world's disabled population lives in developing countries, and within those countries the disabled are last on the list of social and economic initiatives. Third, ethnographic studies on disability can focus on tensions within the disabled community, everyday coping, and the various forms of oppression experienced.

Those anthropologists who have been able to describe the tensions within the disabled community and everyday coping, however, fail to address what those actions mean when considering the wider sociocultural context. How are such divisions created or maintained? The people they study may be struggling with issues of identity; creating, modifying, or recreating meaning through their lifetime and with community interaction; or creating new practices to challenge the dependency forced upon them. Some of these studies cannot answer how discourses emerge. The research design may be too narrow, only including one type of disability (such as blindness or deafness). Disability then becomes a small, specific sector of health or welfare that calls the attention of specific professions or charities to remedy rather than the larger categorical identity and rights issues it has become. Certainly, each disability type has its uniqueness and intricacies of experience, but researchers need to assess how each type fares with other disabilities in competition for resources and representation by organizations. Research in disability studies, however, is also guilty of focusing on disability type. Disability studies is a relatively new field incorporating critical theory and the spirit of liberation. By placing people with disabilities in wider social contexts, researchers hope to spur social change. As with the literature on feminism and disability, it is also within disability studies that people with disabilities are not placed within an individual model, targeted as "ill," or reasons for telethons. Rather, people with disabilities are viewed as social agents.

The age of disability onset, the other characteristic form which this dissertation departs from social science research on disability, is important to identify a range of experiences and discover some of the thoughts and actions of the disabled in important life events. People disabled at an early age often have choices made for them by parents while those disabled after their social and economic positions are established face redefinition. One study with a representative sample was able to estimate the levels of integration of a disabled person within the family. Schneider, Claasens, Kimmie, Morgan, Naiker, Roberts, and McLaren (1999) found in South Africa that the age of onset and the number of disabilities are the two most crucial variables in determining the level of integration in an individual's family:

> The earlier the onset and the greater the number of disabilities, the less integrated the person is likely to be within their family. The later the onset and the less number of disabilities, the more likely the disabled person is to be integrated within their family. Of respondents with one disability 67% had a high level of participation compared to 49% of those with three disabilities or more. Of respondents with age of onset before two years of age, 41% had a high level of participation compared to 66% of those with age of onset after 19 years of age. These two factors override the effects of race, type of disability and sex in determining level of integration. [1999:31]

While the age of disability onset is important in terms of family integration, participants traveled various trajectories in their understanding of disability in terms of personal and political identity. Therefore, attention to the lifecourses of participants produced two needed data components: insight into the personal changes participants experienced in terms of identity, and the multiple ways the disabled experience oppression and repression.

Attention to the lifecourse also structures "accounts of personhood and the quality of experience in a culture" (Marcus and Fischer 1986:61). The emphasis "is not on the cultural construction of personhood, but the typical phases and events that each individual passes through" (Marcus and Fischer 1986:61). Therefore, although many of the life events vital to personhood are generally said to accept the disabled, they are discussed more in terms of achieved experience or desired goals. The lifecourse also offers a window into identity and representation, memories and experiences of fundamental perceptions. By examining local concepts of 'person,' 'individual,' and 'self' a better understanding emerges of the promotion or restriction of access to personal and subsistence security, responsibility for action, and definitions of conscionable behavior, thereby contributing to human rights research (Messer 1993:241).

The lifecourse helped structure narratives and is a way to emphasize personhood in finding typical phases and events participants experienced in relation to their able-bodied peers (see Marcus and Fischer 1986:45-68). Disability often questions personhood, and the issues of personhood are both implicit and explicit in the collected narratives. The lifecourse and everyday life encounters with the able-bodied highlights this unstable ground. The attention to lifecourse structures "accounts of personhood and the quality of experience in a culture" (Marcus and Fischer 1986:61). The emphasis "is not on the cultural construction of personhood, but the typical phases and events that each individual passes through" (Marcus and Fischer 1986:61). Therefore, although participants reported that many of the life events vital to personhood are generally said to include the disabled, their narratives described this more in terms of their achieved experience and desired goals for all disabled people than common experience or expectation. Everyday life experiences are covered in a separate section of this chapter because they contribute to illustrating the practices participants used to combat negative treatment based on their disability. These are everyday resistances practiced in the face of those who treat them as objects. Everyday life becomes key in a social suffering perspective. At once collective and individual, everyday life embodies the connectivity of social suffering. Perhaps unique to the disabled, these everyday resistances can be directed to family members who "don't get" disability.

Attention to the lifecourses of participants produced two needed data components: insight into the personal changes participants experienced in terms of identity, and the multiple ways the disabled experience oppression and repression. Lifecourses also helped structure narratives and was a way to emphasize personhood in finding typical phases and events participants experienced in relation to their able-bodied peers (see Marcus and Fischer 1986:45-68). The age of disability onset becomes integral to investigations of disability identity formation because chronic illnesses and disability at different times in the life course force reevaluation of life choices. Those disabled since childhood or at birth have many life choices made for them, such as career choices, education, and marriageability. Those disabled during adulthood, or after their social and economic position is well established, face a different constellation of challenges that include navigating their environment with a now disabled body. Personhood often changes with illness and the need to preserve a social self becomes integral not only to persons affected (Luborski 1994; Nydegger 1986; Talle 1995; Udvardy and Cattell 1992) but to their family and community. Personal support to those with chronic illness or disability further illustrates these changes (Ben-Sira 1983; du Toit 1994; Fisher and Galler 1988) and is dominated by interaction with the able-bodied and inaccessible environments. Chapter Four describes the concrete differences in lifecourse expectations with disability and where and how and if disabled South Africans are treated as their able-bodied peers.

Contact with over fifteen disability-related organizations in the Johannesburg and Soweto areas during predissertation visits provided a solid sample of disabled people to involve in this research. Organizers, members, and former members were approached for interviews and 40 narratives were collected. Of the 40 participants, 17 are women and 23 are men. As for the ethnic or racial composition, the numbers can be related in several ways. As the saying that will be repeated often in this dissertation goes, "South Africans have multiple identities in common contexts, and common identities in multiple contexts" (Thornton 1996:150). One breakdown of the sample is that 24 participants are black, 13 are white, and three may be "other." The three in the "other" category are self-descriptions. Another way to put it is in this South African way: 13 white, 27 non-white.

People with various disability types were approached, including d/Deafness, blindness, mobility-related disabilities, and mental disabilities. Though I do not particularly favor splitting the disabled by 'type,' it is how people have been treated, as discussed in depth in Chapter Two, and advocacy issues are largely spearheaded by various organizations based on disability type. The Deaf and wheelchair users are often loud organizers and the issues of other disabilities, especially mental disabilities, become overlooked. People often have multiple types, such as the deafblindness or those with cerebral palsy with speech and mobility related disabilities. Epilepsy and albinism are also considered disabilities in South Africa. With albinism, although the pigmentation is not a "medical" disability per se, vision and skin cancer are related concerns. Albinism certainly exists as a cultural construct, a person with albinism is generally considered "disabled." Nevertheless, the breakdown of participants is as follows.

Fifteen participants have mobility-related disabilities. Of these 15, six are female, nine are male. They have varying ages of onset and mechanisms of injury, including car crash injuries, sport injuries, shootings and stabbings, complications at birth, and polio. Of the 15, two have cerebral palsy, but three participants in total have cerebral palsy. Cerebral palsy could place them in a "mental" category, but I favored their self-descriptions regarding difficulty in accessibility. The two I categorize as having mobility disabilities are also quadriplegic, while the other one identifies her speech difficulties as her primary disability. Rather than place the three in a medical typology according to "cerebral palsy," I prefer to interpret their main concerns in terms of access. Participants with mobility-related disabilities used wheelchairs or calipers and crutches.

Six participants are d/Deaf. This number also requires explanation. I say six participants are d/Deaf because of that six, two are considered "culturally Deaf." I capitalize the "D" in Deaf to differentiate between being deaf or having significant hearing loss and being culturally Deaf or the cultural experience of deafness.[6] Cultural Deafness relies less on auditory status because children of deaf adults (or CODAs), for example, can be considered culturally Deaf. One participant who has worked extensively with the deaf was not considered culturally Deaf by the other Deaf participants. She also did not align herself in that manner. Of the four who are physically deaf, and claim that

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[66] Members of the deaf community and authors are not at all certain what that means and lack concrete clarifications in their communication and writing. Preston (1994:13-14) writes: "For some, difference from others is sufficient to merit cultural designation. Using difference as a criterion, however, bypasses an important component of culture: those aspects which are shared within the group. Many writers have emphasized the distinct language of deaf people. Yet equating language with culture overstates the relationship and ultimately provides a circular definition of Deaf culture, ignoring the variations in sign language fluency and usage within the Deaf community. Other writers have become bogged down in the issue of whether to describe the Deaf as a culture or a subculture."

identity, and are therefore Deaf, two are female and two are male, three non-white, one white. Their causes of deafness include meningitis, a mother having rubella during pregnancy, other illnesses, and suspected sorcery. All were born deaf or became deaf by the age of ten. Two interview methods were used with Deaf participants. My knowledge of signed languages includes a working knowledge of American Sign Language and basic South African Sign Language. In some cases interpreters were used while in other cases total communication worked well.[7] With participant observation and casual conversation, sign language and total communication also worked well.

Of the eight blind participants, two are female and six are male, one is white. The causes of blindness varied, some were born blind while others sustained gunshot wounds or survived explosions that damaged the optic nerve. Braille copies of the informed consent forms, audio tapes for those who are illiterate or could not read Braille, and a contact card resembling a business card (with Braille overlay) were made available.

Two participants have epilepsy or are epileptic, and both are female.

Like the participant mentioned above who has cerebral palsy with good mobility but speech complications, there are those who transcend categories. Another participant is deafblind, and a third has learning disabilities but works in a field of another disability type and does not necessarily consider himself disabled.

The remaining six are able-bodied but have devoted much of their professional and personal lives to disability. Two of these six are mothers who became advocates when they had developmentally disabled children. One, as I mentioned, was bumped from the Deaf category. Others are activists, usually parents, who represent those who cannot represent themselves, (e.g., people with mental disabilities and children).

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[7] Total communication is a method that combines sign language, lip reading, and residual hearing.

Cognitive and developmental disabilities pose ethical dilemmas and methodological challenges in any type of research. Edgerton (1993) and Angrosino (1992) have each invested much of their careers in this greatly unexplored area. They have found new ways of understanding the realities and experiences of people with difficulties in expression and communication. Angrosino (1992) has found that the ethnographic interview and narrative are qualitatively different with this population. The anthropologist must not concentrate on what they say but on their abilities to create culturally appropriate metaphors to convey their sense of identity (Angrosino 1992:172). The question of informed consent, however, needs further clarification but the data from these researchers aid in accounting for or exploring potential outcomes of the actions of anthropologists. I chose to interview the people who spoke on their behalf as they are the ones who mobilize others and participate in advocacy efforts. Those people generally represented those with developmental disabilities such as autism and Down's syndrome.

Disabled or able-bodied participants had to have been active in disability related organizations during some period of their lives. Organizations are important in this research design for several reasons. First, knowing the history of organizations, if organization membership and activity changed or is changing given the transition to democracy is an important indication of wider social change. Second, participants discussed their experiences with various organizations and highlighted tensions among the disabled. Third, it is through organizations that the movement gained ground and fought early battles. This is an important distinction because it locates tensions both within the disability sector and movement efforts. A passage by Burdick (1995:368) clarifies this distinction:

> Neglect by researchers of heterogeneity within targeted constituencies is paralleled by an avoidance of differentiation among that part of the constituency that is actually mobilized. This avoidance is clear in one of the chief current sociological definition of a social movement as a collectivity of actors "sharing the same beliefs and sense of belongingness."[8]

People, therefore, from various organizations were interviewed, as were people who have left organizations. Pre-dissertation field experience helped identify people and organizations. Most participants referred me to people they thought would be good participants for this project or mentioned people with whom they have cut ties, and those people were also sought. Further, a range of organizations was approached based on the population they serve, i.e., on disability type, to be more inclusive of various disabilities.

Forty narratives were collected. I understand *narrative* as research through storytelling. In my use of the method, narratives are not limited to verbal storytelling. Rather, storytelling includes, but is not limited to, field notes, journals, oral history, and observable behaviors. With rapport, asking, “what happened?” and following the themes touched upon makes the meanings attached to events and experience more understandable than interviews because participants would emphasize or shadow contributing events to the narrative telling of their experiences. I feel my rapport with the disabled was enhanced because I have adult onset hearing loss and learning disabilities. My experience is suited to the project because it compensates for the unequal power relationship between the disabled and the able-bodied (Stone and Priestley 1996:700; Oliver 1992 and 1996). My rather large hearing aids mark me, and many people ask what happened to me and this usually spurs the telling of their own disability experience. My speech is very clear because my hearing loss is post-lingual (after the acquisition of language skills) and I have some residual hearing. As part of participants' narratives, sit-

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[8] Mario Diani, “The Concept of Social Movement,” in *The Sociological Review* (1992), pp. 2-23.

down interviews were audio taped and transcribed after leaving the field using various playback methods and amplification technology to type the text of the interview. During these interviews I asked participants about important life events. In this way the narrative had some structure with regard to the lifecourse, but inevitably was interrupted for other stories. I met with every participant at least once and interviews lasted one hour at the minimum. Some interviews lasted more than three hours at one time, with short breaks. I met with approximately twelve people more than once. Interviews were held in places where the participant felt comfortable and was convenient for them. An enclosed room was used for privacy in interviews with Deaf participants when signed languages were used. Informed consent was obtained in an area where the participant felt comfortable to ask questions. The informed consent form was put into accessible formats when needed. The subjects' rights to privacy will continue to be protected to the best of my abilities by following prescribed anthropological methods according to the Principles of Professional Responsibility adopted by the Council of the American Anthropological Association, May 1971 (as amended through October 1990). The names of participants have been changed in this dissertation.

LIMITATIONS AND CONTRIBUTIONS

Limitations

This study is limited to the experiences of activists. It is further limited to the greater urban and township area in only one province. The rural context is not investigated. Disabled South Africans still experience injustices, the worst of which is abuse. There are incidents such as a 20-year old disabled man being hidden by relatives, locked in a backroom of a house for four years (Malatji 2003); the 13-year old boy with cerebral palsy with cigarette burns, knife gouges, needle marks, and rope marks around his neck as a result of his parents trying to hang him (Cox 2002). This boy was also punished with lock ups for entire weekends in outside squatter camp toilets without food and had a steel pipe pushed up his anus (Cox 2002). There were hosts of other stories of abuse in narratives from participants as well. The majority of disabled South Africans, though, face high levels of exclusion based on gender, where disabled women are more likely to be poor or destitute, malnourished, illiterate, and have a lesser chance of founding a family than their able-bodied peers (South Africa 1997a:4). More than 80 percent of black disabled children live in extreme poverty with poor access to appropriate healthcare facilities and early childhood development opportunities (South Africa 1997a:5). People with severe intellectual or mental disabilities are often excluded from development efforts, subject to abuse in institutions, and vulnerable in the justice system because their testimonies are not taken seriously (South Africa 1997a:5-6). Elderly disabled people, the rural disabled, disabled youth, disabled refugees, and people with multiple disabilities are also identified in the White Paper on an Integrated National Disability Strategy (INDS) as particularly susceptible to human rights violations and neglect.

Activists have been able to change their lives through various means, but the majority remains unmobilized. Those experiences are not explored in this dissertation, but ideas about how their lives may have turned out or through the work they do serve as indicators to the realities of other disabled South Africans. They, of course, have faced discrimination. Examination of the life course was helpful in identifying some of the key areas that reinforce their disability as exclusion. These are explored in Chapter Four and involve accessibility in terms of employment, transportation, education, and the built physical and social environment.[9]

Contributions

This dissertation contributes to anthropology and disability studies. For anthropology, it identifies disability as a human rights issue, highlighting the fact that disability is more than an individual tragedy. Rather, it is a status that is embedded and shaped by larger political, economic, and social forces. The research demonstrates how people with disabilities develop understanding and strategies to institute changes that work in their collective interests. For medical anthropology, this research finds that the disabled are often qualitatively different from those who are ill. Exploring the realities of the disabled who do not feel they are ill reveals the inadequacies of traditional evaluation methods where the lives of the disabled are viewed through diagnostic category. This research contributes to disability studies by filling the void left by ethnographic fieldwork that tends to focus on North American and European contexts.

This research also serves as a record for disabled South Africans by reclaiming their history. Because multiple disability types are included and the emphasis is not on participants' treatment by authorities alone, disability as a political identity becomes a unifying element, moving beyond the unique characteristics and needs of a disability type that make up so much of the work and research on disability. This dissertation is another account of the movement, but one where the disabled participated in its creation. In

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[9] For example, less than one percent of the disabled are employed – "People with disabilities compromised [sic] less than one percent of South Africa's workers sampled for the second annual Commission for Employment Equity (CEE) report tabled yesterday" (*Sowetan*, April 23, 2003). "Besides the fact that people with disabilities were poorly represented demographically at 0.9 percent in 2001, the report noted that the data had been of a poor standard since very few employers managed to report on the flow of data, such as recruitment and termination of employment" (*Sowetan*, April 25, 2003).

another way this dissertation also fills a gap in South Africa's modern history. The history of disabled South African's is significant to further understanding of power, coercion, domination, and hegemony in the workings of apartheid.

CHAPTER SUMMARIES

The three parts to this dissertation are intended to guide the reader through the temporal and social changes in South Africa. Part II contains Chapter Two and Chapter Three. Chapter Two is a collection of critical histories of disabled people prior to 1980, before disabled people organized more aggressively on their own behalf. The histories are split by disability type given the way the disabled were treated, and in so doing the apartheid imagination is highlighted. The created dependence of the disabled on the state has a metaphorical link with bantustans (the former "homelands" or "reserves") and is presented in the discussion. Against the backdrop of Chapter Two, Chapter Three provides a chronology of the movement and a description of the historical moment that ignited its major achievements. The chapter investigates the shift from self-help, as characterized by the Self-Help Association of Paraplegics, Soweto (SHAP) and Disabled People South Africa (DPSA), to a more rights-based philosophy. This shift occurred only once the footholds of democracy were in place in the early 1990s. Disabled people and organizations had to participate in the country's transformation in order to elevate the status of disabled people from one of charity to a rights-based inclusion of all citizens. Individual organizations also had to change, and this transformation produced tensions and factions that are characteristic of any movement. Chapter Three, therefore, covers three time periods: the beginning of the movement in the 1980s; the 1990s when the movement was said to be at its strongest; and the current situation, after a decade of democracy. In sum, Part I provides historical background to the treatment of the disabled in South Africa (Chapter Two) and efforts made to change such treatment and gain more accurate representation and appropriate resources (Chapter Three).

Part II, Chapters Four, Five, and Six, present the situations of disabled activists through the lifecourse, in everyday encounters, and in collective action. Through these chapters an additional process is described: the various ways and the extent to which disability is understood by participants as a politicized identity. Chapter Four investigates personhood through the lifecourse. Participants' lifecourse and memories and experiences bring forward the disabled subject. The injustices and questions of personhood are highlighted and lead to a wider defining of accessibility as equality beyond just the provision of ramps and sign language interpreters. This is paired with how people with disabilities articulate their treatment as objects when negotiating the public arena and indicates rejection of able-bodied beliefs. This chapter also provides a lengthy presentation of data on language. Language is highly politicized in South Africa. People can use several languages during the course of one day depending on where they are and to whom they are speaking. Access to various places can be made easy or difficult based on language. Disability in the languages most frequently used by participants is described, and illustrates how language functions in merging and dividing. Some participants taught me the word *abakhubazekile* as a word that underscores humanness with disability and as uniting to the movement. *Abakhubazekile* is an isiZulu word black participants claim to have conjured that means "persons with disabilities." This is significant because it reappropriates the negative meanings of isiZulu words for disability that mean people with disabilities are not human. At the same time, however, not all participants are familiar with this word. In Chapter Five the age of disability onset is further discussed after its brief introduction in Chapter Four by way of institutional experiences in hospitals, rehabilitation facilities, and special schools. The actions or practices and memories from the narratives are rich with complex and shifting interpretations of disability acceptance. Processes of understanding disability and what it means to individual participants are the thrust of this chapter. The concepts of shifting selves and what this means to identity formation are introduced as it pertains to understanding personal, political, and social change. Chapter Six extends the examination of disability and identity by way of liberation philosophy. For some participants disability is as integral to them as their gender and race. For others, their disability identity shifts, is negotiated, or rejected.

Part III is Chapter Seven, the conclusion. Global disability rights efforts are explained in terms of lessons learned from South Africa's labors and success. Future directions are given that concern academic accountability with the inclusion of disability into the identity politics arena. Plans to transform this dissertation into a movement discussion document are also presented.

CHAPTER TWO

CORPOREAL BANTUSTANS: HISTORIES OF THE DISABLED IN SOUTH AFRICA BEFORE 1980

This chapter describes the context of disability prior to the 1980s, before the South African disability rights movement defined its purpose and goals. The data come from historical records and interviews and illustrate care for the disabled in the form of institutions, sheltered and protected workshops, and segregated education. These conditions still persist, but as the following chapters show, alternatives were created. Rather than organize this chapter by special schools, institutions, adaptive technologies, professional approaches and other areas of concentration, it is organized by disability type. While various disabilities undeniably have different practical needs (for example, accessible buildings, medications or therapies, or sign language interpreters), they are only to a degree "medical." People with disabilities were, and to a large extent still are, split into groups based on western medical categories and charity efforts targeting their favorite "group." To a greater degree, personally and to social society, these needs are accessibility based. In following chapters these histories help illustrate different trajectories in the development of disability types, and how this was handled by the movement. For this chapter, though, a parallel can be made with the metaphor of bantustans and will be covered in the discussion. These histories concurrently identify processes of relegating the disabled to the fringes of society and represent material to include in a history of the movement or a reclaiming of history by the disabled and their heritage.

CREATING DEPENDENCE: CHARITY AND WELFARE

Social and political intersections of nineteenth and early twentieth century South Africa shaped the positioning of the disabled into disability types.[10] From these intersections and forces vying for state control, something had to be done about the disabled. Clergy from Europe, local authorities, well-to-do women with time on their hands, people with medical training, and people wanting to "do something" for the disabled began providing services and establishing places for their care. They effectively carved a space separate from society to house or keep the disabled, occupying their time with little hope for "rehabilitation." Often with various foci, these able-bodied people navigated the political climate by harnessing scientific knowledge. Scientific racism provided proof for the superiority of the "white race" and flourished in the first half of the twentieth century. It was essential for the maintenance of apartheid through biological determinism (Baldwin-Ragaven, de Gruchy, and London 1999:132). Disability was embedded in this discourse. For example, in the nineteenth century, doctors' definitions of insanity were close to social definitions, merely adding a diagnosis or label to the belief (Deacon 2003:33), and black "lunatics" were thought less curable in the colony than white "lunatics" (Deacon 2003:22). Further, terms were applied based on race with diagnoses following racial lines (Jones 2003).

Emphasis on various social impacts and estimated contributions of people with disabilities traveled different routes. Given the data, though not comprehensive, different interests were developed, it seems, based on the contributions people with disabilities could make or, at the very least, be humbly allowed to exist. Since historical documents mostly concern white welfare, blacks were left largely to develop separately according to

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[10] The first Dutch settlers arrived in Cape Town in 1652. In 1806 the British occupied the Cape, an incursion that lead to the Anglo-Boer War (1899-1902). The Union of South Africa came into being on May 31, 1910 with four colonies: Cape, Natal, the South African Republic, and the Orange Free State.

the period and stage of apartheid legislation. Ethnographies were consulted, but they were largely fruitless because anthropologists either did not see the disabled, excluded them from participation, or the disabled were not there. For the deaf, education records are available and demonstrate how the field of education gauged the intelligence and potentials of the deaf. For mobility-related disabilities, war, epidemics, and injury somehow meant that the minds of those so affected were still intact. However, the question of economic contributions loomed, and competition for labor was already high between British, Afrikaner, and African workers. The blind, like those with mobility disabilities, also perhaps had good intelligence, but could they fill an occupational niche? Mental disabilities have multiple issues that impinge on stability of performance based on capacity, yet can pose a public threat. Fractured not only by perceptions of helplessness by the able-bodied, the disabled were subject to existing fault lines as well. The following histories are a more in-depth description of these states of disability.

Deafness

Much of what is known about d/Deaf history in South Africa is through the establishment of schools for the deaf. This is not limiting because several issues have their genesis in deaf schools and continue to this day. Education for the deaf has always been controversial because it surrounds issues of language and comprehension. Descriptive names such as "deaf and dumb" and "mute" demonstrate the level of subjugation initiated by the hearing and make the deaf charity objects by questioning their intelligence. Earlier pedagogies questioned whether the deaf could learn or have meaningful and abstract thoughts without spoken language. Two approaches addressing the development, quality of life, and education of deaf people competed during the late

1800s: oralism and manual or sign language. The oralist approach seeks to utilize residual hearing the deaf person may have to capture sounds, and together with reading mouth or palatal formations, the deaf person makes guesses as to the spoken words or phrases (known as lip reading or speech reading). One could argue that oralism aims to make the deaf appear hearing, and therefore, more intelligent. Conversely, sign language, now understood as a natural language with its own syntax and grammar, was perceived as primitive, basic, and incapable of conveying complex concepts. This debate of oralism – sign language still exists and other models have been implemented since.

One of many factors shaping deaf education in South Africa came from international decision. The Milan Conference of 1880 was a gathering of hearing educators for the deaf and effectively banned sign language as a medium of instruction for the deaf. The German oral method was authorized as the official method for educating the deaf. Two countries, the United States and Britain, opposed this convention. According to Lang (2003:9-20), educators supporting sign language were unable to attend the conference and the deaf were excluded from the vote (Lane 1984:394). The oralism–sign language debate is made more complex in South Africa by religion and nationalism. From the establishment of the Union of South Africa in 1910 until 1948 with the election of the National Party, white schools were under provincial control (Saunders and Southey 2001:67), but blacks and whites were educated in schools founded by missionary societies with a curriculum of vocational and manual training. After British occupation of the Cape, teachers were recruited from England and Scotland, and in 1939 a Department of Education was established (Saunders and Southey 2001:67). Mission schools and smaller farm and community schools were entitled to state subsidies under certain conditions (Saunders and Southey 2001:67). Private schools based on religious principle were permitted as well.

The educational system parallels the general British framework of education, and is evident in the development of schools for the deaf in South Africa. Irish Roman Catholic sisters opened the first school for the deaf in 1863 in Cape Town (Jones 1994:698; Morgans 1999:53; Penn 1992:281). This was the Dominican School and was later renamed the Grimley School for the Deaf and Dumb in 1874 (Simmons 1994:80). Mother Prioress, who came from St. Mary's Institute for Female Deaf at Cabra in Dublin, Ireland, initiated the school (Haycock 1936:134). As for the medium of instruction, the nuns introduced Irish Sign Language (ISL), thereby making this school the first for English-medium of instruction for deaf children (Simmons 1994:80). German nuns soon followed, opening a school in King William's Town in the Eastern Cape (Simmons 1994:81; Penn 1992:281).[11] The German sisters generally followed an oralist method, but sign language was permitted and was based on British Sign Language (BSL) (Simmons 1994:81). People within the Dutch Reformed Church, however, were conflicted about whether to send their deaf family members to Holland for education, or, to their dislike, to the Catholic Dominican School in Cape Town Van Reenen 1956). These concerns were brought to the local leaders of the Dutch Reformed Church. Therefore, in 1881 the De La Bat school opened in Worcester for white deaf children of an Afrikaans background (Penn 1992:280-281). Afrikaans was the language of instruction with English taught as a second language (Penn 1992:280). The British two-handed alphabet was used along with signs that developed in that deaf community and became known as the Worcester Sign System (Penn 1992:280). Another Afrikaans-

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[11] Simmons (1994) states that the school opened in 1884 while Penn (1992) cites 1877.

medium school did not open until the mid-1950s.[12] Tensions between the Roman Catholic Church and the Dutch Reformed Church, and English and Afrikaans languages were felt throughout in the Cape. The opening of the Worcester school reflects these tensions and is an example of the move toward Christian National Education developed in the 1880s based on Calvinism and Afrikaner nationalism (Saunders and Southey 2001:67).

Though these schools are "officially" oralist, the German sisters in King William's Town used signs based on BSL. What needs to be emphasized is that sign languages are natural languages for the deaf. Regardless of teachers who refuse or who can not sign, deaf children in deaf schools often sign in areas out of reach of authority. Another example of clashes with sign language and oralism is that of the Worcester school. When the school started at Worcester, the founder, de la Bat, intended to teach deaf children in the oralist tradition but abandoned it for fingerspelling and signs (Van Reenen 1956:7).[13] The school outlined the dangers of sign language in the development of the deaf:

> This later method [signing], however, has three serious drawbacks, although it is perhaps at the outset easier to master. Firstly it tends to make a deaf person conspicuous, something of a curiosity, among a group of hearing people, and thus underlines the fact that he is different and emphasizes his loneliness. Furthermore, there must of necessity always be people unfamiliar with finger spelling who, therefore, can understand him no better than he can them. Finally, perhaps the gravest objection of all, the linguistic ability of the deaf who avail themselves of this method must always remain extremely primitive. They will speak and consequently write as they express themselves by this method – in crude, rough-hewn language units. *Man sit chair.* This is language with little grammar and no subtlety. [Van Reenen 1956:7]

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[12] Van Reenen (1956) states the Transoranje School in Pretoria opened in 1955 while Penn (1992:280-281) cites 1954.

[13] Fingerspelling is the use of a manual alphabet, using the fingers to represent letters. It is often used for proper names and for clarification in deaf communication.

The persuasive arguments in this passage are presented as linguistic fact. In Worcester's professional opinion, it is the deaf person who must adapt to appear hearing, and therefore, intelligent. Equating the deaf to a lower form of human further objectifies them, making their management necessary for not only for the betterment of the deaf, but for the betterment of society.

Old de lat Bat retired in 1927 (Van Reenen 1956:15). D. F. Malan, then Minister of Education, and his secretary urged Gawie de la Bat to succeed his father (Van Reenen 1956:15).[14] The Rev. G. de la Bat, son of the founder, became principal of the Worcester School for the Deaf and published a book in 1930 titled *The Deaf Child in the Home* in which he provides guidelines for parents of deaf children. Under the topic "If The Child Uses Signs," de la Bat suggests:

> When a deaf child, in trying to give expression to his thoughts, makes use of mimicry (imitation), and of natural signs of his own invention, or if he points to a person or a desired object, immediately make use of the opportunity to SPEAK the corresponding word to the child as distinctly as possible, repeating it several times. Make sure that the child is WATCHING your lips. [de la Bat 1930]

This seemed to help him in his own mission: banning sign language. Although going against the measure of his father, Gawie de la Bat tried to implement oralism. It was, however, a tough task. The following account of this attempt illustrates the inequality, disdain, and paternalistic view of Worcester teachers and administration toward "them":

> It was no use trying to reform the senior pupils. A start had to be made with the new arrivals. But, sure enough, within a term they too had been "contaminated" by the signs of the rest. The new method pupils would have to be housed and taught quite separately from the others. This speeded up the intention of moving the deaf away from the central block to the edge of the town. But for seven years "Meneer" [Mister] had to shuttle to and fro by car between his talker and his signers! In 1937, however, the first deaf mute confirmation class was examined

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[14] Daniel Francois Malan became Prime Minister in 1948 serving until 1954. He was instrumental in forming the Purified National Party.

> viva voce like the rest, and to-day, officially, signs are banned at the School. [Van Reenen 1956:7]

Apartheid education policies separated the education of black and white deaf South Africans. In 1948 educational policy was reformulated along apartheid lines, and in the 1950s churches and missions were to give up control of education. In addition, the Bantu Education Act of 1953 initiated separate and inferior state controlled education for blacks (Saunders and Southey 2001:67). Penn asserts that by 1948, with the fragmentation of educational policy, manual communication was deemed acceptable for black deaf students, but anti-signing policy forced white deaf students into oralism (1992:281). Anti-signing sentiments were almost certainly evident in white schools for the deaf, but it does not mean that teachers in schools for the black deaf knew or used sign language as a medium of instruction. Further, as the Worcester example demonstrates, sign languages are often learned through peers. Some participants, however, observed that despite formal oppression through apartheid legislation, sign language in black deaf communities developed a richness and complexity that may have been hampered among the white deaf communities.

To buttress this argument, there is great language movement during this time. Moving north out of the Cape toward Johannesburg in the early 1900s, a private school was begun by British-born teacher Miss Jessica Davis (Simmons 1994:81). Dominican sisters established a convent and school called St. Vincent's School for the Deaf and joined Miss Davis' school in 1934 (Simmons 1994:81; Penn 1992:281; Steinberg 1998:61). St. Vincent's may have been started by the school in King William's Town because this school developed the St. Vincent Sign System that relied heavily on BSL (Simmons 1994:81). Race and sign language intersect again because prior to 1937 both white and non-white (meaning "colored" and Indian) deaf students were accommodated at the Grimley School (Simmons 1994:80). Because the state introduced compulsory education for all disabled children of European descent in 1937 (Simmons 1994:80), these students were moved in 1937 to Wittebome with their ISL having been learned and used at Grimley (Simmons 1994:80). The "colored" deaf community in Cape Town uses this Wittebome Sign Language, which also is sometimes observed in the white deaf community in the Cape Peninsula (Simmons 1994;80).[15] Indian and other Asian deaf children attended the schools in Worcester and Wittebome, but the first school for Indian deaf children opened in Durban in 1969 (Simmons 1994:81). Thus, sign languages saw life in non-white areas and contributes to the diversity of South African Sign Language.

Blindness

Though data and records concerning blindness and blind people are scarce for nineteenth-century South Africa, the deaf and blind were taught under the same roof for a brief period.[16] In the years shortly after Worcester was established in 1881 there was one blind pupil, but in 1891 Worcester educated a deaf woman (Van Reenen 1956:14).[17] In the early 1900s, however, the Cape Secretary for Education recommended that Worcester have separate facilities for the blind and the deaf for departmental purposes (Van Reenen 1956:15). Now separate from the deaf, the blind at Worcester were given training in various trades. Sheltered work for the disabled remains a dubious "tradition." A

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[15] Penn states that the first school for black deaf was established in 1941. She does not explicitly name the school but notes that it used the Paget Gorman coding system (1992:281) which is not a sign language or natural language for the deaf.

[16] One reference is David Livingstone who noted in his 1859 diary that trachoma in southern Africa had been recognized for many years (Malan 1988:343).

[17] Worcester's jubilee publication describes: "During the first ten years no blind pupils arrived, not counting Daniel Simonis of Goudini, who came soon after the school opened but had 'neither the inclination nor the courage' - and in fact not the mental ability - to stay longer than three months. But in 1891 came the first real blind pupil, Issie Schoeman, daughter of oom Jurie Schoeman, the Oudtshoom member of the Legislative Council" (Van Reenen 1956:14).

distinction can be made here between sheltered work, protective work, and *service products*. Sheltered workshops are designed for the more able disabled who can make a product. These workshops pay a higher subsidy than protective workshops that are for the more severely disabled, (i.e., mental disabilities and multiple disabilities). Protective workshops essentially look after people rather than provide them with a livelihood or sense of well-being from work. Service products, are known as workshops run by the state, and are the worst in terms of morale and pay.

The work of Rev. Dr. Arthur W. Blaxall (1891–1970) proved to be a bit of a thorn in the sides of at least two established orders: the charity ethos and racism. Blaxall came from London and stayed in South Africa for over forty years. He was instrumental in establishing the South African National Council for the Blind (SANCB), serving as its chair until 1952 when he was appointed a vice-president for life (New Beacon 1971); he also was the first chair of the South African National Council for the Deaf (SANCD).[18] Both organizations were founded in 1929. Blaxall and his wife, Florence, recognized the issues at hand: growing racist authority and its impacts on the disabled. He established two organizations for blind non-European South Africans, the Athlone School for Colored Blind in Cape Town and the Transvaal Society for the Care of Non-European Blind, with its center at *Ezenzeleni* (the place where you care for yourself) in 1937 (Blaxall 1965:32-43; New Beacon 1971). Florence, his wife, attempted to teach deafblind people. Arthur Blaxall was not necessarily following the racist paradigm by establishing separate facilities, and he thus was watched by the state. Blaxall was

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[18] The South African National Council for the Deaf was founded as an umbrella organization, indicating that other organizations for the deaf were in existence. This organization was controlled by hearing white people until the early 1990s, when there was a shift toward control by the deaf. The organization has also changed its name to the Deaf Federation of South Africa (DEAFSA).

charged under the Suppression of Communism Act and tried in Johannesburg in 1963, but he left South Africa with Florence to retire in England a few months after the trial (New Beacon 1971). Nevertheless, the Blaxall's legacy remained, and the disabled had some exposure to the politics of disability.

This was especially true for non-whites. For example, some older participants remark that the school in Cape Town was indeed for coloreds only, but they attended that school because "Dr. Blaxall broke the rule and admitted blacks because they had nowhere to go." Once out of school, however, there were no jobs for blind people, let alone black blind people. Nevertheless, Ezenzeleni did have a sheltered workshop and some of the graduates from Athlone went to Ezenzeleni as adults. While at Ezenzeleni they learned knitting, basket weaving, cane work, and other crafts and skills thought suitable for the blind. White blind people by that time were finding work as switchboard operators and Ezenzeleni "quietly" also embarked on teaching the skills necessary for employment as a switchboard operator. One participant remembers: "What used to happen is that when they had new avenues for white people then we would take over where they left off." Two participants and some of their classmates with secondary or high school education traveled from Cape Town to the Johannesburg and Soweto areas to become switchboard operators. The older participants recall talking about the problems of suppression and the noninvolvement of the blind into solving blind problems. They did not collectively act on these obvious problems until the early 1970s.

These participants formed a group in Soweto, growing to form the Transvaal Association for Blind Black Adults (TABBA). They wanted projects that were oriented to self-help. They recognized that the traditional plans "for the blind" only served to occupy the time of blind people, often manufacturing products for the state. Their voice as blind people was ignored, as specialists believed they knew what was best for their development. TABBA consulted the South African Blind Workers Organization in Johannesburg but was told that blind organizations must affiliate with the SANCB.[19] By this time Consolidated Circular No. 29 of 1966 called for the SANCB to segregate by population group. In accordance, the SANCB had white services, an Indian division, a colored division, and black people had a committee of black blind which some of the participants served. The plan was that each division would become separate and self-governing.

TABBA met on November 12, 1973 to define their mission. They decided that they needed to do some research, to obtain some proof of the needs of black blind people in the township. They went to pay points where people received their pensions to look for blind people. They also used the radio and other media to connect with blind people. By 1974 they began to apply to the SANCB for affiliation but were rejected many times. They believe the SANCB responded by saying they already provided services and there was nothing they could not provide. It was also rumored that perhaps the SANCB thought this group was formed by dissidents to discredit their work. The group, however, was formed because the SANCB did not reach them. There were no black staff in the townships and the efforts of SANCB did not develop them.

TABBA worked out of a member's home, presenting their research in search of support, visiting workshops and schools around the country to conduct further surveys, and spreading their message. As one participant explained, TABBA was "quietly

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[19] The South African Blind Workers Organization was established in 1946 and was mainly a white organization until they opened their doors to all "races" in 1992.

conscientizing the people in charge [of workshops and schools] there you know. Whether they are *aware* of the exploitation that is taking place, and that there was no progress."

Mobility-Related Disabilities

Mobility disabilities can present a different set of circumstances for the state to contend with than do other disabilities. Conflict, war, epidemics, and occupational injury from mine work have a louder political element than other disabilities, though the outcome of such events can also produce deafness, blindness, and mental disability. For example, closed head trauma, or blindness or deafness from buckshot occurs from such events. The critical differences generally lie in the mechanism of injury – giving life and limb in conflict, for example, or important economic efforts, as in mine work, is accompanied by general emphasis on state responsibility for the welfare of the injured. What the state does to support its disabled veterans involves public scrutiny, whereas other disabilities appear more neutral as to causation, its nature, and assessment of needs. In this latter instance "special" can be read as "segregated," whereas the former involves the best interests of the state in its decisions to enter war. Similarly, where commerce and labor, colonial and imperial interests intersect, state interests must be preserved.

South Africa's long history of diamond and gold mining provided its massive state revenue in the late 1890s and early 1900s. Gold, in particular, sparked the Anglo-Boer War (1899–1902), bringing the establishment of the Union of South Africa in 1910 (Saunders and Southey 2001:79, 159).[20] Essential to Britain, the gold industry on the Witwatersrand was under the governance of Paul Kruger, and both British imperialists

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[20] Historians have two general perspectives on the Anglo-Boer War: that it was fought for primarily economic purposes or for Britain to protect its route to India (Saunders and Southey 2001:159).

and mine-owners thought Kruger was unwilling to develop the mines (Saunders and Southey 2001:159). To a certain extent industry must manage its workers who become disabled, but the potential for injury is generally left to the worker as a gamble. The Workmen's Compensation Act (Act 30 of 1941) transferred the cost from industry to the State in the departments of welfare and health, and was largely ineffective in rural areas, leaving rural families and communities to bear the burdens of disabilities and diseases workers returning home incurred in urban workplaces (South Africa 1997b). Compensation should have been the responsibility of the employers, according to the White Paper for Social Welfare, General Notice 1108 of 1997. Another critical difference is that mobility impairments from injury in the above scenarios occur after one's social and economic endeavors are in place, unlike congenital disabilities. Knowledge of their profession before injury is still intact, but whether these occupational duties could still be performed was questioned. Beliefs about ability and plans to change the political and economic machine of the workplace, and public acceptability are too much for industry to handle given larger goals. Further, with sources of cheap and replaceable labor (i.e., black males) injury simply meant replacing the damaged worker.

Perhaps the earliest example of the disabled being an economic drain in what was to become South Africa was in the 1640s. At that time, the hospital at Batavia cost the Dutch East India Company funds because it was "crowded with invalids, who often lie there for months without doing any work, but withdrawing wages notwithstanding" (Katzen 1969:189). The early records of mass disablement from the Anglo-Boer War (1899 to 1902) involve what to do with disabled soldiers and prisoners of war. In communications from the fort in Johannesburg to a Burgher camp in Natal, the Provost

Marshall writes of "a cripple": "This is a man with one leg and arm, a Quaker. He is constantly causing unrest. Was a strong member of the Brocksma gang" (National Archives of South Africa, "Mr. P. F. von Straten, A Cripple, Caused Unrest in Johannesburg and Should Be Sent to a Refugee Camp", 1901). The response was to send him to a Natal refugee camp because "We can hardly send such a cripple away as a prisoner of war" (National Archives of South Africa, "Mr. P. F. von Straten, A Cripple, Caused Unrest in Johannesburg and Should Be Sent to a Refugee Camp", 1901). Because this "cripple" was a POW, a Quaker, and a member of the opposition, his status as a disabled person afforded him a different measure of management.

Other wars would prompt organization to help disabled soldiers. Some recorded efforts are the Lord Roberts' Memorial Fund for disabled soldiers and sailors administered by the Soldiers' and Sailors' Help Society (National Archives of South Africa, Lord Roberts Memorial Workshop). This society established workshops similar to those for the blind and deaf. The 1920s saw disabled soldiers from World War I. Cripple Care associations were born in the 1930s to help the disabled and were and, some still argue, remain a charity organization.[21] They started in the Cape to provide rehabilitation, but new theories surrounding what to do with the disabled, people with mobility disabilities in particular, were developing in Europe and America. Guthrie (1961:308) explains that the object of rehabilitation is to cure or reduce disability so people may return to work in the industry in which they are employed or, if that is not reasonable, to enable them to find alternative work in the same industry (Nicoll 1941:501). These efforts, however, had to operate in an apartheid framework. The following example illustrates one strategy. In 1955 the International Labor Organization

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[21] Cripple Care is now known as the Association for People with Physical Disabilities.

adopted recommendations to pursue vocational rehabilitation of the disabled with attention to the following issues: training and placement of disabled people; administrative organizations; cooperation between medical treatment and vocational rehabilitation; locating more employment opportunities; sheltered work; and provisions for disabled children and young people. The South African government would not conform to this as explained in a memorandum to the Governor–General of the ILO:

> The principles contained in the Recommendation are acceptable and, in the main, have been put into practice in the Union in respect of Europeans, but it has not yet been found possible to extend the same facilities to all members of other races. The Recommendation requires that vocational rehabilitation services should be made available to all disabled persons and its acceptance would imply the willingness of any government to take positive action to give full implementation to its provisions.
>
> Under existing circumstances there seems little likelihood that such action in respect of all Non-Europeans will be taken in the near future, and it is accordingly recommended that the Director-General of the International Labour Organisation be advised that the laws in force in the Union cannot be said to be in full conformity with the terms of the Recommendation and that at present action to bring them into conformity is not contemplated. [National Archives of South Africa, "ILO Recommendation (No 99) Concerning Vocational Rehabilition of the Disabled, 1955"]

Shortly after this failure to comply with ILO recommendations throughout the Union, the Department of Labor in 1957 started a pilot industrial rehabilitation center in Johannesburg on an outpatient basis for men and women with less severe disabilities (Guthrie 1961:308). They were provided with three months of treatment in the Sheltered Employment Factory that included physical therapy and vocational counseling (Guthrie 1961:308).

Although other workshops for injured workmen existed, such as the Workman's Accident and Rehabilitation Center in Johannesburg, built in 1953 by the Rehabilitation Association for Injured Workmen (Guthrie 1961:308), Welsh (1975:194) notes that apartheid African hospitals, including institutions for the deaf and blind and old age homes, had to be moved to the reserves with no new ones to be established in "white" areas (Botha 1964:17). Though medical treatment became the responsibility of the provinces during the 1960s, the central government became responsible once treatment included rehabilitation or vocational training (McMurray 1961:2). Either way, black disabled people were not eligible for such training as they were not considered citizens, and primary health care on bantustans was nearly non-existent.

Mental Disabilities

Questioning the mental often means questioning the moral, be it 'race' or disability. As mentioned above, various terms were applied based on race, and diagnoses fell along racial lines (Jones 2003). While some authors discuss 'lunatics' (Terre Blanche 1999; Kruger 1980; Moyle 1987: Lea and Foster 1990:11) and 'idiots' (Minde 1975a:1716-1720), Deacon explains that nineteenth-century doctors' definitions of insanity are close to social definitions, merely adding a diagnosis or label to the belief (2003:33). Most of the colonial 'insane' were cared for at home or in private boarding houses, while asylums were used to house the most desperate or most dangerous (Deacon 2003:20, 22). An asylum provides a holding place and in the context of growing racism in the colony, black 'lunatics' were thought less curable than whites (Deacon 2003:22).[22] Delusions, however, characterized 'the insane' according to both doctors and lay people (Deacon 2003:34), and the content of the delusions reflected general social tensions. The

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[22] Lunatics' were at Robben Island in 1718 (Terre Blanche 1999; Kruger 1980) and 'idiots' were mentioned during 1803 to 1806 (Minde 1975a:1716-1720). A commission of inquiry in the Cape in 1852 investigated 'lunatics' cohabitating in the asylum on Robben Island (Lea and Foster 1990:11). A classificatory system seems to have been used because during this inquiry attempts at classifying 'lunatics' found a group of female lunatics as 'the imbeciles' and two 'idiotic' children (Lea and Foster 1990:11). Lea and Foster (1990:11) say these women were exempt from hard labor and spent much of their time sewing (see also Moyle 1987).

"Malay" (read Muslim) were perceived as a threat in Cape Town, and the white middle class believed the 1882 smallpox epidemic was spread by Muslim burial practices (Deacon 2003:35). Trickery by the Malay was a theme found in the delusions of the insane (Deacon 2003:35). Thus, racist notions tended to color perceptions of mental impairment.

As far as "care" for people with mental disabilities is concerned, the earliest records are in the form of legislation in Natal and the Cape Colony. In 1868 Natal was the first area to make legal provision for the 'insane' or 'mentally unsound' by passing the Custody of Lunatics Act (Lea and Foster 1990:11). The Cape Colony followed with the Lunacy Act No. 20 of 1879 (Lea and Foster 1990:11). In June 1913, a Cape Town society started providing for the protection and training of feebleminded persons (Minde 1975a:1716-1720). Shortly thereafter the Mental Disorders Act No. 38 of 1916 provided "for certification, care and supervision of mental defectives and mentally disordered" (Minde 1975a:1716-1720). Changing the language a bit, the Mental Disorders Act of 1916 appointed a Commission of Mental Hygiene (Terre Blanche 1999; Minde 1975b) and in 1920 the National Council for Mental Hygiene and for the Care of the Feeble-Minded began (Terre Blanche 1999; Hurst and Lucas 1975; Vitus 1987). Mental hygiene, however, can be read as racial hygiene (Swarts 1994) and is indicative of the racial beliefs and tensions of the time. The Valkenberg Asylum was founded in 1891 (Terre Blanche 1999; Hurst and Lucas 1975) and was initially for whites only until a "black side" was added in 1916 (Terre Blanche 1999; 1994). Mental institutions, according to the Truth and Reconciliation Commission report (1998:149), "did nothing to foster mental health. Inmates were used as sources of income-producing labor and there are (unproven) allegations that black patients were used as 'guinea pigs' in research."

Epilepsy is considered a disability in South Africa and is usually categorized by health authorities under mental disabilities. Scholars on mental health and medical history do not typically include epilepsy in their research, perhaps treating epilepsy as a special category or focusing on mental disability where epilepsy is only secondary. But epilepsy in South Africa exists in an odd space in the early twentieth century, because a distinction between 'sane' and otherwise uncontrollable epileptics meant separate treatment. For this second type of epileptic, care was included in the Mental Disorders Act (No. 38 of 1916) and administered by the Department of the Interior. Plans for an Epileptic Block and Cripples Home at the Lunatic Asylum in Pretoria were found in documents dating to 1909 and 1910 with the Public Works Department in the Transvaal and the Treasury (National Archives of South Africa, "Erection of Epileptic and Cripple Home, Lunatic Asylum, Pretoria"). Most sane epileptics were probably cared for at home, and the solution of what to do with them is similar to that of the deaf and blind: send them to school.

The historical records show differences in approaches to sane epileptics. The Secretary for Finance in 1936 communicated that not all epileptics require special treatment in institutions or would they be prepared to accept it if provided (National Archives of South Africa, "Special School for Epileptics at Kuils River Under Act 29 of 1928"). A proposal for a school for sane epileptic children by Mrs. Rev. J. P. Kriel of the Parsonage involved much consultation with government departments, but communication was exclusive to European children and made small estimates as to sane epileptic children needing special education provision. Nonetheless, a representative for the Union Department of Education notes:

> I should point out that, generally, epileptic children should be required to attend ordinary classes with normal children, unless their presence seriously disturbs the ordinary education procedures, when they become candidates for special schools. This happens when the fits are of such intensity and frequency that they disturb class teaching and exercise an undesirable psychological effect on the other children. [National Archives of South Africa, "Special School for Epileptics at Kuils River Under Act 29 of 1928]

The same ethos exists today.

Yet there is caution about assuming care. William Russell of the Office of the Commissioner for Mental Hygiene in 1936 explains in a letter that:

> I am sure that there are in the community epileptics who are genuinely in need of assistance and care, in a special institution or colony, apart from the mental hospitals, but only some of the epileptics at present outside of institutions require or would voluntarily accept this care. Although efforts to provide proper treatment for those who really need it must naturally receive my support, I could not approve of any movement which attempted to label all epileptics as a class apart, and requiring special care and help from the State; such a policy would be contrary to the interests of many epileptics themselves. . . . Also, I think we must be careful not to launch any scheme which would place the epileptic at an advantage over his normal fellows, by transforming a dread disease into an economic asset. [National Archives of South Africa, "Special School for Epileptics at Kuils River Under Act 29 of 1928]

Russell's department did assume responsibility for sane epileptics who are "unable, because of their disease, to adjust satisfactorily to ordinary social situations, and who are therefore in need of special assistance" (National Archives of South Africa, "Special School for Epileptics at Kuils River Under Act 29 of 1928). The government's language seems quite progressive for the 1930s, but in letters requesting donations for the school, Mrs. Rev. J. P. Kriel, the initiator of a school for sane epileptic children, uses language that was perhaps more accurate of the general beliefs about epilepsy:

> We are asking for help to make these bleak and empty lives fuller, richer and more worth living. They are almost unwanted and avoided by most. Can we form any idea of the effect upon them? Just the fact that they feel useless and in the way makes them moody, restless, unhappy and retards or prevents any chance that they may have of recovering. Their consciousness of their condition makes them among the most lonely of people. [National Archives of South Africa, "Special School for Epileptics at Kuils River Under Act 29 of 1928]

DISCUSSION:
CORPOREAL BANTUSTANS

Bantustan policy was designed to maintain and strengthen white supremacy in South Africa. Devised by Minister of Native Affairs (later Prime Minister) H. F. Verwoerd and Secretary for Native Affairs Dr. W. M. Eiselen, the African reserves were to be transformed into self-governing states, or bantustans. With the intention of having the bantustans achieve full "independence," the policy was a token response to international pressure on South Africa to give some political rights to Africans while maintaining a master plan of apartheid. A series of acts implemented bantustan policy. The Bantu Authorities Act of 1951 created a hierarchical system of authority in the reserves where appointed chiefs and headmen played a key role. Territorial authorities were set up for each of the so-called ethnic groups.[23] Chiefs who did not cooperate in the new system were deposed and replaced, while those who cooperated became clearly identified as instruments of the state. The Promotion of Bantu Self-Government Act of 1959 recognized eight "national units" or "homelands" on ethnic grounds, providing for self-government. An additional homeland in the Transvaal came later. Limited self-government came for the largest homeland, the Transkei, in 1963. Beginning in 1976 the bantustans were to transition from self-government to full "independence." An integral part of apartheid, bantustan policy created a state without black or African South

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[23] The Xhosa posed a different situation and therefore had various authorities (Saunders and Southey 2001:19).

Africans. Bantustans were recognized only by South Africa and other independent bantustans, receiving no international recognition. Africans essentially became temporary residents of South Africa, subjected to pass laws, influx controls, and forced deportations. They were residents of the new states whether they lived in them or not. The bantustans were, however, rural slums, totally dependent on South Africa.

Bantustan policy essentially questioned citizenship, divided by "type," and depended on an illusion of "best-interest." The word "bantustan" remains pejorative. Similarly, a corporeal bantustan as it relates to the disabled is not only in the physical sense as in special schools and institutions or behind closed doors, but in a realm of control reinforcing the inferior status of the disabled. Regardless of "race," many of the disabled are cast into corporeal bantustans incorporating institutions, occupational niches in workshops, or the protected environment of the home. Divided by disability type, what is known as the individual model of disability (see Oliver 1983, 1990a, 1990b) prevails in keeping them aside. Although labeled "special," the disabled are "segregated." A general dichotomy, however, can be drawn from the above histories. The white experience of disability is one of health and welfare with support from organizations and the state. The lives of the disabled are run by the able-bodied, professionals, and family members speaking who speak on their behalf and create the conditions for their control through institutions. The disability experience of black South Africans, however, is characterized by poverty, violence, and the system of apartheid. Disability, however, remains bantustan.

Because the disabled are consistently considered as belonging to a social welfare category [which has become the new term for "charity" (Coleridge 1996:4-6)], some organizations of rehabilitation professionals and other specialists are created with the seemingly wholehearted acceptance and desire for their help on the part of the disabled. Thornton and Ramphele (1988:32) find that genuine representation of those affected is overshadowed by the status of leaders (usually doctors, rehabilitation professionals, or other health and welfare related workers) by virtue of their social visibility and association with high education and economic status (Chambers 1983:18). The decision-making process lies with the able-bodied professionals rather than with the disabled. This is consistent with what has been coined the individual model of disability. Oliver makes a binary distinction between an individual model of disability and a social model of disability (1983, 1990a). An individual model views disability as an individual tragedy with psychological and medical aspects, but Oliver is cautious not to call the individual model the medical model because in his view the medicalization of disability is but one aspect or component of the individual model. I agree with this diagnosis. Scholars in disability studies have equated the individual and medical models and perhaps overstretched its boundaries. The success of the individual model is in creating a population that is: dependent on the state; able to emotionally and financially drain the family; duped into believing that they need to be cured and are curable; and believed by authorities to be uneducable and unemployable. The social model, conversely, views society as creating and maintaining the inferior status of the disabled through its failure to integrate and provide for the needs of the disabled. Blaxall's efforts, in the above section on blindness, to somehow emancipate the blind from the bantustan of disability during his tenure in South Africa in the first half of the last century is, I fear, one of the few records of resistance to the racist and ableist ideology of the time. Blaxall recognized what is now referred to as the social model of disability. As there were those who rejected bantustan policy, there were those who rejected the individual model of disability.

The next chapter concerns the clashes of the individual and social models in the realm of the bantustan, corporeal and apartheid. The South African disability rights movement is traced from the early days in Soweto during the 1980s to its current state. Within the span of approximately twenty years, South Africa has experienced rapid social change and disabled South Africans had to participate in these changes to elevate disability as a social issue.

CHAPTER THREE

REDEFINING ENGAGEMENT: THE DISABLED ORGANIZE

The purpose of this chapter is twofold. First, it chronicles the South African disability rights movement in context. Second, it highlights the importance of social and political change in the potential for identity formation. The discussion is an analysis of the movement in terms of an integrated approach to social movement research. New social movement theory and resource mobilization theory approach social movements at different but complementary levels of analysis (Canel 1997:189; see also Cohen 1985), and I will use Canel's (1997) assessment as an explanatory model. Such guidance allowed me to see how meaning and identity could be mobilized, an essential component germane to this study comprised of activists, but also seemingly lost by social suffering theorists. Escobar (1992) and Burdick (1995) have called for a return to examining social movements and to a rethinking and developing of aspects of political practice in anthropological theory. Both recognize that, in the1980s, anthropology focused on power and everyday resistance, but that sociologists were actively developing social movement theories. Meaning production is not lost on sociologists, and by using qualitative methods such as narrative they are producing well-rounded assessments of social movements [for examples see Zugman's (2003) work on Fuerza Unida and Gongaware's (2003) work on Native American educational social movements]. Canel's model is enhanced with attention to meaning production. This chapter, therefore, views social movements as bringing about new social practices operating in part through the constitution of spaces for the creation of meaning (Escobar 1992:408).

As explained in Chapter One, the 1980s were a time of states of emergency and unrest. The 1976 Soweto uprising was a result of schoolchildren protesting the use of Afrikaans as a medium of instruction in schools.[24] This spurred riots throughout the townships and lasted for months. The government's "total onslaught" was escalated and amplified violence, widespread torture by security police, military occupation of the townships, mass detentions, mysterious deaths and disappearances of political activists, and police immunity from prosecution for abuse. These efforts to suppress unrest forced leaders in the liberation struggle to rethink their strategy because many of their fellow leaders were either imprisoned or exiled from the 1976 uprising. The uprising strengthened division in the National Party and Afrikaner community. While the uprising caused some whites to call for reform, others believed a stricter reprimand was appropriate to maintain white power. Nevertheless, the struggle during this time was making it impossible for the government to maintain apartheid. It is against this backdrop of intense conflict and impending change that disabled South African's began to organize.

The South African disability rights movement began this transformation essentially with the Self Help Association of Paraplegics of Soweto (SHAP) as an income-generating project run for and by people with disabilities in the township. In so doing, as with other social movements and collective action, "questions about daily life, democracy, the state, and the redefinition of political practice" (Escobar 1992:408) were recognized and people discovered their interrelations. This chapter covers three time periods: (1) the beginnings of the South African disability rights movement with SHAP,

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[24] The uprising began on 16 June and is now remembered as Youth Day. Evolved from Dutch and now one of the eleven official languages, Afrikaans was the language of the government during apartheid and used as an instrument of Afrikaner nationalism.

(2) the height of the movement, when participants describe it as at its strongest, through the transformation to democracy in South Africa, and (3) the current state of the movement.

LIVING CHANGE, CHANGING MEANING: 1980s SOWETO

SHAP was conceptualized by Friday Mavuso who gathered other disabled people in Soweto to start an income-generating project.[25] Friday was a cult figure in the township (OSDP/Howell) and possessed the street smarts and charisma necessary to ensure the success of such an endeavor. The preliminary planning meetings included a social worker with a sense of politics, but otherwise the participants were people mainly from the township contacted from a list of paraplegics. They were conscious about professional privilege, the efforts of well-meaning social workers, and others practicing prescribed methods developed from a medical and charity ethos that had little application in a place such as Soweto. Rehabilitation at the time had people lying in hospital beds for sometimes years after injury. They knew they were not going to get jobs because of their disability. Economic empowerment, therefore, became the critical component of SHAP's ideology. Income generation was the primary goal and was not viewed as a rights activity. SHAP was indeed working for the interests of economic and social transformation.

Collective action is nourished through the daily production of alternative frameworks of meaning, according to Melucci (1988:248), "because conflict takes place

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[25] Friday Mandla Mavuso (1949-1995) was known in Soweto as a soccer player, a goalkeeper. He was shot by an off-duty police officer trying to settle a dispute, rendering Mavuso paraplegic. After six years at Baragwanath Hospital and some failed business attempts selling ice cream and fruit, he gathered people to form SHAP. I will refer to him as Friday because he is still referred to by first name and I cannot see myself calling him anything but "Friday." A majority of participants had stories to relate about Friday touching their lives in positive ways and imparting that their disability should not deter them from participating meaningfully in life.

principally on symbolic grounds, by challenging and upsetting the dominant codes upon which social relationships are founded in high density informational systems" (cited in Escobar 1992:408). Escobar elaborates (Melucci 1988:248) that "the mere existence of a symbolic challenge is in itself a method of unmasking the dominant codes, a different way of perceiving and naming the world" (1992:408). The perspective of SHAP members at the time was that there is more pride of ownership with self-help, being more of a cooperative than managed by a social worker or other able-bodied person in the interest of charity or profit. Sheltered workshops and protected workshops were generally government funded. SHAP never took government money and promoted that as a selling point. They were, as one participant says, "against the sheltered workshop because the sheltered workshop didn't develop us." SHAPs plan was to build a factory where people do not sit forever (and the less able-bodied involvement the better.) The idea was to train people for six months and then place them in the open labor market. They would tell people, "Be on your own, be independent. We will assist you, some funding."

The "symbolic challenges" SHAP members found themselves in during the organization's early days expanded the definition, impact, and effect of self-help. They had practical needs, such as procuring and repairing wheelchairs, and solutions for living with a disability. At this stage, "It was never like we are going to the street, fight these things, no, no, no." It was needs-based. However, as put by one SHAP member,

> Before we formed DPSA, we wanted to show government that we needed – because we were not manufacturing things there. We were contracted, by companies. And in our own place, operating and fixing things and then send them back – to prove – given space, we can manage to do things on our own. That is why – ideology around SHAP.

They were beginning to live a collectively defined reality based on self-help that, because it manipulated "symbols" of production and ability, began to transform their realities.

SHAP continued to challenge the structures that previously objectified or denied the disabled proper service or representation and soon attracted disabled people from all over the country. SHAP provided a useable model in the townships, where resources were meager and tensions were high because of apartheid's policies of having such areas "develop" on their own. New relationships were formed to accommodate the influx of people SHAP attracted. People coming from "homelands" and other areas would arrive at the local police station in Soweto, looking for the man they saw on television. The police then transported the newcomers to SHAP. A relationship with the Salvation Army was fostered because the organization had an old-age home to accommodate people who had come to SHAP but for whom was able to pay.

Others arriving at SHAP's doorstep were disabled youth, many of whom were disabled during their high school years. People with disabilities have different experiences with the education system, but there is a general trend of ignorance on the part of schools about the ability and performance of people with disabilities. Rather than having young people work at SHAP or go home to rural schools, SHAP would send them to school, provide for them, and feed them. Two SHAP members were disabled during high school and desperately wanted to finish. They attended adult education classes from six o'clock to nine o'clock in the evening using Cripple Care transport. When school was over sometimes the transport was late or did not come at all, forcing them to go to people's homes nearby for safety and shelter. These people ended up forming a student group at SHAP. The limited number of special schools in the township was one issue, but this group did not want to attend special school. They wanted to be integrated, to compete equally. They wanted to make the schools accessible.

> I was doing the running around you know, to place students, the same students from that group you know. We were doing peer counselling. Saturdays we would go to [various areas] in the community, saw the people, counselled them and said "Do you want to go back to school?" He says yes, give us the school name, give us the principal, we go there, we ask for a meeting, and this person is coming there. So we started demanding it. That's how we started there. So we placed *a number* of students.

The school's faculty, staff, and students would have been agreeable to lift the disabled students in and out of the school building and classrooms and that happened, but SHAP also built ramps in some of the schools. The schools acted out of sympathy, rather than seeing accessible schools as a rights issue. Nevertheless, they pushed for their inclusion and right to education.

Another need fulfilled by SHAP was taking people to Baragwanath Hospital.[26] Every Monday when SHAP employees and members requested, they were driven by the service coordinator, also disabled, to the hospital. During these outings, the service coordinator would teach them that they can ask the doctors questions about their disability. The assistive devices available to blacks at the time were basic. Many artificial limbs were fragile, yet heavy and bulky. SHAP took people to the orthopedic workshop at Baragwanath on Thursdays, but also learned on their own how to repair wheelchairs. In these ways, they were gaining a voice in their own care and learning practical survival skills.

As SHAP began to grow, it influenced many organizations and became well known. People would visit SHAP, wanting to know how it worked. With help from

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[26] Renamed Chris Hani Baragwanath Hospital in 1997, with 2,964 beds it is the largest acute hospital in the world. It is the only public hospital serving approximately 3.5 million people in Soweto and provides half of all the hospital services in southern Gauteng.

SHAP, similar self-help organizations formed, the strongest existing around Soweto. This is important because of the nature of popular control in Soweto and the immediacy of living in conflict. Such organizations are Zicabangeleni Self-Help Association of Paraplegics which was founded in 1987 and was known as ZISHAP.[27] Others include the Tembisa Self-Help Association of the Disabled, the Alexandra Disability Movement, SHADAX or the Self Help Association of the Disabled of Alexandra, and Itsoseng Peoples Organization from Krugersdorp. Members of these and similar groups were taught two key principles through workshops sponsored and conducted mainly through people from SHAP: how to speak politically, and the functioning of organizational structures. They learned they were organizations *of* disabled people conducting their own affairs and all the new organizations wanted income-generating projects with factories.

Growth in the movement, which began to establish wider momentum around disability issues, was the founding of Disabled People South Africa (DPSA) at the Fourth Congress of People with Disabilities in 1984. Occupational therapists had been holding congresses for rehabilitation professionals, individuals, and organizations for the disabled to meet and discuss quality-of-life issues. It was at the 1984 congress that people from SHAP, TABBA, and other disability organizations met with occupational therapists and other medical professionals. This was quite a collection of experiences and perspectives in one place. First, there were people with multiple disability types. Second, there were black people and white people with disabilities. Third, there were professionals and able-bodied people. This made for a matrix of representations. For many Africans it was also

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[27] ZISHAP is still in existence with the official name of Zicabangeleni Self-Help Association of People with Disabilities. Still known as ZISHAP, it went through various names such as Zicabangeleni Self-Help Association of Paraplegics, then Zicabangeleni Self-Help Association of the Physically Disabled, and to its present name.

the first time they ventured out of "their areas." "Quality-of-life" issues were put to the side, however, when it was announced that DPSA would be an umbrella organization for the self-help organizations with the objective of restoring dignity and empowering the disabled through income-generating projects like SHAP. DPSA was housed at SHAP, "in that *zozo* structure."[28] They encouraged people to break away from organizations such as Cripple Care and fostered the idea of independence from the state through helping oneself.

As it expanded, SHAP leadership needed to figure out how to handle additional sources of unequal, able-bodied dominated, and apartheid structures. They were conscious of white privilege and professional dominance, and this awareness shaped how SHAP organized. DPSA knew they would need representation, but a representation that could work within larger frameworks dominated by apartheid. This meant having the input of some white members. White disabled participants invited to DPSA leadership understood that SHAP leaders had more experience and were the engine for the movement, but also that their 'race' would provide something the black leaders could not at the time. The white members of DPSA lent a public face and maneuvered white dominated sectors, but felt comradeship based on a shared knowledge or experience of repression as disabled, exploring these feelings more explicitly, together.

But at the same time there were influences from Zimbabwe and internationally that touched DPSA. These developments helped to refine DPSA to operate on a larger scale. One such development was the outcome of the 14th Congress of Rehabilitation International (RI) in Winnipeg, Canada. In 1980, this congress was attended by medical professionals and activists. Dissension began to be felt in the mid-1970s among the

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[28] A zozo is a prefabricated building for accommodation or storage.

Swedes, the Dutch, the Danes, and some British who felt that RI needed to be governed by a larger proportion of people with disabilities, and these opinions and debates continued into the 1980 conference (Groce 2002:68). These groups were supported at the congress by Canadian, Irish, and American organizations of people with disabilities (Groce 2002:68). "There was loud debate, backroom negotiations, an on-site newsletter that was printed nightly by the activists and hushed discussions in the halls" (Groce 2002:68). Some of the professionals believed that they knew what was best for disabled people and argued that their detached perspective was valuable to the betterment of the disabled (Groce 2002:68). Others were deeply troubled that they could not see the obvious problems or inequalities of the system they perpetuated (Groce 2002:68-69). Still others were worried that their careers were in jeopardy (Groce 2002:68-69). The Swedish delegation at the congress proposed an amendment to RI's constitution, calling for an immediate majority (at least 51 percent) of the voting delegates to be people with disabilities (Groce 2002:69). With some opposition, RI leadership agreed, but insisted that the shift should be gradual as each representative's term ended (Groce 2002:69). A secret ballot voted down the amendment (Groce 2002:69). This resulted in further dissension and the birth of Disabled People's International (DPI), an organization that would be run by people with disabilities. People who would be associated with SHAP and DPSA attended the RI conference and returned to southern Africa inspired.

Further, the birth of DPI at the RI conference had a Zimbabwe connection when Joshua Malinga became DPI's Chairman (Groce 2002:69). The disabled in Zimbabwe had started mobilizing before South Africa but had not achieved the mass movement that those in South Africa would have. The disabled in Zimbabwe and South Africa teamed together to raise consciousness and politicize disabled Africans throughout southern Africa. The movements were effective in countries with a military-armed struggle (South Africa, Zimbabwe, Zambia, Namibia, Mozambique). Many participants in the movement agree that Zimbabwe added a new dimension by further politicizing the movement, yet recognize that SHAP played an important part. DPSA's well-known slogan, "nothing about us without us," coined by SHAP's founder Friday Mavuso, is echoed by disability rights organizations internationally. Participants recall Friday saying, "If you want to talk about disability, you must involve us." Professionals did not ask what people with disabilities needed or how they could be assisted. One young participant says "They'd just say for instance if you are disabled, even at homes you know, families speak to them, they will buy you a sewing machine, as if he cannot speak for himself."

DPSA was in full operation, and the group adopted methods of operation resembling other resistance movements of the time. The congresses of people with disabilities became more lively and provided an opportunity to protest rather than debate the pros and cons of specific catheters. At one such congress in Durban, there was a protest against how government was handling disability grants. On a Friday during rush hour they took to the streets and the riot police forced them to disperse (Rowland 2001:electronic document). Memories of DPSA's regular meetings describe how disability became translated, understood as political:

> It was like, it was a time of real brotherhood-sisterhood, uh, of comradeship and we of course addressed each other as "comrade." The chairman would be "comrade Chair" or "com Chair" and we spoke in, in, in a certain style of speaking we would speak with "comrade." Not all the time, but a good deal of the time. A lot of people confused that with supporting communism. The use of "comrade" in Zimbabwe struggle in South Africa was a struggle, a struggle title of respect of being together.

Indeed, identification with the struggle would elevate DPSA as the mouthpiece of the movement, really putting disability on the agenda of the coming government.

TRANSFORMATION: THE MOVEMENT AT ITS STRONGEST

Participants in Change: DPSA Steps Up

One participant estimates that at its strongest DPSA had 10,000 to 12,000 members. DPSA had established itself as the mouthpiece of the disability rights movement and in the early 1990s was able to cast large advocacy campaigns. The early 1990s are characterized by violence and unrest on the doorstep to democracy, and thick webs of politics had to be traversed. In 1991 various apartheid legislation was repealed, namely the Native Lands Act, Separate Amenities Act, Group Areas Act, and Population Registration Act. The Further Abolition of Racially-Based Measures Act removed racial distinction in other laws. The National Peace Accord was signed by the ANC, the government, the Inkatha Freedom Party (IFP), trade unions, and others in the same year. By December, the Convention for a Democratic South Africa (CODESA), the negotiating body to draw up a new constitution, met.[29] In 1992 the Record of Understanding between the ANC and government broke a deadlock in negotiations, including the release of more political prisoners.

A series of strategic involvement of DPSA on the behalf of all disabled South Africans in this transformation ultimately won their rights. The years leading to free elections in April 1994 were critical. Two developments in 1991 essentially began this journey. The Disability Rights Unit of Lawyers for Human Rights and DPSA worked

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[29] CODESA first met in December 1991, but with deadlocks on the number of votes needed to adopt the new constitution, the NP wanting three-quarters of the vote and the ANC going no higher than 70 percent. A second CODESA met in May 1992 in an effort to resolve this issue, but ended in disarray. A similar negotiating body in 1993 was named the Multi-Party Negotiating Forum, not CODESA 3 as it was perceived as a failure. See Saunders and Southey (2001:51-52) and Friedman (1993).

together on a charter of demands for disabled South Africans. They consulted disabled people's organizations (DPOs), collecting input. The Disability Rights Charter of South Africa was finalized and adopted by DPSA in December 1992. At the same time, people with disabilities participated in CODESA.

DPSA had maintained itself as a non-aligned organization, but with the release of Nelson Mandela from Robben Island and the legalization of the ANC and other previously banned political parties in 1990, preliminary talks between the ANC and the NP began, and DPSA reevaluated its stance on non-alignment. Although there had been a few early SHAP members who were members of political organizations such as the Azanian People's Organization (AZAPO), Friday and the majority of people at SHAP were not affiliated with any organization or political party.[30] As DPSA grew from SHAP and the township and wider into South Africa, however, affiliation may have proved dangerous for staff in other areas.[31] By the early 1990s, though, the ANC was recognized as the government in waiting and DPSA leaders were also members of the ANC.

In a more general sense there is a symbolic or ideological bond between DPSA and the ANC.[32] It is at this time that DPSA identified itself with the larger struggle and actively pursued engagement with the ANC. On March 24, 1993 the ANC and several of its departments met with DPSA in Johannesburg to discuss issues affecting disabled people (Mayibuye 1993:22). At this meeting the Disability Rights Charter of South

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[30] AZAPO is the mass organization of the Black Consciousness Movement.
[31] The political clash of the ANC, the National Party government, and the Inkatha Freedom Party in Natal is one such example.
[32] See OSDP/Howell.

Africa was adopted by the ANC (Mayibuye 1993:22). Also at this time, the ANC was developing its Bill of Rights andm in a preliminary revised version, Article 9 states:

> (1) There shall be no discrimination against disabled persons.
> (2) Legislation shall provide for **measures to promote** the progressive opening up of employment opportunities for disabled men and women, the removal of obstacles to the enjoyment by them of public amenities and their integration into all areas of life. [African National Congress 1993:10]

There is a note to this article: "This addition is in line with recommendations by the Disabled People of South Africa, which is actively promoting discussion amongst disabled people on their future constitutional rights, and which points out that there are nine million disabled people in our country" (African National Congress 1993:10).

To reach all constituencies, DPSA held a summit in Johannesburg in 1994 for all political organizations to ensure people with disabilities were in their political agendas (OSDP/Howell). Because of poor response, especially by the ANC, DPSA approached the ANC again to encourage a stronger engagement with disabled people. It was around this time that people with disabilities were thinking of forming their own political party, the Disability Front, after the disappointing outcome of the summit (OSDP/Howell). The Disability Front did not emerge because people with disabilities already belonged to various political parties and many DPSA members, who were voting for the first time in their lives, wanted to vote for the parties leading the liberation movement (OSDP/Howell). In addition, the ANC, as a result of DPSA's persistence, proposed to include at least two people with disabilities on its election list for the National Assembly and deployment to parliament.

With the triumphant election of the ANC and in the process of demolishing apartheid structures, disabled people became more active participants in the newly inaugurated legitimate democratic government. People with disabilities are specifically included in Chapter Two of the Bill of Rights to the 1996 Constitution of South Africa, which is among the most liberal constitutions in the world. Another landmark in the rights of disabled people was their inclusion in the new government's Reconstruction and Development Program (RDP). A Gender Desk and Youth Desk were established within this program, and a Disability Desk followed in 1995. When the RDP dissolved in 1996, the Gender and Youth Desks remained as government programs, as did the Disability Desk, in the Office of the Deputy Presidency. A Green Paper was drafted in 1995 on the rights of the disabled as a guideline for disability's inclusion into all government departments, and the need for a permanent office to implement and monitor these guidelines became the duty of the Disability Office.[33] In November 1997 the Green Paper was published as a White Paper on an Integrated National Disability Strategy (INDS). The INDS is the culmination of an "extensive, consultative and participatory policy formulation process" (South African Human Rights Commission 2002:20). It is premised on the 1996 Constitution of South Africa and largely informed by the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities, which were adopted by the UN General Assembly in 1993. The Disability Desk was officially established as the Office on the Status of Disabled Persons (OSDP) on May 1, 1997 in the Deputy President's Office, and in 1999 in the Office of the Presidency after the second democratic elections. South Africa also has a large number of disabled Members of Parliament in comparison to other countries.

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[33] A Green Paper is a consultative document that offers opinions and poses questions to stimulate public response and inform policy. It is not a government policy. After the Green Paper process, it can become policy as a White Paper.

These landmarks essentially transformed South Africa's individual model of disability into a social model, integrating disability into government departments through the INDS, the new Constitution squarely placing the disabled as citizens with equal rights and better inclusion into new legislation where they had been previously neglected, and a government office in the Office of the Presidency to monitor these new objectives. Internationally, with the process towards the establishment of democracy in place, DPSA became recognized as the national assembly of disabled South Africans and granted full membership status in DPI (OSDP/Howell).[34] This is important because DPI has Special Consultative Status with the Economic and Social Council of the United Nations and is well established in the international disability movement.

Is DPSA the movement?

While all participants agree that DPSA has been instrumental in putting people with disabilities on the national agenda and the movement was at its strongest prior to elections, for the most part, inevitably, the specific character of mobilization includes some and excludes others (Fox and Starn 1997:11). DPSA needed to exclude some social workers and other "charity" workers based on professional paternalism; but they also excluded other people with disabilities or kept them at arms length. Burdick explains that current writings on social movements tend to assume that they are trying to mobilize whole constituencies such as "women," "middle peasants," "cannery workers," and so on (1995:366). The use of such language veils the fact that, in almost all cases, the majority of people who belong to a movement's potential constituency remains

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[34] This is interesting because the European Economic Community announced its lifting of sanctions in January 1993 and the UN lifted its sanctions, except for its arms and oil embargoes, in October 1993. DPI was granted Special Consultative Status with the Economic and Social Council of the United Nations in 1981.

unmobilized (Burdick 1995:367). While it is difficult not to equate DPSA with the disability rights movement, there is a vital difference. DPSA is an organization and as either part of DPSA in name or participation, or, as separate and unaffiliated with DPSA, many new organizations emerged in South Africa during the 1980s and 1990s, filling in gaps left by DPSA. The actions of other DPOs are critical to understanding and differentiating "the movement" and DPSA.

Large organizations based on disability type were generally for whites, as explained in Chapter Two, but they also had to grapple with transformation. In 1981, the South African National Council for the Blind (SANCB) decided to write race out of their constitution, which was illegal at the time. By 1994 they decided to have their own transformation evaluation to address remnants of racism in their organization. They now have a national executive committee that is majority black, majority blind. This is not surprising, because there were leaders in DPSA who were also affiliated with SANCB. Still, other organizations acted within an apartheid framework, creating a segregated section for blacks. For example, the South African National Epilepsy League opened their first workshop for colored people in 1983 and two for black people.[35] There was, however, resistance to apartheid in smaller ways and changes in the perception of people with disabilities as less able to govern organizations. The South African National Council for the Deaf began to include more deaf members on its executive committee in 1987 (Jones 1994:689) and indicates a different kind of change. Before this time deaf people were appointed only to subordinate committees (Jones 1994:698). Until the 1990s

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[35] The South African National Epilepsy League was totally reorganized in 1982, after the death of its national director in 1981. The organization changed from a national organization with decentralized branches to one with a centralized national organization, but restructured again in 1987 with regional branches. A second workshop for colored people was started in 1985, but closed in the late 1980s due to financial difficulty. They changed their name to Epilepsy South Africa in 2002.

the organization was controlled by hearing white people until the shift towards deaf control. The situation of the deaf, however, remained the same: black deaf South Africans were to sign in school while white deaf South Africans could not. By the 1990s, though, the South African National Council for the Deaf changed its name to the Deaf Federation of South Africa (DEAFSA) and made a shift to actively promoting sign language. Although a majority of the schools still held onto a tradition of oralism, St. Vincent's in Johannesburg chose to defy apartheid policy by hiding black pupils in hostel toilets when education authorities visited the school (Steinberg 1998:61). Through these examples and in interviews people felt some kinship with the disability rights movement, yet were not committed to that change or were kept at arms length by DPSA. This may be because DPSA was perceived essentially as an ANC structure and there were those not ready or willing to change.

Of course, there are factions in any movement. Those who did not change were essentially tangents to DPSA. DPSA did represent some of the interests of other disability types, but one critique echoed by many organizations is that DPSA remained both for the black person and for those with mobility impairments. Many organizations felt and still feel left out of DPSA purposefully and that their participation in the movement is overlooked. Participants told me many examples of the tensions between their organization and DPSA. Three examples are People for Awareness on Disability Issues (PADI), Autism South Africa, and the Disabled Children's Action Group (DICAG). PADI started in 1987 with educational and life skills programs for children. Founded and run by a woman with cerebral palsy, she had prior involvement with DPSA, but her proposal for PADI was rejected by DPSA. PADI is still in existence and focuses on employment equity training in the corporate sector and life skills training in rural areas. Autism South Africa was founded in 1989 by parents and professionals as a lobby organization and has had difficulty with DPSA in getting autism-related issues on their agenda. DICAG was set up in 1993 to promote the rights of black disabled children and was part of DPSA, but branched off in 1997 due to DPSA's mismanagement.

CURRENT ASSESSMENTS: LOSS OF MOMENTUM

The consensus is that currently the movement has lost momentum. Although the movement achieved many of its goals, participants believe that these goals have not been maintained. Participants had a variety of reasons for this loss in momentum: a leadership style that was insufficiently active, or a weak leadership, or the organization lost its main activists to government positions without proper replacement, or many leaders died. Some even said the movement has lost its spirit or that current problems are based on apartheid hangovers on a personal level, or that individuals are caught up in "empire building." The most frequent assessment of the movement is that it is fragmented, and that organizations do not communicate with each other to establish a common agenda. As for what the movements needs, participants identified the following: leadership in order to institutionalize concepts, work together to common goals, refocusing and advocacy, input to the development puzzle, pursue political advancement and self-representation. Some understand that although there are fragments based on disability type and tensions with organizations and DPSA, the best way forward may be for DPOs to focus on what they do best.

Participants also shared various memories and current experiences about DPSA. They generally believe that DPSA was good for the specific moment when it was part of the wider liberation struggle. But as for their opinions on DPSA now, they unanimously say it is not a cross-disability organization. Although another umbrella organization, the South African Federal Council, was established to include all DPOs to act as a liaison to government, some believed that OSDP only recognizes DPSA. Whether this is the case or not, that is a belief. In addition, organization leaders feel DPSA does not work for them. Some participants were called negative or were edged out of discussion for bringing certain debates to the table.

There are organizations, old and new, that are not formal members as such, yet work closely with DPSA (such as Epilepsy South Africa and Deafblind South Africa). There are those that receive no communication (Quadriplegic Association of South Africa), or have no formal affiliation (for example, DEAFSA, the Miss Confidence pageant, and PADI). DPSA enjoys a reputation of having mobilized people during the 1980s and early 1990s, but people are not able to explain what DPSA does now. DPSA worked politically while other DPOs struggled to see how they would fit in after change. Other organizations that speak of the movement wanted change, but were not motivators for change. The movement was led by DPSA. This is not to say that after 1994 DPOs did not become active in pursuing goals within the new framework. They were ignited and became better at pinpointing the departments responsible for their respective issues. Many people have left DPSA and other DPOs because of disability politics. Their reasons for leaving include DPSA not providing a secured contract for their employment, that their chosen organization no long provides a real service, or the new leadership does not account for their input. Participants also explained their devotion has contributed enough and they now must spend time with their families and develop other interests.

For all of these reasons, OSDP called a *legotla* (gathering) in 2001 to refocus the movement. Position papers on transport, education, economic empowerment, social security, and access to justice were prepared (OSDP/Howell). OSDP has the tremendous job of trying to put itself out of business by implementing disability into all government departments. It is an ambitious model and will take time. A recent assessment of whether government departments are integrating disability is bleak. Eighty-three percent of government departments do not have disability policies and those that were found to integrate or include the disabled were not translatable to strategies or programs that seek to integrate the disabled into society (Research Dynamics South Africa and Office on the Status of Disabled Persons 2000:vi). This lack of integration is an identified problem in the disability sector and movement.

Self-Help?

In the early 1980s and up to the rise of DPSA, self-help associations were a development activity to emancipate the disabled in the townships. They relied on donor support and procuring work contracts for sustainability. "It's a wrong philosophy now. It was okay in the apartheid days, but it doesn't work now. Consciousness-raising is not an issue for them. Those who were encouraged by Friday, that was a long time ago." SHAP now resembles the very structure it was against: sheltered work. There were various changes in leadership, but generally contracts to assemble or make various products came from a white company that employed SHAP. Many people with SHAP's best interest in mind have proposed changes without success. Some have given them models to phase out the party who obtains contracts for SHAP because SHAP could do it on their own now. This has provided reason for people associated with SHAP to leave, and they have.

SHAP has a reputation for the workers owning a part of the factory, but in reality it is in the form of the workers promoting whom they want as a chairperson. For the past two years, they have been enjoying a chairperson they chose and trust, but he faces difficulties in implementing change with the board of directors. He, too, is disabled and realizes the problems.

> The problem, it's, what I've experienced you know, the eleven months I have, it's, you know people out there are exploiting people with disability. Because people with disability here has this mentality of you know uh thinking that we are doing them a favor, they don't deserve what they are working for. Like with me here there are so many guys that didn't want to form partnership with them because of what they wanted to give me you know. What they wanted to give me, they were going to exploit this organization you know. They were going to make money out of this organization. At the end of the day they are the ones who are benefiting and the organization does not get a thing. So why should I go and sign a contract like that? You know.

SHAP currently has 400 people on its waiting list for training.

DISCUSSION:
PRACTICE BETWEEN CONDITION AND ACTION

New social movement theory (NSM) and resource mobilization theory (RM) seek to explain the emergence and significance of contemporary social movements in post-industrial societies (Canel 1997:189). Both NSM theorists and RM theorists reject traditional theories that explained collective action with reference to structural dislocations, economic crisis, and exploitation (Canel 1997:190). These traditional theories assumed that collective action in reversing such a condition was a simple, direct, and unmediated process (Canel 1997:190). NSM theorists and RM theorists agree that the process of condition to action is discursive and mediated, but each theory identifies different conditions in this process. According to NSM theory, new actors are not class actors because they are not fighting traditional working-class struggles and their identity is not constituted by their place in production (Canel 1997:190). NSM theory critiques Marxism's inability to understand new conflicts in modern society (Canel 1997:190). Marxism would postulate that economic logic provides unity for social transformation (Canel 1997:189-190). While NSM theory developed in Europe, RM theory developed in North America in response to Durkheim's view that collective action is "anomic and irrational behavior resulting from rapid social change" (Canel 1997:189). RM theorists also question collective behavior theory for its functional basis emphasizing integration (Canel 1997:191). "RM theory proposed that the passage from condition to action was contingent upon the availability of resources and changes in the opportunities for collective action (Tilly 1978:99)" (Canel 1997:191).

NSM theorists emphasize discontinuity when comparing new movements with traditional struggles and collective actors (Canel 1997:198). New actors emerge because of a growing intervention of steering mechanisms in the regulation of economic and social life (Canel 1997:202). A supposed lack of material concerns encourages pursuit of personal and collective identity (Zugman 2003:173). Identity, then, is constituted at the intersection of state and civil society (Canel 1997:202). NSM researchers focus on macro levels of analyses to understand identity, but this comes at the expense of understanding group decision-making and mobilization (Canel 1997:202). Conversely, RM theorists focus on the continuity or relationship between the movement and the political system (Canel 1997:213). Affluence, prosperity, and growth of the welfare state contribute to social movement activity in this perspective (Canel 1997:206). RM focuses on the political nature of new movements because they are conflicts over the allocation of goods in the political market (Canel 1997:190). Mobilization, according to RM, is "the process by which a group assembles resources (material and/or non-material) and places them under collective control for the explicit purpose of pursing the group's interests through collective action" (Canel 1997:207). RM, therefore, is more concerned with micro processes. In sum, the two theories can be characterized as follows: NSM theory addresses the "why" of social movement activity (struggle for meaning production, communicative action), where RM targets the "how" of social movements (strategies, decisions, resources, social networks). Social movements, however, possess aspects of both continuity and discontinuity. Canel suggests a more eclectic approach to the two paradigms. Such an integrated approach must account for the "structural constraints and the range of possibilities available to social movements, but it must also examine how the actors interact with their environment, manage resources, and devise strategies in order to pursue their goals" (Canel 1997:217).

In light of Canel's suggestion for a more eclectic, integrated approach, where the micro and macro, how and why of movements are addressed, I suggest that there is a connection between this model and semiotics, or making meaning in everyday life. Local practices can conceptualize the dynamics of domination and resistance (Escobar 1992:398; de Certeau 1984). Introducing some of de Certeau's terms is helpful here. Ordinary people develop tactics, or the art of the weak, while the dominant elite employ strategies. Strategies create their own space while tactics are the response of the powerless. Escobar (1992:398-399) highlights de Certeau's (1984) point that because strategies organize space and knowledge that colonize the physical, social, and cultural environments, those living within such environments are not passive receivers but 'users' of the conditions. Hence, "as 'users' of these conditions, people effect multiple and infinitesimal transformations of dominant forms, in order to adapt them to their own interests and partially subject them to their own rules" (Escobar 1992:399). These popular tactics effect 'anti-discipline' and 'art of making' that operates at the level of everyday life (Escobar 1992:399). These changes are important to the study of social movements because they provide clues to the reasons, methods, and intersections of daily life, resistance, and collective political activity.

Fiske (1990), influenced by de Certeau, proposes an ethnosemiotic approach to the study of popular culture (Escobar 1992:409-410) to gain insight into such domains. Although developed by social scientists devoted to understanding popular culture, semiotics can offer tools to explore the connectivity and creative uses between strategy and tactics, domination and resistance, and practice in everyday life. Fiske examines how people use the products of the culture industries (such as TV, music, videos, shopping center, and the like) in a process of appropriation, rather than concentrating on the dominant text itself (Escobar 1992:409-410; Tomaselli 1996:33-39). Tomaselli provides an example of Fiske's understanding. "Television programs as inactive texts, for example, are produced, distributed and broadcast by the television industry: while activated texts are created both by their producers and by their audience (Fiske 1987:14)" (Tomaselli 1996:33). The uses of such semiotics are cautioned with regard to Third World actors. Escobar (1992:409-410) warns of relating and reducing cultural production to the uses of dominant products or texts because of the state's inability to provide for the needs of the population. Socially significant groups, nonetheless, exist in the Third World and can represent alternative cultural possibilities (Escobar 1992:410).

Further, as said in Chapter One, semiotics offers conceptual tools, and is not a theory in itself. Anthropologists have been using some of the tools, such as metaphor and discourse. They acknowledge that discourse is the locus of power and knowledge and therefore must be viewed as discontinuous and fragmented, the uses of which are neither uniform nor stable (Foucault 1978). Semiotic tools enable understanding of the pushes and expanding of discourse in a different way by not separating the performative aspects from discourse, and recognizing that discourse includes the unsaid, silenced, and emotionally unavailable. These signs and codes are what "make sense" to the people involved through the construction of counter ideology. A disability identity, developed through participation in the movement, provided some of the vision needed to break from an embodied social suffering. They are pushing the limits of embodiment. Therefore, although embodiment is important in a social suffering approach, the epistemological underpinnings are on grounds that distract collective struggle. Nordstrom and Martin (1992:7) further illustrate this point:

> When resistance is confined to the level of cultural expression the task of specifying the nature and form of opposition is often left to the anthropologist – who, inspired with a critical spirit – discerns the hidden meaning behind the informant's statements and practices. In contrast, when informants begin to organize consciously, they specify their own understanding of structures of domination and employ tactics that respond to local circumstances. [. . .] organized social movements may find enemies and allies in persons and places that the anthropologist, embedded in a tradition of critical theory, would rarely anticipate.

Such an understanding of the possibilities or potential for identity formation through social movements is more accurate than a social suffering perspective to the experiences of participants in two additional ways. Discursive identity may be perceived as a matter of free choice in the postindustrial marketplace of identities and discourses according to NSM theory (Zugman 2003:172). It is important not to confuse or categorize collective action based on popular and democratic distinctions in such an example. "The popular subject is solely concerned with the politics of distribution, and the democratic subject with identity and meaning" (Zugman 2003:173). At the time of the rise and strength of the disability rights movement in South Africa, the country was in conflict and transition. Although the state could but would not provide for the black population, let alone black disabled people, the struggle was both one of distribution and humanity. This returns us to the argument of condition and action and the conceptual tools of semiotics in order to more accurately analyze the movement than assuming the disabled are simply just now finding a voice. The leaders of the South African disability rights movement knew they had to act aggressively at that time of change to elevate the status of disability from one of charity and welfare to social and human right. The second way semiotics and anthropology contributes to the understanding of social movements is that identity develops in the process of interaction with other social forces (Canel 1997:202). Identity is a signifying practice. Disability identity, like other identities such as race and gender, works for the pursuit of political goals, and it is based on an expanded definition of accessibility that includes the removal of physical, social, economic, political, and other barriers for meaningful participation in society. Many social movement theorists assume that a given social group develops an identity first and then engages in strategic action (Canel 1997:202). It is more accurate to say that social movements foster identity formation. Therefore, the following hows (micro view), and whys (macro view) of the South African disability rights movement is given with attention to meaning and strategy in the life of the movement.

Social movements do not exist only in their cultural dimension, but can assume organizational forms (Melucci 1985:813; Canel 1997:200). Offe (1985:830) and Melucci (1980, 1985) describe such organizations and their actions as de-emphasizing traditional structures that produce dichotomies of the leaders and the led, members and nonmembers, private and public (Canel 1997:201). As a social movement organization, SHAP's conceptualization was possible for the following reasons. People in the townships during the mid-1980s used civic organizations as a form of popular control and direct democracy, reclaiming authority with the loss of state control (Cherry 2000; Chabedi 2003:361). This is one contributor to the possibility of an organization such as SHAP. The ideas and concepts of black consciousness, rising in the mid-to-late 1970s and growing in the 1980s, became instrumental in freeing Africans from negative self-opinion. The 1976 Soweto uprising also disabled many people and the incidence of disability from violence and poverty were escalating. The government during this time was struggling to maintain apartheid, as described earlier in this chapter. Organizers of TABBA and other people with disabilities were also acutely aware why organizations in Johannesburg and Pretoria were not reaching them. Friday and the people he brought together in the early days of SHAP was the necessary social network that provided horizontal links for the promotion of group identity and solidarity (see Oberschall 1973; Canel 1997:207).

Where SHAP inspired others to start their own localized organizations, DPSA organized self-help organizations to break away from more traditional "corporeal bantustan" organizations. Although there is no single model for empowerment, in its broadest sense "empowerment is the expansion of freedom of choice and action"

(Narayan 2002:14). SHAP was founded on the self-help philosophy of economic empowerment. Income generation was and remains SHAP's primary goal. The concern was not centrally identity-based, but achieved some new meaning to disability by pursuing goals that were essentially practical. SHAP's interest was economic empowerment as personal independence and freedom. SHAP itself was not primarily concerned with challenging dominant structures and ideology, but DPSA would take up that task. Beginning as an umbrella organization for the increasing number of self-help organizations based on the SHAP model, DPSA would become the medium and message of the movement. SHAP, as a base, could "facilitate mobilization by providing precarious organizational bases from which more complex forms of organization can develop" (Canel 1997:207). The SHAP – DPSA relationship essentially provided a link between micro and macro levels of organization for collective action.

A democratic-participatory organizational form is only one possible arrangement for the emergence and articulation of a social movement, a point made by resource mobilization theorists (Canel 1997:211). The public and private roles in such an open organization encourage everyday practice of the movement's principles (Canel 1997:201), but a similar practice, the struggle against apartheid, promoted everyday practice for justice. To elevate disability, DPSA needed to be strategic on several issues. First, it had to have some members who could navigate the terrain under apartheid, hence having white members. But those people also needed to be disabled. Outside leaders can play a role in mobilizing groups with low organization, power and resources, but theorists disagree in how the role of leaders and masses initiate mobilization and sustain movement activity (Canel 1997:208). In its formative stages DPSA also met with occupational therapists and other medical professionals, provided a forum for black people with disabilities and white people with disabilities to exchange and communicate. With such open participation there is a loose definition of who belongs to the movement and diffuse roles encourage practice of the movements message by all (see Canel 1997:201).

DPSA's reevaluation of non-alignment with the legalizing of political parties in 1990 was a critical turning point for the movement. Pursuing engagement with the ANC indicates recognition of disability as a political identity and, most importantly, the value of the humanity of persons with disability in the democratizing of the state. This is a critical strategic component missed in new social movement theory: social movements are struggles for institutional reform as well as cultural phenomena (Canel 1997:204). Identification with the larger struggle against apartheid is a part of understanding disability identity formation and progress toward movement goals, but the strategic component in the South African movement was in participating in the events during the transition to democracy that ultimately won the disabled their rights.

Institutionalizing the movement's vision through the creation of OSDP was a fight won and, according to Melucci, social movements seek control of a field of autonomy vis-à-vis the political system (1985:815; 1980:220; Canel 1997:200). So with rights won, is DPSA still necessary? DPSA, as an umbrella organization, remains engaged in the imagination of other DPOs. The establishment of OSDP and its design is a tremendous goal achieved through the disability rights movement, but DPSA, as the social movement organization, itself an integral component of the message, is still perceived as a generative nexus for meaning if not direction. What is compelling is that when participants were asked about the movement, they eventually talked about DPSA. Conversations about the reported lapse in the movement evolved into a critical appraisal of DPSA in its current state. Perhaps DPOs are critical because DPSA was responsible for the articulation of movement goals. The distinction between social movement and social movement organizations is helpful here. Social movements indicate a preference for change while social movement organizations are organized action for change (McCarthy and Zald 1977:1217-1218; Canel 1997:211). As the social movement organization, DPSA is itself an integral component of the movement message. Actions of social movements are focused on cultural codes, as Melucci calls them, and the movement can be a message or symbolic challenge to dominant patterns (1985:801). As informal networks such as SHAP and the early efforts of DPSA were instrumental to the emergence of the movement, McCarthy and Zald (1977:1218) argue that in most cases formal or complex social movement organizations become the carriers of the social movement (Canel 1997:211). Many DPOs felt and feel tangential to DPSA. While DPSA considered them members, DPOs became uncertain of their status or only felt they were fulfilling a supporting role. RM theorists "warn that the goals, strategies and actions of social movement organizations are not always those of the social movement as a whole" (Canel 1997:212). South African DPOs certainly are feeling this disjuncture.

Central themes or dominant signs of the movement were created, changed, modified, or in other words can be changed during its course by individual participants and wider social change. The slogan "nothing about us without us," provides a good example. The influence of the wider struggle against apartheid and ideas of black consciousness influenced the application and meaning of this slogan. In terms of semiotics, it is a trope or figure of speech that helps distinguish the importance of disability in participants' lives and the uses of identity. The slogan effectively quashes the authority of able-bodied people attempting to affect the realities of the disabled without the input of the disabled. Therefore, disability in "nothing about us without us" elevates the status of disability to that of other authorities. Another example is the symbolic or ideological bond between DPSA and the ANC. This relationship strengthened the goals and purpose of the disability rights movement, highlighting that disabled people are part of the larger struggle. This is part of the collective identity of the South African disability rights movement. The collective identity of a social movement "implies the unity of a shared sense that it is a coherent actor with shared ends, means and fields of action, shared relationships, and shared emotional investments" (Gongaware 2003:486; see also Jasper 1997; Melucci 1995, 1996). Regardless of whether participants were part of DPSA at the time, disabled people began to feel a part of the fundamental human rights of all people, the struggle against apartheid. Practice of justice overlapped as DPSA also used practices common in the struggle against apartheid, such as marches and the way meetings were held. Another important postulate in social movement theory comes from NSM theorists and concerns meaning. They assert that the "creation of new meanings and the reinterpretation of norms and values take place at the level of social integration, not at the level of steering mechanisms (the state)" (Canel 1997:199). While the movement achieved many of its goals and elevated disability in the new South Africa as a social issue to be integrated into all sectors of government, the meaning and experience is not being felt on the ground.

But perhaps there are more reasons for a loss of love for DPSA and feelings of a loss of movement momentum. As illustrated in Chapter Two, apartheid affected the experience of disability: the white experience was one of health and welfare with support from organizations and the state. The black experience of disability was characterized by poverty, violence, and the system of apartheid. Corporeal bantustans, nonetheless, contributed to embodied social suffering. The movement's contributions in redefining a disability identity mediated, borrowed, and manipulated this now legitimate discourse of equality and non-discrimination in South Africa. But there are subtleties in narratives about "white" organizations and "black" organizations. Only one participant explicitly says that DPSA remains for the black disabled person, but that black disabled people need development too. The national office of DEAFSA is generally observed to be white while the provincial office is black, though both are located in Johannesburg. Organizations based on medical distinction have basically become a sort of interest group or issue-based group according to disability type. For example, many of the organizers of the Quadriplegic Association of South Africa wish it to remain for quadriplegics only, while recognizing a need to include paraplegics and widen their nets to share resources (such as information on wheelchairs and healthcare maintenance issues) and to advocate together (on road accident prevention or improvement on removing physical barriers). The critique by participants that DPSA is not cross-disability as they claim can often be made about their own organizations. The promotion of awareness and the improvement of the specific needs of a disability category or type, like deafness, epilepsy, quadriplegia, or other disabilities, are the mandates of the organizations to which the participants belonged. Their role, as representatives of their particular organizations, is to inform the umbrella organization, DPSA in the past, and more currently, the Federal Council. It must be noted, however, that the Federal Council has reduced much of its function as national representative of all disability interests. Participants feel without a map or resource to direct their concerns and propose relevant actions.

Another influence on perceived loss of movement momentum involves thoughts on the disability community. Although the theme of accessibility, discussed in the next chapter, is found in all narratives and provides a common thread, the "disability community" was conveyed as fragmented. Much of what has been said about 'hidden transcripts' (Scott 1990) and 'imagined communities' (Anderson 1990) has been instrumental in rethinking the shifting nature of identity for political use and the making of spaces for resistance. Much of this work, however, does not give proper attention to the multiple possible readings of signs and processes of signification that may further the analysis of what happens when 'offstage' discourses or hidden transcripts become public. "Community" divisions based on disability type are influenced both by compartmentalized organizations, schools, and medical specialties and ontological knowledge of one's own disability. For example, a variety of distinctions can be found under the label "deaf." There are the hearing, hearing impaired, hard of hearing, deaf, Deaf, and still more distinctions can be made. Most deaf parents have hearing children (often referred to as CODAs, or children of deaf adults) and the hearing children can be "culturally Deaf." CODAs can be multilingual, fluent in sign language and various spoken languages (such as isiZulu, isiXhosa, and English; or English and Afrikaans), and they often act as the liaison and interpreter for their parents in hearing-deaf interactions. Yet another component includes hearing people who aggressively and whole-heartedly want to help the deaf. Their narratives had a vicarious or mimetic quality, a compulsion to become the other. These people are usually recognized as "outside the Deaf community." Deafblindness is now just beginning to be brought into the disability politics arena in South Africa. But among deafblind people there are further divisions: those from a deaf background who become blind when they are older, as those with Usher's syndrome; those who are congenitally deafblind, from Rubella, for example; and then there are those from the blind community who became deafblind from injury and age. Those from hearing blind backgrounds often become representatives in communicating or teaching the wider public about deafblindness. Deafblind South Africa is a new organization started by white Deafblind people who attended special school together, but contact black Deafblind people to train as facilitators and future administrators.

Part One, in conclusion, has provided a history of disability and the disability rights movement in South Africa. The treatment and placement of people with disabilities during apartheid resulted in qualitatively different experiences of disability yet the disabled were able to organize given the availability of a democratic discourse and breakdown of the apartheid regime. Part Two explores the realities of participants through the lifecourse and everyday life (Chapter Four), the experience of becoming disabled and appropriation of meaning toward disability identity (Chapter Five), and the connectivity of disability identity to a changed South Africa (Chapter Six). The above presentation on language serves as an introduction to the ways the disabled are treated as objects and identifies one way the disabled have been able to articulate disability on their own terms. This is the outline for the following chapter.

PART II

CHAPTER FOUR

THE DISABLED SUBJECT: ACCESSIBILITY AND RIGHTS

This chapter contains two sections. In the first section, lifecourse, I present participants' responses to questions about the people on whom they relied with the onset of their disability and what decisions were made for them. These inquiries lead to many stories about parents, childhood, and household; their schooling; and relationships. Further questions were sometimes needed to clarify whether people with disabilities are treated similarly to their able-bodied peers when it comes to important life events. Through this reflexive storytelling many participants broke off on tangents, relating experiences that happened at a different time and place. These tangents or inserts describe when they were placed aside or belittled, and were often followed by techniques to handle the encounter. Participants also recall events when they were not able to act because they were too young or did not understand their unfair treatment was related to their disability. The second section, everyday encounters, describes how people with disabilities are treated as objects and navigate the public arena as adults. It is a collection of portions from narratives that address common problems which at the very least irritating and unnecessary encounters with the able-bodied. A closer reading indicates able-bodied assumptions of human difference. Both sections identify the ways people with disabilities are consistently, implicitly and explicitly, denied full and meaningful participation in society. A definition of accessibility that is specific to South Africans with disabilities will be composed from the two sections and presented in the discussion.

Disability often questions personhood, and the issues of personhood are both implicit and explicit in the collected narratives. This unstable ground was evident in narratives and participant-observation, and attention to the subject-object relationship helps determine how disability figures in participants' lives. The ways participants in this study are created as "disabled" are paired with how they handle, make meaning of, or signify their placement. As Das elucidates, contributions to the theory of the subject argue that the experience of becoming a subject is linked in important ways to the experience of subjugation (1997:205; she references Butler 1997, Mohanty 1993). Disability, as subject, as a social construction, can become challenged or modified in everyday interaction with the able-bodied. The move from studying individuals with one disability type to individuals oppressed and repressed by virtue of the social category of disability becomes essential and more critical of able-bodied culture. It allows disability to become Subject rather than objectified Other (see Peters 2000:598-599) and locates disability as a potential site for identity creation. What type of disability a participant has in the following passages does not necessarily matter. Though there are language differences and certain stigmas that each disability type carries, they remain under the heading or topic "disabled." While participants conveyed that many of the life events vital to able-bodied personhood are generally said to include the disabled, these events are discussed more in terms of their achieved experience and desired goals for all disabled people. This is particularly evident in their interpretation of accessibility as acceptance, inclusion, and fulfillment of rights.

LIFECOURSE

Childhood, Parents, and Household

Parents played critical roles in deciding the futures of participants who were born or disabled during their childhood years. Preparing disabled children to become active adult citizens offers a window into decisions such as schooling and basic responsibilities, and many participants described and analyzed their parent's actions. Thabo, who is blind, said "My mother played 99 percent of what you see me being today." She taught him, for example, how to dress properly and use good sitting and walking posture. Tumi, a woman with cerebral palsy, speech impairment, and mobility disabilities, said that when she was a child, people thought her parents were nasty because her mother made her do chores, such as having her cook and iron. Tumi explained that these chores helped her to become independent and that her mother was very fair in assessing her capabilities. Mabel, who has cerebral palsy with mobility disabilities, was given the responsibility of budgeting for groceries and checking their delivery to the house. These mothers were doing what mothers do, teaching basic life skills to their children. They were also providing basic mobility skills as in Thabo's case.[36] Nevertheless, many people remember their parents being especially protective of them as children, because their parents considered them fragile. Nombuso was raised by a single mother who did not let him do things around the house, and he learned those skills at a residential school for the blind. Nkeli's father did not want her to play with other children, she says, because he was overprotective.

Mothers and other family members accommodated their disabled kin by making the home more accessible. The standard house in the township is a four-room structure. In the 1950s, the Council for Scientific and Industrial Research and the National Building

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[36] Mobility skills for the blind develop a blind person's ability to navigate with safety and speed through the environment. It is also commonly referred to as "orientation and mobility."

Research Institute devised a standard design for these low-cost, four-room houses. They dominate Soweto's landscape. Joseph grew up in the township in a four-room house shared with his brother, who slept on the couch in the sitting room, his grandmother, grandfather, mother, two sisters, and their children, yet his mother made the small space accessible. Stephen's parents made a separate room for him when he was paralyzed, but he was not secluded. Ben also lived in a four-room house, but noted that there was no ramp, a stoop in back, an outside toilet that did not fit his wheelchair, a gate that was difficult to reach, and a shop down the bumpy dirt road that took effort to reach.

Fathers of disabled children, though, may leave, believing the disabled child is not his because the disability does not run in his family, or a taboo was breeched. One mother of an autistic son says it takes fathers much longer to accept their child's mental disability, feeling that they have somehow failed. Indeed, the birth of a disabled child is often startling to the family. Parents and family members must cope with shattered expectations of a healthy baby, and raising him or her to be an active participant in society. Researchers have long speculated that children born with deformity were taken to the bush to die by their grandmothers, regarding the disability as a curse. Some of the older participants noted this scenario. However, another hypothesis is that children with disabilities were not given special treatment, letting them live as other children, but they died because special attention was needed.

Domestic workers are a common addition in South African households, for families that can afford such assistance. Domestic workers comprise 11 percent of those employed in the formal economy (Goldman 2003:74; Grant 1997; Momburg 2003) and they are usually black women. Two white disabled participants conveyed they have "black mothers." Goldman (2003:74) finds domestic workers are employed not only by the affluent middle class, but the white working class as well (Cock, Emdon and Klugman 1990). This was true not only during apartheid but continues today. Goldman (2003:72) describes the context:

> Arguably, while the political context in which nannydom occurs has changed significantly, overall, the post-apartheid domestic worker's lot has not changed much. It is probably fair to say that even in the post-apartheid era, the oppressive nature of domestic work continues to be hidden from public scrutiny and perhaps is more subtle.

Whether hired as a nanny or those duties are assumed as part of "domestics' work," many (now adult) white children describe a deep and meaningful connection to at least one domestic worker (Goldman 2003:165). Perhaps it is as simple as children inevitably having attachment to a caring adult, as Goldman states (2003:165-166). They have already suffered disappointment – "the loss of their first love object, to pregnancies, to employment, to the mothers decision to employ a childminder" (Goldman 2003:165-166).

A domestic worker employed in a household with a disabled child, however, brings an additional emotional component because of the intimacy involved. For example, disabled people may require lifting into a bath or assistance in dressing, handing over their bodies in these situations. Perhaps domestic workers should be called "caregivers," because able-bodied and disabled children fondly describe bathing, playing, and other meaningful activities. However, calling a domestic worker a "caregiver" may imply she has specialized skills, and cost and training then become sticky issues in hiring. Some disabled children may need more care than others. Nonetheless, domestic workers may be over burdened or purposefully overlooked as caregivers.

Mabel calls the domestic worker of her childhood her "black mother," and explains "she was more my mother than my mother," finding needed comfort in the domestic worker because her own mother "didn't know how to handle me." The life story of another white woman, Josie, with cerebral palsy, describes her 50-years-plus relationship with her black domestic worker-cum-attendant. Josie remembers when Precious needed permission to live in a white household, but because Josie did not have a permit for her, Josie would hide Precious from the police if she thought the police or authorities were coming for inspection. During this long relationship Precious had a daughter, Nokthula, and Josie refers to her as her black granddaughter. With no children of her own and with such a strong relationship with Precious, Josie takes her grandmother role very seriously.

Josie described one of the many events where, both as a disabled person and as a grandmother to her attendant's child, she protects her attendant. The following passage is about vacationing at Warmbaths, "a very Afrikaans area," with a water park:

> Its taken us *ages* to get where we are. I mean when I was bringing up Nokthula, my black granddaughter, we weren't allowed to go into places here. Because I mean some of the places we went into they said, "You can come in and look at the scenery, but you can't drink tea here." So I said you can go to hell. I don't want your tea. And then Nokthula, we went to Warmbaths and Nokthula was anxious to get into the water by one of the kiddies in the water – she was little! She was two. And she was dying to get into that water, okay, but her mommy was with me because she was helping me. Her mommy was my, my attendant. And then I got a message from the manager to say that this little black kid had the audacity to be in the water and she had white panties on. . . . So I said you can go to hell. And they wouldn't even allow Precious into the baths to put me into the water because she was black. So I said fine, I'm leaving out straight away, you can stick your park up your jersey.

Josie is also very aware about what Nokthula's friends think. Nokthula's friends acknowledge Josie as Nokthula's grandmother, but are generally cautious. These experiences have anthropological import into studying family; but they also provide insight into disabled peoples' lives. The disabled woman–caregiver relationship has been given attention in feminist literature within disability studies. Hillyer Davis explains that "For both the disabled woman and the caregiver, achieving these insights involves an intensive, integrated, emotional, intellectual, and physical process of self-centering that includes recognition of the reality of the problem and the experience of grief" (1984:3). The story of Josie and Precious is one where the relationship is more equitable, perhaps because of a shared responsibility for each other's well-being.

Disabled children learn early in the lifecourse that they are somehow different. Participants able to access or afford medical attention, the white participants, tell early childhood stories that involve hospital and rehabilitation experiences along with residential school experiences. The periods of surgeries and therapy are conveyed as memories of childhood tinted with hope of walking (with physical therapy or surgery) or speaking (with speech therapy), of being able to have a better life. Mabel's childhood is full of emotional bruises from medical experiences. Describing an incident in a residential school for students with cerebral palsy, she recalled in the following excerpt:

M: And then when I was in Standard 8, I needed some more surgery and it took a whole term. The only problem with most of it was the aftercare stuff. You know, I don't know now, but at that stage you were in for like six weeks, in a plaster for nine, you know. You know, long periods of time. Hectic stuff. And I can tell you some grand stories about thinking I was going to die because nobody informed me about anesthetics and stuff. My first operation I was nine years old and nobody sat with me and said, "This is what's going to happen."

ML: You mean that you're going to come out of it, you are just going to sleep for awhile?

M: Yes. They had put me on the trolley and they wheeled me away and I thought this is it, I'm going to die. And they say, "Count backwards from nine" and you start – I'm going, bye! . . . So, um, ja. I think from a, the medical point of view I was

> given the best. I really was. Um, the school specializing in cerebral palsy didn't know exactly what to do. But they were learning and I was one of their guinea pigs. And sure there were improvements, but each time I had surgery I had to start from the beginning. [They told me] sit there, need to stand, and then, you know, and it was a whole new, "I have a new body now." And my perception was I'm going to get up and walk. Because nobody geared me to the whole thing.

ML: Ohhh.

M: Until I was 15 somebody said to me don't expect to move or walk.

ML: Okay, okay. Was it a shock or did you kind of figure it out by then?

M: Well I had become streetwise by then.

Another woman with cerebral palsy, Josie, understands how medicine has contributed to her disability in a similar tone:

> I'm born cerebral palsied, but um I'm now in a wheelchair as a result of being mismanaged. Medically I've had loads of operations and most of them, in fact all of them except maybe one, I've had about 30 ops altogether. Most of them have gone wrong for me so I'm now in a wheelchair as a result of people cutting muscles that they shouldn't have cut and taking out things they shouldn't have taken out.

At such young ages both Mabel and Josie have extensive experience with medical professionals and defy subjugation by characterizing themselves as rebels throughout their lives.

J: But I mean I'm, I'm, I'm blessed, really because I come from a family, I'm adopted originally and um my father was amazing. He brought us all up single-handedly because my mom died when I was seven, so it was a long time ago and he was amazing because I have three brothers as well and he educated everybody and he put the houses together and there was a roof over everybody's head. But lucky for me that I was a rebel because I fought against being mommy-coddled otherwise I would never be where I am.

M: I'm not in this for the "Ach, shame" syndrome, you know. And when I do need an "Ach, shame" I'd rather go to somebody whose eventually going to say, "So what are you going to do about it?" I don't need to be cloned into a group to be identifiable. And that's what makes me the rebel.

Knowing the life history of these two participants, special schools and medical treatment are two contributors to their feelings of being outsiders and their struggle to demand equal treatment. A common expression used by South Africans is, "shame." Whether someone has died, stubbed a toe, lost a bet, or some other unfortunate occasion occurs, an often-heard response is "shame." It is also used as a comment on the state of a disabled person. An able-bodied person may see a disabled person and comment, "shame." This word is used to acknowledge an unfortunate state, and the disabled are coming to reject this application to their reality or state of being.

Narratives also showed that participants understanding of other disability types can be based on misrepresentations. The Deaf are, for example, "rude with sign language, can call you by what you are," and "do not associate with other disabilities." An example of the first comment refers to name signs, where a sign is created for a person based on her or his characteristics, and the person is then known by this name sign, rather than the given name fingerspelled. The name sign is the person's name, in sign. Other comments from people with other disability types included "A lot of blind people are very intellectual," and that "Epilepsy is scary because of seizures." In summary, as a few participants echoed, "each disability sees itself as better than the other."

To extend the argument for attention to meaning in anthropological research generally and collective action specifically, a semiotic examination of language produces yet another component of the disjuncture of the disabled and difference in disability experience stemming from apartheid. Although South Africa has eleven official languages and other languages are used within its borders, many of the participants discussed language, helping me understand how they use various terms. In isiZulu and all other Bantu languages nouns are classified into various categories or noun classes (Wilkes and Nkosi 1995). In isiZulu, classes one and two designate persons while classes seven and eight designate objects. Classes seven and eight also contain personal and impersonal deverbatives (Taljaard and Bosch 1988:19). The personal deverbatives are usually names of people who are known for their special qualities, some of which can no longer be considered deverbatives, but are used nonetheless (Taljaard and Bosch 1988:19). An example is *isisebenzi*, a worker. Classes nine and ten or the "animal classes" are described this way because "the animals are usually only those that traditionally were useful to man in one way or another" (Taljaard and Bosch 1988:20-21). Taljaard and Bosch explain that the people in the animal class are there "because of the status they have attained in life," but a variety of other objects are also in this class (1988:20-21). For example a girl is *intombi*; or *inkosi* (singular) or *amakhosi* (plural) is a chief (Taljaard and Bosch 1988:20-21).

Many of the words described to me for various disabilities fall into classes seven and eight, and designate material objects. The various disabilities were not in classes one or two, the classes that designate persons, except for *abakhubazekile*. People explained that people with disabilities are in the animal class or used the idiom that they are objects or somehow related to the level or status of animals. They do not favor these terms, explaining that the 'izi' or 'im' prefix means "some thing." It was explained that people with disabilities are in an object class, a lower class description. One said it was an ancient description to be called a word in an object class and that this started to change in the 1980s. Most said that these prefixes denote an object that is not human, an object, or a thing. A few said that the prefix describes an animal or object.

The word people had the most to say about and rejected is *isidalwa*. The variety of translations included "cripple," "disabled person," "disabled," "a creation," or "freak." The most common response was "cripple," followed by "disabled person" or "disabled," yet all agreed that *isidalwa* is used in an object class. *Isidalwa*, however, elicited responses surrounding the notion that people with disabilities are children of God. Able-bodied people may be looked on favorably in God's eyes for helping the disabled. One participant said that helping a disabled person is like a blessing, "You can even win the lotto." Such a blessing works with an individual but not for family members because they are obligated to take care of their disabled family member. It stimulates notions of sympathy, charity, and pity.[37] Another girder in this matrix is that an *isidalwa* is a creation. A person with a disability is a different creation or a special and separate person, or a different creation of God. One said, "It is something that was not supposed to be," and this was echoed in almost all the responses about the word *isidalwa* in finer ways. Stigma attached to the meanings of *segole* (singular) and *digole* (plural) in Sesotho are similar to that of *isidalwa*.

There is further classification by disability type in isiZulu. *Izixhwala*, for example is an object, "not human" meaning "physical disability." This includes people in wheelchairs, on crutches, people with polio, and amputees; but not epileptics. *Ihlanya*, "It's a mad case, a mad case. In Zulu it's bad, bad . . ." and it also means that the person is uncontrollable. *Isithulu* basically means a quiet thing, because a deaf person cannot

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[37] *Isidalwa* is insulting in isiZulu and isiXhosa, but not in Ndebele where it is perceived as a more human word and carries a different connotation.

speak. The belief is that deaf people are dumb or a reject, that because one cannot hear they cannot learn, and are sub-human. *Isinqekle* was described as someone with a mobility related disability. Taljaard and Bosch explain that this word means "a cripple" and that *nqekle* is an ideophone meaning cracking or breaking (1988:19-20). They also list *isishosha* as a cripple, *shosha* being an ideophone for dragging oneself along on the ground (Taljaard and Bosch 1988:19-20). Both words are classified in the material objects or noun classes seven and eight.

Impuputhe in isiZulu and *imfama* in isiXhosa are words for blind, blindness, or blind person. It also means "feeling around" or "a fumbler." The belief is that people who are blind touch everything and feel their physical surroundings. People who fumble are not bright, because if you are bright there is no reason to be fumbling, as it was explained. This was also described as being in an object class yet blind people using this word explain that "if the person is blind." Like isiZulu and isiXhosa, people described various disabilities in object classes. *Sefofu* (singular) and *difofu* (plural) in Sesotho have a similar meaning to *imfama* in isiXhosa: "As you walk you are feeling around. I do not like the term because it is not true. It doesn't mean that wherever you are you are just feeling around your way, it's not true. But unfortunately, um, they prefer to call us that."

Abkhubazekile was translated most commonly as "persons with disabilities." This is a significant distinction because it reappropriates the meaning of isiZulu words that mean people with disabilities are not human. It further breaks with disability type because various disabilities can fit within that term. People explained that "aba-" means it is plural and in class two, or the person class. For many Africans with knowledge of isiZulu or isiXhosa *isidalwa* was most frequently heard growing up. Other interpretations of abakhubazekile included "person with a disability," "the disabled," and "disabled community." Some participants only learned the word after they became disabled and was used by both people with disabilities and the able-bodied. For others it is used the most in meetings of people with disabilities, but is part of their everyday vocabulary. Almost all people interviewed with knowledge of this word say they teach it to others to replace *isidalwa* and the other object-class words. It is isiZulu and used by the able-bodied and disabled, but home languages other than isiZulu can override the use of abakhubazekile for words such as *difofu* in Sesotho.

Abakhubazekile was known only to African participants in this study. As for Afrikaans, there are multiple ways of communicating about the disabled. People have been choosing to use person first-language in Afrikaans, but also use English terminology because it is more accurate. With the word *gestremde* there is no distinction between "disabled" and "impaired," and therefore it is difficult to make a distinction about what a person would like to be called. *Ligaamik gestremt* means physically disabled or physically impaired, *ligaam* meaning "body." *Gestremde persoon* is not the person-first variation. It merely means a disabled person rather than a person with a disability. One could say, "I saw a *gestremde,*" meaning "I saw a disabled person," however. *Verlam*, on the other hand, means "cannot walk." "If you are in a wheelchair and you cannot walk, you are *verlam.*" *Krupel*, meaning "cripple," is also common. It is possible to politicize the difference between Deaf culture and deaf, as in loss of hearing, in Afrikaans. *Die Dowes* or *die dowes* can and has made some use. In South African English there is a lot of variation and it is politicized as well. People comfortably use both "disabled people" and "people with disabilities."

As stated in Chapter Two, the disability experience of black South Africans is characterized by poverty, violence, and the system of apartheid. Nine participants born able-bodied were disabled between the ages of nine and seventeen, and four of them attended special school. Four of them were disabled from violence, either being shot or stabbed. The next section, education, also describes childhood and young adulthood experiences. Of twelve participants disabled at birth (four white participants, eight black participants), over half attended residential schools for the disabled. School was delayed for some of the black participants because their parents did not know about special schools, the children were not allowed in schools, or parents did not see how their disabled child could attend school. Special schools for black children were also scarce. The potential reasons why parents do not send their disabled children to school will have to be answered by the parents. Nevertheless, participants socialized mainly through residential schools for the disabled have a qualitatively different experience than those who attended "normal" schools.

The individual model of disability can be seen in Mabel and Christine's example. Segregated schools and experience with western, institutionalized medicine have contributed to their desire to change and overcome their so-called individual tragedy. To the majority of Africans, however, does the individual model apply? Whyte and Ingstad explain that where infrastructure exists to only a limited degree that "disability as a concept and an identity is not an explicit cultural construct. The meaning of impairment must be understood in terms of cosmology and values and purposes of social life" (1995:10). But this is true of any culture. Africans were not untouched. Neither can it be assumed that we know our own concepts so well, nor that the medical and social models are as encompassing. These models are about power, and the social model of disability, although only somewhat successful, is needed for an inclusive society. In an effort not to draw a circle around the African experiences of disability so narrowly, it is more productive to illustrate that South African disability experiences are based on sociopolitical, economic and other circumstances. The experiences are influenced by cosmology and values, but the changes, meanings, decisions are also informed by living in conflict. In other words, values and purposes of the disabled to social life are dynamic. Education, as will be demonstrated in the following section, can be a locus of empowerment. The experiences of special schools and normal schools show how participants navigated that terrain and reinterpreed their experiences.

Education

Primary and Secondary Education

Many memories of childhood and early adulthood of participants emerged through narrating their school experiences. Those disabled at birth, childhood, or early teen years have traveled various trajectories. They either (1) were exposed to other disabled children through special schools, (2) attended "normal" schools where they were likely to be the only disabled student, or (3) did not attend school.

Two contributors to the variety of educational experiences of disabled South Africans are the education system under apartheid and the "special needs" philosophy. The Bantu Education Act of 1953 separated the financing of education for Africans from the state to direct tax paid by Africans, meaning less would be spent on their education (Saunders and Southey 2001:18; Kallaway 1984). The strategic idea behind Bantu Education was that Africans do not belong in the European community above a level of certain labor, and therefore education was deemed unnecessary beyond a certain level. The act effectively took education out of the hands of churches and provincial authority and placed it in a unified government department. Ideas of Black Consciousness motivated the resistance in the 1976 Soweto uprising, and many (especially teenagers) died and were injured by gunshot and other overt violence by security forces. People interviewed were inevitably affected by this experience, their schools having been destroyed during the uprising. In the 1980s, there were 14 different official departments responsible for education in various areas of the country (based on various bantustan authority), but private schools began to implement non-racial education (Saunders and Southey 2001:67; Kallaway 1984; Hlatshwayo 2000). It was only in the 1990s that state schools began to admit all students. The passing of the Schools Act of 1996 provided equal access to education, yet there are still special schools. These schools generally do not provide a comparable education and many graduates leave illiterate.

Those disabled during their teen years in the township had a difficult time, as most schoolchildren in the township did, but the disabled had to cope with the onset of a disability and continue with life. Special schools and organizations for the disabled, structures set-up to aid the disabled, seemed more of a hindrance than help. For example, the high school education of two SHAP members came to a halt when they were disabled. After a few years, the two people pursued adult education classes from six o`clock to nine o`clock in the evening. They had to use Cripple Care transport because *kombis* would not stop for them, their wheelchairs and disabilities proving too cumbersome.[38] Sometimes Cripple Care's vehicles were late or did not come at all, and the two people then had to approach nearby homes to stay for the night. These two

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[38] A kombi is a Volkswagen mini-bus and cheap form of transportation.

people ended up forming a student group at SHAP. Special schools being limited in the township was one issue, but this group did not want to go to special school. They wanted to be integrated, to compete equally. They wanted to make the schools accessible. As described in the previous chapter, they created a relationship with the schools to make them accessible. The schools allowed these changes (such as adding a ramp built by SHAP), but did so out of pity and a charity frame of mind.

Another example of township unrest, education, and disability is Sipho's. He was shot by security police in Soweto at age 17 and left blind from the bullets which are still lodged in his head. A rehabilitation therapist told him he must go back to school. Sipho was a good scholar but knew about the age limit; at age 18 he would be too old to be admitted to the special school. She told him that in America the blind often attend mainstream school. Sipho then went to a school, one where he was not known because his previous school had been demolished during the uprising. He developed a way to keep up with his assignments by using a typewriter and tape recorder. For eight months he did this, but the principal expelled him, telling Sipho he was wasting his time. Sipho was called in front of the school where his expulsion was announced to the school. Sipho then stayed at home, but his classmates came to visit him and learned what happened. They were angry, but there were additional problems with this principal molesting children. The students went on strike and the principal was replaced. Sipho went back to the therapist and together they went to the district inspector to tell him Sipho's story. The district inspector said he must choose another school that he wanted to attend. Sipho did and when the principal interviewed him, Sipho proposed his method of taking notes and exams. He passed the interview and the principal called all the teachers into a meeting and explained the plan. It worked and Sipho was successful, participating in sports and the debating committee. Sipho exemplifies the need for appropriate understanding and accessibility.

Schooling, however, is often determined by parents. Nkeli's overprotective father wanted her to go to special school, but her mother objected. This produced a lot of tension between the parents: "He went and packed my bags, and my mother packed her bags." Her mother said if her daughter was leaving, then so was she. The mother felt that the daughter can go to a normal school like everyone else. The father felt that the school was going to help his daughter. "Then, the following day, I remember, father started the car, pushed my bags into the boot and my mother, she started her car." Nkeli's mother was going to return to her parent's home, and conveyed this to Nkeli's father. Later, the father asked his daughter where she wanted to go to school. Nkeli replied and it was a normal school near her home. The mother used to teach her what Nkeli's older sister learned at school, and therefore Nkeli was prepared to keep up with her classmates when she entered primary school. Nkeli knows that she could have ended up in a sheltered workshop.

Another woman, with one leg, says her mother refused to send her to special schools, but that it was hard because she was teased. While she was in school she developed an interest in athletics, but she was told to just watch and support the athletes. It was not until 1993, when Friday encouraged her in to participate in sports that she pursued long distance running. She has since run the New York Marathon. She thinks her mother made the right decision, because both knew parents would hide their disabled children, and they in turn did not learn how to interact as adults, saying "They don't get used to that society."

These experiences are from people growing up in the township. With hindsight, they rarely question their right to education. Although the above examples are not the full range of experience of apartheid education for disabled people living in the townships, the examples speak to the ways in which the matrix of restriction on daily life made an impact on the disabled and what participants did to push or carry on in a conflict society. Generally, education is perceived as a way to give back to the townships, or, to intercept a perceived lifecourse that resembles those of their parents or peers. For example, some women work for a high school education, or college education, because they do not want to become pregnant at an early age or otherwise forced to work the low-paying jobs of their mothers. Education in fields like social work, law, or teaching provides either a way to help township development, a better life for a graduate outside of the township, or a mixture of both. Apartheid effectively restricted education, but for disabled South African's black or white, the situation is compounded by special schools.

As mentioned previously, many special schools are residential schools. There are also "integrated" schools. Integrated in this sense means deaf and blind pupils, and often pupils with other types of disabilities as well. There are also schools only for the deaf in South Africa, but even those who are deaf who went to integrated schools have a bond based on issues surrounding sign language and deaf education. Justice, deaf since age ten, was taught sign language in primary school, but once he was in high school the teachers could not sign. This school was in an integrated residential school, and he and others who could sign taught their deaf classmates who could not sign. Sign language is often learned by peers, and although black students were supposedly able to sign in school where white students were not, teachers in the majority of schools did not, and still do not, know how to sign. Schools for the deaf emphasizing sign language can feel like more of a home because of communication ease and students may not want to return to their parents for holiday breaks.

An older white woman with cerebral palsy started special residential school when she was two years old. She would later rebel in her early twenties, noting that she was labeled "special": "Special doctor, special physio therapist, special this, special that. I was special but in a negative sense. Special in different and separate." This is where she learned to be grateful, that people do not need to help. At such an early age she was forced into a wheelchair by the school administrators so she could arrive to class on time from the hostels, her crutches and calipers not allowing her to move fast enough. Residential schools can be thought of as a total institution in the Goffman sense (1961). In the case of residential schools, the total institution is a building and grounds were all aspects of daily life are enclosed within its boundaries, accompanied by and perpetuating an equally encompassing philosophy.

There is an underlying opinion by participants that those who attend special schools have a difficult time participating in mainstream society. Many participants considered themselves "special school survivors" and when looking back on their experiences are not sure how they survived. Those who attended normal school explained that they learned to be outspoken because they could compete as an individual. But this was true for both normal and special school students, with onset at birth or early childhood and during their teen years. Some go so far as to call themselves the "liberated disabled" because it was in school that they learned not so much about competing equally with others, but about the injustices that they would be subjected to as adults after school.

College

Choices in advanced education are fraught with accessibility issues, often ending in career changes. Before any organized university input into making a campus accessible, many people were forced to change courses of study because of accessibility. One woman on crutches was told she could only study logopedics because the faculty and classrooms were located in the only "accessible" building.[39] There was a ramp, but it was topped by two steps into the building. She says she did not know how to fight then, so she postponed advanced education. Another student who wanted to study science was told to choose another field, because he would not be able to reach the laboratory tables or look into a microscope from his wheelchair. Other participants postponed their studies because of negative high-school experiences, or because their disability care cost so much that they could not afford tuition and accessible transport.

In one case, a black Deaf student was assigned an Afrikaans speaking and signing interpreter. Although there are some similarities in signed languages used in South Africa, the interpreter used the two-handed alphabet while the student uses the one-handed method. Specific information in class (such as names and dates that would be communicated through fingerspelling) was often lost. The student would miss classes in order to go to the library with friends to catch up on what was lost in interpretation. It is also difficult to take notes and follow an interpreter. No choice was given to him, and no backup was provided when the interpreter did not show up. The INDS outlines the need

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[39] Logopedics is the study and treatment of speech defects.

for interpreters and other accommodations at universities and technikons, but it is not enforceable because it is only a guideline and not an act.

Initiation

Initiation happens not at physical maturity, but later, typically to announce eligibility for marriage. It is more commonly practiced with males than females, usually including a three-month seclusion during the winter on the mountain, stick fighting, circumcision, and other elements. In other words, it is physically demanding. Two blind males talked about their initiations. One said that everything was done just as it should be done, but care was taken. For example, when initiates were driven with sticks to the river to wash, the leaders were careful not to harm him. But he did not stick fight. At the end of the ceremony a man came to him and said, "I give you a stick," and hit him on the head with the stick before it was given. It was explained to him that the stick means he is a man. Another had to craft his way onto the mountain because it is very uncommon for a blind person to participate. He came during the night and talked to a traditional healer. He participated in stick fighting, hunting, and the other aspects of initiation, and now returns to the mountain, taking up initiates, and leading them out of the initiation school.

Initiation of boys and girls into men and women has long been a practice in South Africa, although it has changed given various social and political circumstances and some have even abandoned the practice (see Gasa 2003). Many participants explain that urbanization changed initiation practices, and today urban boys of a certain age go to hospitals for circumcision. Recently, however, initiates have died or suffered serious complications at the hand of self-proclaimed "traditional surgeons" who have turned this rite of passage into a business. Boys have been abducted from their homes by "traditional surgeons" who later demand money from the parents for their services (See Maponya 2003; Maponya and Mabasa 2003). The importance, however, is in the becoming of men and establishing a matured cohort of males who have learned how to cope with the coming trials of life, and these aspects need to be maintained in the wake of social forces. "Man" is a new personhood. For many, initiation still socially defines a man. Turner's (1969; also see Van Gennep) analysis of ritual – the three-step process of change in status where one is separated from his previous social status, moved into liminality, and reintegrated with a new social status – is still applicable.

Both men said they are proud to be recognized as men. The most important aspect of these initiation experiences is to feel accepted, to be a participant. "They recognize me. They loved me, you know, the guys I went through it with." But what about those who are refused this rite of passage? Discussion involved being seen as boys, often teased, bullied, and called various names. One participant said that the feelings of exclusion become internalized. One incident, however, was not so rewarding. I was told a story about a man who uses calipers and crutches who worked for initiation and while on the mountain his cohort's shack began to burn. He was forgotten and had to crawl out of the fire where his calipers and crutches were destroyed. The leaders and initiates could only think of carrying him around, which would have embarrassed him. Instead, he fashioned crutches from sticks, wanting to be independent. In this way, he was able to claim his manhood on his own terms.

Gender, Relationships, and Sex

A vital part of personhood concerns gender, and the disabled are often seen as asexual because of their illness or impairment. Disabled women, for example, face suggestions that they are not really women (Fisher and Galler 1988:177; Asch and Sacks 1983; Campling 1981; Fine and Asch 1981). One disabled woman grew up terrified of boys and men, saying her sexuality "wasn't there" for a long time and that it was not until she recognized she had a body that she was really a woman. The wife of Bongani asked him if he could have sex after he was diagnosed with epilepsy. For many, the issue of sex becomes unstable ground. "People still have the impression of whether you can be sexually active or not," says one woman with cerebral palsy. The able-bodied are easily embarrassed and do not know how to approach touching disabled people, not wanting to hurt or offend them at best. There are also beliefs that people with disabilities are promiscuous, or that people who pursue the disabled in a sexual relationship are promiscuous. As a teenager disabled during high school, Ben remarked: "Young. Boy. Injured. Teasing up the girls, I couldn't do that – you know that stigma." In other words, the onset of a disability brings gender expectations.[40]

Gender expectations impact prospects for long-term relationships. Through marriage, individuals develop important components of their personhood (Udvardy and Cattell 1992:280). "Marriages create different pathways for women and men through which to seek the same ultimate goal of monetary and food security, physical and social support, influence in the affairs of younger kin and community members, and positions of power" (Udvardy and Cattell 1992:280). In South Africa's male-dominated society, marriages are often unequal gendered hierarchies. Further, disabilities require people to learn to be dependent in varying degrees based on the nature of the disability, the environment, social support, and beliefs about disability. Some of the men who are disabled and married able-bodied women faced difficulty from their in-laws. Their

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[40] See Gerschick 2000 for more discussion.

spouses' families believed that they would overburden their wives. Thabo is blind and only after he installed an electrical extension in his mother-in-law's house while visiting did she tell her daughter she married a "real man." Disabled men who married disabled women faced similar concerns from in-laws. How will the two keep a household? Still, other beliefs persisted, such as the belief that the children of a disabled union would be disabled too, and a stigma that the disabled person could be a beggar and not proper marriage material.

Like many "identities" experience, people with disabilities have opinions on whether to marry a disabled person or an able-bodied person. Some are critical in saying that marrying an able-bodied person is denying a culture of disability, while others think it is practical. Who is going to change a light bulb if both people are in wheelchairs? Henry was disabled as a teenager and remembers thinking, "Will someone love me?" His first girlfriend was in a wheelchair and said they would not be able to make it as a couple. They thought they could hire people when needed, but then argued that they would not have privacy. After that relationship, more dating, and living in his wheelchair, he became "outspoken" and began to understand his disability differently. He saw "no difference" with a wheelchair and began pursuing able-bodied women.

One older blind woman said in the past it was easy to date a blind person. She says, "But now we are trying to shift away from that" because of wanting to live interdependently. Another said people should date whomever they want and that a successful relationship depends on how much love is felt for the other person. Some blind participants said there is a preference for blind–blind marriage and that those marriages last longer, but it is progressive for blind men to marry sighted women.

However, some did share stories of women taking advantage of their blind husbands. The situation is qualitatively different for blind women. I was told, "If a woman becomes blind married to a sighted man I can't think of such things." She went on to hint the potential dangers he would inflict on her. If a married man becomes blind, she explains, the partner "becomes disillusioned, or becomes distant, the relationship actually withers away." There is the potential of relationship breakdown with the onset of a disability in a marriage, for reasons such as the person becomes a burden, the person becomes a different person, or that the person's disability may be considered contagious.

Another reason for instances of disabled–disabled marriages stems from growing up in residential schools or special protected environments. For the deaf, sign language provides a method of communication and deaf schools are a place for deaf people to meet. In the United States at least 85 percent of the deaf marry the deaf, and deaf–hearing unions are more susceptible to divorce (Nance and Kearsey 2004:1081-1087). A Deaf couple participating in this study met in an integrated school, and followed a trend similar to the American example. Other people with disabilities may choose to marry other disabled persons based on shared knowledge of disablement. But there is more to it than simply shared knowledge. In her fieldwork experience, Sentumbwe (1995:160) found blind Ugandan women more prone to blind–blind unions than blind men. While education and rehabilitation factored heavily into the sample's pattern, blind women may be attractive as a lover, but marriage is not socially acceptable because she would not be a good housewife, leaving her status of "woman" unfulfilled (Sentumbwe 1995:166-167). She may mother children with a sighted lover, elevating her status because childlessness evokes barrenness, but all the responsibility is shouldered by her and she may not be able to afford the expenses (Sentumbwe 1995:170). Hence, Sentumbwe found that blind Ugandan women have sighted lovers, but blind husbands. A woman needs the ability to prove her skills in an economic capacity to ever be considered marriage material.

Participants always brought up friendships in interviews. The area of friendship in anthropology seems relatively new, though it is everywhere in our work, the field experience being comprised often of what we may consider "friendships" or at the very least cordial acquaintances. There is, however, a lack of agreed upon and socially acknowledged criteria for what makes a friend (Allan 1996:85). Perhaps our shakiness is this regard is that, except in the last ten years or so, ethnographies concentrated on kinship as the most important social relationship (Beer 1998:191:213). Perhaps our interests were on finding political, economic, or other aspects, and that friendships came in the form of "social networks" rather than "friendships." Nonetheless, people reported a variety of experiences with their friends. Able-bodied or disabled, people described the joys and annoyances of friends. Does disability provided a basis for friendship? It can certainly play an important role in understanding one's disability regardless of the age of disability onset. Education at special residential schools often creates cohorts of people in which relationships can last a lifetime [See Becker's (1983) account of an aging cohort of deaf people in the United States; and Fisher and Galler's (1988) account of lifelong bonds forged in a polio ward and special school]. Able-bodied friends, however, are also treasured. Sometimes able-bodied friends make comments such as "I don't see you as disabled," and some participants felt disregarded because of such oversight. The friend's lack of understanding that disability contributes to the individual's sense of person has a prejudicial effect.

With regard to additional important life events, participants generally agreed that the disabled are given proper funerals and weddings; and *lobola*, or bride-price, where applicable, was also observed. This is significant because with disability, personhood, and self can be thrown into question for the individual and those perceiving that individual and "the disabled." However, some older participants said that disabled people were not supposed to have children.

> In fact up to this day you know when you, when a disabled, when a pregnant disabled person with a disability goes to the clinic you should hear the remarks of the nurses. These are educated people, you know. They don't even want to know whether you are married or not. They just want to know how can you and how dare you and what type of man, you know.

Comrades

Comradeship is a special kind of friendship, one that embodies shared principles, caring, and strong commitment. Those who had political involvement in the struggle against apartheid and became disabled were asked about their comrades. Comrades often came to the hospital to visit and take care of those disabled. Only one person who was blinded explained that he withdrew a bit and became less active, but the comrades would still come around and provide emotional support. Of the others, comradeship continues, providing a special bond. For those heavily involved in the struggle, they were never phased out when disabled, surviving as a unit together. Although those disabled say the comrades did not understand the disability component as a parallel struggle, they nonetheless continued to fight.

EVERYDAY ENOUNTERS: PITY AND FEAR IN LIFE'S LESSONS

The life histories and memories of participants in the above section are paired with more recent memories and common problems participants face as adults. The section is divided into three areas that were common in narratives and illuminate the finer logic in interactions with the able-bodied. The ways the disabled are treated as objects is evident in how the able-bodied friend, family member, or aid is addressed. Often a family member serves as a go-between, and service-based employees address the able-bodied companion rather than the person with the disability. However, participants were very articulate about what was happening to them in these everyday interactions. They have ways of approaching those who are undermining them and demand equal treatment. These stories deserve attention, because they describe the practices South Africans with disabilities use and make common a rights-based approach to their own self-representation.

Tea with Soured Milk: Outings with Friends and Family

People with disabilities are often ignored or treated as something other than ordinary when venturing into public spaces for typical services. The following is a very common story regardless of disability type:

> They stare, you know. And when I'm in the township, even today, when I walk into a *shabeen* with my friend or somebody, they ask him you know, "Does he drink, really?"[41] They don't ask me, you know. And I don't understand this. But I've learned to come to terms – I used to be angry before. But now I've learned to come to terms with it. Fortunately I have very supportive friends, myself. You know if you ask me whether I am drinking tea or not then you say, "Ask him, not me. He's going to drink on his own behalf." You know, "Ask him whether he wants to drink beer or not. Don't talk to me." Things like that. Which is quite good. I have very, very supportive friends.

Employees at restaurants, bars, movie theatres, check-out lines, and other establishments with a service component often approach the able-bodied companion as the go-between for the person with a disability. Not being recognized as a person able to speak for oneself frustrates people with disabilities. They feel patronized or are purposefully

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[41] A shebeen is an informal bar.

ignored. Many people told story after story about turning the situation around and Mabel provides an example:

M: What *is* going to happen is my quality of life for the day must be fulfilled. And if I have any choice in how it's going to happen, I'm going to make it happen. So if there's weird things like, "Hello, I'm the customer here, why don't you talk to me?" I usually do it with a smile; and then, "Good luck to you." And I can get bitchy enough for them to wake up; but if they don't wake up at that point, you know. Um, would be to movie houses where the guy who chose to ignore me – well, that was his peril, because in the end he wanted to give me the whole house free, you know, for the next movie. And I just made him squirm even more until he, I was happy.

M and ML: [laugh]

M: On the other hand it's not worth that kind of effort, you know, it's um . . . what have I achieved for myself? The point is that he'll never forget me.

ML: Yeah, that's true.

M: But . . . I mean if I can spread the lesson *and* get lots of fun out of it as well – it's win-win for all of us. It's good, you know. It doesn't always happen.

Friends and family can determine the outcome of public encounters. Generally, the support from those who understand disability turn the situation around or make accommodation based on the disabled person's understanding. Sometimes disabled people need an alternative support network of sorts in order to accomplish equal ground, because the family fails to understand the needs of their disabled kin. Walter tells how a core of able-bodied friends understands him, while Josie's family does not seem to "get it."

W: Um. You know what? I'll tell you one thing. My friends, I have about five friends. They are all able-bodied people. And uh . . . they treat me like them. You know when I'm with them, they do forget that I have the disability and I also forget when I'm with them that I have disability, you know.

ML: You're just friends.

W: Yeah. But you know the way they describes it, it's they normally say to me you know what Walter, when we are with you, there are these unique things that we do with you. You know. We don't do common things. Then I ask them what do you mean when you say you don't do common things? They say we know that when we go into a building where there are no lifts, it's only steps you know, we know that you are not going to climb those steps like us.

ML: Right.

W: We are going to climb that the unique way, you know.

ML: [chuckles] the unique way.

W: Yeah! And *we* are going to climb them commonly because we do that on daily basis, you know. And there are so many things. There are so many examples that they did with, you know when I'm with them like the other one is a lawyer, this other one, the two, they are managers and then this one is an accountant, this other one is a director, you know.

ML: Okay.

W: So when I'm with them they, they talk these things that makes sense to me, you know. And they always encourages me. Actually they also play an important role in my life, you know, like you know they have accepted me and you know like . . . on Tuesday we went to watch the match at night, at eight, at Ellis Park. And what happened there, it was so ironic, and I was not aware of that, you know. Uh, we went into the stadium. I didn't go to the place of people with disabilities. I just told myself that I'm going to sit with my friends, you know. You know, it was five of us, then when we enter the stadium you know there are so many people that we enter the stadium – two of them, they will run you know and go and check the space, whether there are seats.

ML: Five seats together.

W: Yeah. Then they will quickly come back and say no, there's no space in this tunnel. They will run to another target, and so I'll be coming the other three, you know. And they said no, there's no space. They'll come running to us and say go straight.

ML: The next one.

W: Yeah, to the next one *until* they find the tunnel where there are seats. Then, what did they do? This other one went there and booked five seats and this one was standing at the entrance for us to see him.

ML: To see where you were at, yeah.

W: Yeah, you know, then we went in, you know. Then, the two went in, then it's me, then the other two, I was in the middle of them. Then after the game I asked them, why did they do that? They said no Walter, first thing you know you cannot run. So we had to make sure that we get the space for you. You must not go into the tunnel and go back you know, it's, it's, you, eventually when you sit down you will be exhausted and you are not going to enjoy the game. You know. So I said wow, this guys, they know they

ML: They fought together, ja.

W: Ja, you know. So, they, they really know me. So they, when I'm with them, I feel encouraged, you know because I know, these people knows that there *are* some things that I cannot do.

ML: And they *know* what your best interests are.

W: Yes.

ML: They don't guess at what your best interests are.

W: They, they know it. You know. Like, you know when, whatever they do you know, they make sure that I feel I'm with them. That's why I enjoy their company. Yeah. It's, and with my family, too, you know, wow.

Josie, on the other hand, asked her father to drive her to a work-related appointment and ended up in a fight for understanding.

> And I said to him one day will you drive me because I've got a couple of appointments and I had to, I had to meet with a company and I had to go up a flight of stairs and my father said, "I'll carry you," and I said, "No you bloody will wait! If I can't get up the stairs then I just won't go." And he said, "Don't be bloody stubborn!" So I said, "I am stubborn! That's why I'm your daughter!" And I locked my hands around the banister so he couldn't pick me up and he was getting very agitated with me and getting all kind of red in the face. I said, "Dad, we're wasting time. I've got an appointment. Just let me get there the way I know how to get there." And I did. I was up.

Josie's family featured in another event:

> They see me as a rebel, because they came here on a holiday, just before Nelson Mandela was released and um they, I went with them to Sun City for a week and my brother is an academic, he can't relate to just ordinary, everyday things. I go with them to Sun City and the host talks to him and not me and I said, "Excuse me, I can tell you what I want," and he just about shrivelled into the ground, and

> he said, "How can you be so rude?" I said I'm being definite about what I want and if he can't talk to me, he needs to know. This is the way it is. He said, "Well you're just being obnoxious."

Encounters like these essentially motivated Josie to seek relationships that were more supportive than her own family. Like Mabel and participants from the previous examples, Josie is aware of being purposefully ignored.

Earning Potential: Adventures in Economics at Pick n'Pay[42]

A common judgment from the able-bodied occured at the grocery store and concerned whether the disabled can afford what they are buying. The able-bodied questioned their ability to work, where the money came from, who would employ a disabled person, and if their resources were legitimate.

W: So that's why I always tell they don't take me for granted like recently, last month we went to town, with my wife to make the grocery and so on. Uh it's a small town and full of white people. And she was pushing the trolley. There are these people following us. Standing in a queue you know if I look I see that oh it's about twenty, thirty people in front of me. I said, "I'm coming." I went to the manager's office. "Can I please speak to the manager?" "What do you want?" "Do you cater for people with disabilities in this store?" He said yes. I said, "No, I've been waiting there for about ten minutes, nobody was looking at me, nobody was willing to help me. So I need help, now." You know I demanded help. He went out of his office. The first thing he want to said, no, go to that lady who will help you. I said "No, you go and tell her to help me." You know he wanted to refuse. Then I said, "If you want to see your store on the first page of the paper. . . ." I said to him you know I threatened him, you don't know who you are messing with. Oh then I called my wife, she came you know and I hear these people. They are talking Afrikaans. I know Afrikaans. [laughs] They don't know that I know Afrikaans.

ML: What do they say?

W: How am I going to pay that? I'm going to pay it with cash or what? Because

ML: Oh how you are going to pay your groceries?

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[42] Pick n'Pay is a popular grocery store chain.

> W: Yeah. Yeah. It was making something like 800 rand. When this lady's finished I ask her, do you take checks, do you accept checks or credit cards? And she said no, we take both. Then I said okay, I'll pay by check. Then I wrote out the check. Then they ask themselves where does this guy get the money? Then I, you know after that I ask them! I said "Don't you think that I can work?" I said you know some of you, I can run your business, your companies. You can give me the responsibility to run your companies. And I said to them you want to know what I'm doing? And they said to me "Yes!" [He tells them what he does.] Wow – they were so surprised. Then I walked out of the store. You know even today they know me in that store. Every time I walk in that store there's this person who comes running to me, push the trolley, you know, just instruct, put that one in, you know. You tend to be the president, that's what I'm saying.

Another grocery shopping adventure involves Dumisani (who is blind), who finds an employee at the store to take him around the shelves to gather his groceries. His driver usually drops him off at the store and a woman who works there comes and asks the driver if Dumisani can pay for groceries. When he shops with his sighted wife she unpacks the groceries at the till and tells her husband to pay. The women who are checking the groceries are usually shocked that a blind man is paying. These interactions are very common, strenuous, and unnecessary. The disabled appear dependent and unable to earn a living and, as in the previous sub-section, must explicitly ask for attention and service.

Forcing Labor: Work, Mental Ability, and Intelligence

In work and other professional situations, the mental capacity of people with disabilities is often questioned. At best they are patronized.

> I arranged to get a job at the railways which is *way* below what I ever thought, um. And, first I had to go through all these academic tests and I didn't finish the tests and didn't know if I would have got it. And *eventually* they gave me an interview. I get there and the guy looks at me and says, "Can you write?" And I said, "I have a matric." And he says, "Ja, but can you write?" And I said, "I think you have to for matric." You know. Cause he, "We want you to write numbers so I want to see how you write." I had to literally write one to ten to show them. It was the weirdest interview I've, now that I know what an interview is all about. I then got this job and I was allocated a supervisor who was a colleague who sat

> with me for two days and taught me. And my supervisor never spoke to me. She spoke to my colleague, to tell me what to do. I don't know what her issue was. Now I'm 19 and I'm treated like a child of 15. *Again*, the same kind of setting, all the girls in my – which is a huge office of about twelve girls – most of them Afrikaans, none of them spoke English and none of them spoke directly to me. Cause if it speaks it's going to cause an infection or something, you know. They would speak to my colleague to give me a message. You know, that kind of thing. So we'd have lunch breaks and they'd all go out and my colleague would say to me, "Do you want anything?" Not "Do you want to come with us," but "Do you want anything?" So again, I was sort of . . . put aside. And that's how I thought life was. You know. It's very strange.

While family members are often an advocate or go-between for their child, such help or assistance is not appropriate once they are adults with jobs. As an adult with cerebral palsy and a speech impediment, Tumi explains that her mother is often contacted instead of her:

> That's why my mom gets so upset when I'm doing a [project] and somebody instead of contacting me they contact my mother. She goes, "She's 25, she can make her own decisions and if you want to be upset with my daughter, continue doing what you are doing." Because I'm my own person.

Others have more positive experiences, such as Hendrik, who is blind. When he is in meetings, the chairperson introduces everyone around the table to orient him to the surroundings. Other disabled people must initiate accessibility and disability issues in frank ways:

> Yeah. So now I tell people that if you are, if you, if you don't have disability, you don't know what you are missing. That's what I normally tell people. They miss something. I was invited by this [organization], you know to one of their presentations and uh . . . before I made my speech there were this able-bodied people. Now when they call me they go running to you know the front there and see me walking so slow. Normally. Then, and I come there and I said, "You know what good people? I don't know if you see the difference between *me* and the other speakers." Say bah! What was it? I said, "The other speakers were running to come and make their speech because they wanted to finish as quick as possible, you know and go and rest and enjoy their food. So with these people with disabilities that's why we don't make mistakes." [We chuckle together.] We don't make mistakes! We, you know, you take your time! Each and everything you are doing, you take your time to do it. So, that's *why*. And each and

> everything that we do, we do our outmost because we take time to do it. So these other people they are always in a hurry.

After many stories, we often discussed how tiresome it is to be the spokesperson for our disabilities. Queen follows a routine when she is tired of the stereotypes of blindness. After a presentation at a woman's conference, Queen was greeted by:

> a black woman to congratulate me, you know your English is so good, where did you learn it from? And I would say from my mom's madam, you know, they wouldn't even get the gist of . . . because nothing comes to them that I can be educated just as they are.[43] Just as they learned English in school I had learnt my English there, but no, they had to ask me and I would say my mom's madam. And they really wouldn't know it was an insult. Until I had to address them on that at some stage. I said you know some of you I always kid you know where I learned my English. And my short reply is my mom's madam, you know, because you don't think I have a right to education. Do you know they all felt so bad. . . . They're very careful of me, too, you know. . . . when I just keep quiet and say why should I dehumanise myself. I'm really not taking myself to this level you know.

Assumptions about the mental capacity of the disabled are similar to racist belief, as discussed in Chapter Two. These are additional examples of assumed difference. Some people felt empowered when they started to work after their disablement; others felt as if they were a token disabled person and found other work. Granted, there are people with mental disabilities who do not have the capacity to perform certain tasks, but they are still able to complete other tasks. Decisions to demonstrate mental ability, skills, and accomplishments are needed and performed by the disabled, often to prove their worth. Similar to the grocery-store experiences, production and ability are related to the sense of person in that they can perform in many aspects of society.

DISCUSSION:
SOCIAL SUFFERING AND IDENTITY

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[43] A madam is the female employer of a domestic worker.

Disability itself is not the origin of the oppression of the disabled. The treatment of the disabled and creation and maintenance of barriers to meaningful participation in all aspects of life are informed by able-bodied assumptions of difference fundamental to what makes a person. Similarly, forms of oppression can create certain forms of disability understanding. This chapter identified experiences and practices for representation that call to be treated as human and living beings rather than objects, or further, a somewhat different entity. The informing discourse is not only from institutions specifically designed for the disabled in the bantustan sense, but from the people and environments common to the able-bodied (such as grocery stores, the household, and other realms).

Accessibility, as described in Chapter One, is what other identities demand: the right to participate in a socially meaningful way, equality, non-discrimination, access to education and employment, and other fundamental components of democracy. An exploration of accessibility was a goal for this chapter and it was examined through the lifecourse and everyday practices of participants. Several rights-based themes are evident in the treatment of the disabled in the lifecourse. Were disabled children allowed to play with other children and contribute to the household? Were they provided freedom to attend school? Are accessible buildings and materials provided? Should the disabled reproduce or even love? Who should the disabled pair with? Questions about ability to learn, earn a living, and basically subsist emerged through the narratives in the everyday encounters section. In these ways personhood is thrown into question. In a larger sense there are bell-curve assumptions of fundamental difference that echoes a mind-frame of speciation.

Although the next chapter addresses identify formation and the onset of disability, a generalized outline of ways able-bodied discourse informs everyday life can be drawn from the above presentation. The themes are signified meanings countering that of able-bodied dominant discourse and ideology. Although the disability rights movement has worked toward fundamental change in the areas of education, employment, transportation, and other critical components for meaningful participation in society, the disabled continue to struggle for access and meaning. In this regard, identity is a socio-emotional need (Shaw 1994) and politically motivated. As I said in the introduction to this chapter, many of the life events vital to personhood are generally said to accept the disabled, but the experiences of participants is discussed more in terms of their *achieved experience and desired goals for all disabled people than common experience*. Thabo may have been accepted to college, but his efforts for advanced education was made difficult by an inflexible interpreter. Dumisani was able to go to initiation school as an outcome of a crafty conversation with a healer, but most disabled boys are not able to do so. These stories and experiences are exceptional. Participants have been, to a degree, able to push their ways into spaces seemingly designed to bar them (for example, by building ramps, fostering relationships that are based on an understanding of disability, and demanding proper service).

What expands or retracts the potential for such appropriation of disability for these South African participants? Appropriation occurs when an interpreter of a text is open to its meanings and creates a personal meaning (Ricoeur 1976:3). Paul Ricoeur uses the term 'appropriation' to identify the process readers of a text undergo that effects a broadening of capacity for self-knowledge (1981:50). Appropriation is a response to the text rather than a remaking of the text in one's own perspective. As introduced in Chapter Three, participation and engagement in a movement can *foster* identity formation. The family, friends, and everyday navigation of the environment influence such components of identity formation as well. Parental decisions on schooling, household accessibility, educational experiences, and other aspects of the lifecourse are guided by able-bodied ideology. Whether this ideology is technocratic, biomedical, community-based or otherwise, the disabled for the most part do not fit in. This can be seen as a response to the text, their experiences informed by able-bodied ideology, but found inappropriate and demeaning. It is appropriation because they are using that text to define their requirements for meaningful participation in society by removing not only the physical barriers, but the social, economic, political, and other barriers as well. It is their definition of accessibility. That participants achieved these standards for themselves should not be interpreted as luck, but an acted upon process of self-examination and the production of a new way of thinking about their disability.

That disability is a politically motivated identity is not lost on the participants. This is evidenced in the distinction people from the township make about two ways disability can be handled. The first way included those who understand disability identity and those disabled who remain controlled by the able-bodied in oppressive ways. Participants involved in shaping SHAP and TABBA, who pushed their ways into able-bodied territory, and those participants who consider themselves "special school survivors" (regardless of disability type or age of disability onset), indicated that they were an accepted part of the scenery. These participants described how they were "naughty" in school like their peers, participated in sports or other activities, or hung-out "in the community" with friends. These scenarios were described more frequently by males than females, however. The young women, when they were children or adolescents, stayed inside and contributed to household activities more than boys, but they still had good friendships outside of the home.

The second way disability is handled in the township includes those unseen disabled people, kept behind closed doors and hidden. A disabled family member may only be known to that family. Stories of persons being taken out of doors to use a toilet once or twice a day were related to me. Another experience of a family that I have known for some years demonstrates the secrecy. I knew my friend had a disabled brother. He told me this only because he knows I work in the field of disability and asked for some advice. The brother was a double amputee (of one arm, one leg) and a diabetic. I had visited the family's home in the township many times, but I did not know the brother lived there. We usually had a nice drink in the sitting room, dining area, kitchen, or back stoop. The brother was in the house the whole time, laying on a bed alone. The following excerpt describes this dichotomy between the two ways of handling disability in the township:

ML: Tell me that story about the man that's in your community at home.

W: Okay. Um this guy, he, he was not being, he was not born being disabled. And he was involved in an accident. So it's about three houses from where I'm staying. And uh he's always sitting under a tree. You know and he always sees me, you know when I go to my wife's place, grandmother's place, you know, by passing you know. Sometimes I'm working with my whole family, my two kids and my wife. He one day asked me, "Walter, tell me, uh why are you so confident? I like you, I like your family, ah you know the way you are." It was simple for me. I just say to him I've accepted my disability and I don't want to depend on anybody. I believe I have to take care of myself. And he said to me what must he do, you know? The problem with people with disabilities he explains that every time he asks you what can I do to, to stay focused? He'll think of you say to him go and apply for a disability grant. I say to him, "Look, it's

> very simple. Go out there, look for the job, you know, and work for yourself. Then you will see. People will start to realise that you are also a human being. But as long as you are sitting under a tree people will see you as a disabled person." You know.

The above presentation and examination of the lifecourse and everyday life allowed an opening of object/subject distinctions. It provided an opportunity to more carefully read assumptions of difference and identify a process of realization. Accessibility will feature in the next two chapters in ways important to identity formation. Though identity is a signifying practice or vehicle for meaning it does not imply that meaning is static. The potential for multiple readings or interpretations can increase in conflict and transitional societies. It can perhaps expand the potential for appropriation. This is in addition to the above identified areas of participation in a movement; family, friends, and everyday navigation of the environment; and lifecourse experience.

CHAPTER FIVE

EMERGING AND CONVERGING: UNDERSTANDING DISABILITY IDENTITY AND SELVES

The goal of this chapter is to further explore the ways in which disabled South Africans come to understand their disability. Disability identity, like other identities such as race and gender, works in pursuit of political goals, and is based on an expanded definition of accessibility that includes the removal of physical, social, economic, political, and other barriers for meaningful participation in society. Identity, therefore, can be understood as a politically motivated, socio-emotional need and is applicable to disability identity as a response to the forces that oppress and repress the disabled. This chapter is divided into two sections. The first section, disability onset, addresses disability acceptance in terms of ontological security and disability identity. The second section, worlds and identity, explores how encompassing disability can be and contributes to a community of knowledge. Multiple identities and contexts can create or foster ontological security, and the two sections address how disabled participants, when confronted with these multiple identities and contexts, incorporate disability into their narratives.

DISABILITY ONSET

Regardless of disability type or age of disability onset, disability identity, as a way of knowing, has its own timeline and history in people's lives. Additional concepts need introduction because they help clarify differences in anthropological and social theories, and descriptions of participants' experiences of disability. Where embodiment concerns the "existential grounds of culture," and attempts to collapse Cartesian assumptions, ontology and epistemology contribute to these postulates. Generally, ontology is the study of being and epistemology is the study of knowing. Influenced by Foucault, ways of knowing are related to discourse. Foucault's 'order of things' are essentially epistemological frameworks, concerning ontological assumptions. When people become disabled they face a change in ontology, and epistemology becomes reshuffled. People who become disabled, having had able-bodied knowledge prior to disablement, grasp signs that are now signified differently.

The fundamental assertions about 'being' change for people who become disabled. For example, the physical living space, a house or dwelling, "looks different." While it is true that this signifying practice involves the body in some way – for example with paralysis, the onset of seizures, gradual loss of sight – ontology may change, but epistemology, or ways of knowing, is influenced through a new mediation or signifying practice. Another way to explain the interplay of ontology, knowledge, identity, and self is through Giddens' (1984:375) use of the concept 'ontological security.' Here, the security of being requires maintenance of identity and self. In semiotics, reality can be said to be an effect of the sign and that contested reality lies in sites of struggle. The onset of a disability can fracture ontological security. For example, expected plans in the lifecourse may be perceived as not feasible with the onset of a disability. Signs will be signified differently, or challenged, or accepted with the onset of a disability. Identity and self are signifying practices, and are impacted, compounded, and influenced by the management of disability. The way society handles its disabled becomes critical. Experiences in or with rehabilitation, special schools, communities, movement, organizations, and relationships shape or influence how people make meaning of disability in their lives. While disability identity, or rather a broader, inclusive meaning of accessibility, has been instrumental to claiming disability, participants' fields of meaning and making meaning are nonetheless shaped by such experiences.

As said in Chapter One, identity as a politically motivated, socio-emotional need is applicable to disability identity as a response to the forces that oppress and repress the disabled. But identity is also a dialectical and discursive relationship of the self and situated experience. Identity used to refer to 'sameness' and in psychology meant 'selfsameness' (Sökefeld 1999: 417). Csordas (1994:331) notes a trend in social psychology to isolate aspects of the self, as in self-concept, self-image, self-awareness, self-esteem, for analytical purposes (Gecas 1982). In terms of semiotics, self means self-representations while self-experience refers to the pre-cognitive; but the self in any of these distinctions remains culturally organized (Ewing 1990). Cultural anthropologists, though, argue that 'selves' are culturally shaped and infinitely variable, hence the idea of 'shifting selves' (Ewing 1990:253-254). Ewing (1990:251) argues:

> . . . that in all cultures people can be observed to project multiple, inconsistent self-representations that are context-dependent and may shift rapidly. At any particular moment a person usually experiences his or her articulated self as a symbolic, timeless whole, but this self may quickly be displaced by another, quite different "self," which is based on a different definition of the situation. The person will often be unaware of these shifts and inconsistencies and may experience wholeness and continuity despite their presence.

In light of this, she proposes that people manage inconsistency through semiotic processes, through the construction of a series of self-representations based on "selected cultural concepts of person and selected 'chains' of personal memories" (Ewing 1990:253). Further, "Each self-concept is experienced as whole and continuous, with its own history and memories that emerge in a specific context, to be replaced by another self-representation when the context changes" (Ewing 1990:253). This is counter to the claim anthropologists make that the "experience of wholeness, continuity, and autonomy that we normally associate with the 'self' is a culture-bound, Western notion that is not applicable to most non-Western cultures, where the self is experienced contextually and rationally" (Ewing 1990:253, citing Shweder and Bourne 1984).

There is a connection with anthropologists seeking selves, and with semiotics. Rosaldo (1984:140-141) finds connections between self and identity, and further detaches from a perceived bounded Western notion of self:

> If culturally organized views of possibility and sense must figure centrally in the acquisition of a sense of self – providing images in terms of which we unselfconsciously connect ideas and actions – then culture makes a difference that concerns not simply *what* we think but how we feel about and live our lives. Affects, then, are no less cultural and no more private than beliefs. They are instead, cognitions – or more aptly, perhaps, interpretations – always culturally informed, in which the actor finds that body, self, and identity are immediately involved.

How we feel, then, can be related to practice.

De Certeau's *The Practice of Everyday Life* is an examination of the creation of anti-discipline. His analysis of the pedestrian speech act identifies characteristics of practice and the relationship between the forms used and the ways of using (de Certeau 1984:98). If it can be said that the environment or 'spatial order,' to use de Certeau's term, "organizes an ensemble of possibilities (e.g., by a place in which one can move) and interdictions (e.g., by a wall that prevents one from going further), then "the walker" in this case "actualizes some of these possibilities" (de Certeau 1984:98). "But he also moves them about and he invents others, since the crossing, drifting away, or improvisation of walking privilege, transform or abandon spatial elements. [. . .] In the same way, the walker transforms each spatial signifier into something else" (de Certeau 1984:98). This is not just a walk in the park. The catalyst or vehicle for meaning is in signifying practices. While a sign stands for something else, is signifies meaning. In other words, "Signs elicit other signs in necklaces of signification" (Tomaselli 1996:35). A relationship is identified between the 'forms used' and the 'ways of using' in de Certeau's semiotics whose possibilities are limitless. The natures of this relationship are evident in analyzing such pedestrian speech acts because they contain statements with truth value (the necessary, impossible, possible, or contingent), epistemological value (the certain, excluded, plausible, or questionable), or ethical or legal value (obligation, forbidden, permitted, or optional) (de Certeau 1984:99).

People were able to reflect on the moments after they were disabled:

> I went through the ups and downs like anyone else: the hope, the expectations, the "don't worry, go to the physio." . . . You raise expectation. No, no, I'm not going to be a disabled person permanently, I'm going to walk. I'm still young, my muscles are going to grow. And then that hope dies a bit.

Another man who was young when a battery explosion blinded him explained that he could see "Something like six meters or so. And then it was gradually dying away until it was completely dead like it is right now." The idiom of something dying was not organically common in the narratives, but important because indeed becoming disabled is like entering a new world, one that looks, smells, and feels familiar yet profoundly different. This is a change in ontology. The fundamental assertions about 'being' change for people who become disabled. Their home, for example, "looks different." How people began to understand their new life as disabled played a role in their understanding of how society and relationships work:

> Staying in Soweto in this four-room house. Ohhh it was tough. House without a ramp . . .. Stoop in the back, no ramp in the house. The outside toilet cannot accommodate the wheelchair! Cannot fit even the wheelchair. Then it began to change and see then, the environment, I'd say– it's not for me! This place is not

> me, I don't belong here. Then ha! Then when you go out of here, you can't even go to the shop! From here a gate . . ..

These are times when ontological security is in jeopardy. Signs are highly unstable in their previous meanings, but there is a need to maintain or regain a sense of wholeness in the face of conflict (Ewing 1990:270). The newly disabled body does not afford security for self-wholeness. This may be true more for those with a sudden disability onset, as with an accident or overt violence than for those with disease characteristics that gradually disable. Ewing explains, "One strategy for restoring [a] lost sense of wholeness when faced with conflict is to create more adequate self-representations, a process that requires an effort of synthesis and integration. Alternatively, most of us simply get by with unexamined inconsistency whenever possible" (1990:270-271). This process of synthesis and integration has its own timeline and will be covered more in the following section, but engagement with some form of medicine or rehabilitation contributes to gaining or inhibiting ontological security.

Sipho's story illustrates a change in his understanding through a disability identity and gained accessibility. He is "just okay" with his disability. Sipho was embarrassed about his blindness in the beginning. He was afraid and withdrawn, but though living with it he became used to it. Rehabilitation gave him independence, learning to read Braille and to use a cane strengthened him :

S: It was very, it was different, because, I mean – and I will tell you something Martha, after I lost sight I was, I was sort of *embarrassed* for people to see that I'm blind now. You know, I wouldn't like everybody to, especially the people that, that knew me, the people that I grow with, you know. There was a little bit of embarrassment that how are they going to look at me if I'm now blind. So that's why, that's why I'm saying I was a little bit withdrawn, you know.

ML: Yeah.

S: I was afraid even to go out. You know going to the shops and so forth.

ML: Did you grieve? Did you grieve at all, like a loss of your sight or anything like this?

S: Um-hm. Yes, yes I did. I did. I did. I was, I mean when the doctor told me that I can't see anymore, I'm telling you, uh, it was very bad, if you can see, if you could see me after that, after the doctor told me that I can't see anymore, you know.

ML: Yeah.

S: Yeah. Yeah. But at any rate, what happened with that, I get used to it . . . rehabilitation also helped a lot because I was taught how to read, how to go I mean using a cane. I mean that independence.

ML: Yeah.

S: Yeah. So it, it sort of *strengthened* you know my will power and confidence, you know. To say okay, I'm blind.

Rehabilitation was not so positive for all participants, delaying an understanding of their situation. Sipho similarly sees change in South Africa generally, but like his blindness he is just okay with the status. Another contributor to Sipho's understanding is that his rehabilitation was through TABBA, the organization that grew out of a response to SANCB's neglect of service provision in the townships and Consolidated Circular No. 29 of 1966 which restricted SANCB's development of black blind people. TABBA was an organization of and for the blind focusing on self-help rather than a service provision, but operated in a way different from SHAP, which was self-help from more of an advocate point of view. At the time of Sipho's disablement, TABBA would teach people orientation and mobility skills from a blind perspective, and more so from a black blind Sowetan perspective.

Being okay with a disability is one thing, naming oppression another. Contrast the above story of rehabilitation with that of Francois. Francois is a trained activist in the struggle against apartheid and was disabled in 1995. He relates:

F: She [Francois' physical therapist] says like you move completely differently. She said you used to move like a puppet, just trying to avoid the pain all the time like you know move almost like in tiny movements. And then mmm . . . no, there, there, I mean fuck – you know, I say I was *released* from hospital. Like released from detention. I mean, you know. [laughs]

ML: I mean was it a similar feeling?

F: Exact [laughing] Absolutely!

ML: Was it a similar feeling?

F: It's a *completely* similar feeling! No I mean fuck! At least in detention they didn't decide when I shat. [laughs] This is the one freedom you had! [laughs] And they did this, because it suited their routine, of the hospital, your body's routine is to shit everyday. *Their* routine is to empty you out every two days. By the time of having been in that place for five and a half months, I had to drink an entire bottle of x-prep and *eight* senakots every night. I mean every night before my emptying out. Because

ML: For the next morning.

F: Yeah. *And* I got it from another medico, that came to one of their spinal days, whatshisnames, about how to train your bowel. That your bowel is very trainable

M: Bowel programs.

F: Yeah. Eat your bran and large volume enema of with a large volume fuck up. But, once I'd taken my bran, and I did everything the guy said – you're also not supposed to do tea or coffee for some reason

ML: Water retaining, probably the caffeine.[44]

F: And uh . . . I'm saying I went to them with a medico they'd invited to this spinal day and said listen, the dude says you've gotta shit everyday. They said no, no. It will fuck up our routine. You can try that when you leave here. [laughs] And so [laughs] I mean, you know, and so ja, the similarity of actually being scared, you know.

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[44] Caffeine is a diuretic, or draws water out, rather than retains water.

ML: I mean surely when you're in detention they, it's a mind, it's a very controlling thing.

F: Mmm.

ML: It's similar to rehab, isn't it.

F: Yeah. I mean look, they switched off the lights. Um . . .

ML: They what?

F: They switched off the lights.

ML: Oh.

F: You know, the "lights off" time. Um, when you went to exercise with, and the hospital wasn't like that. I mean they decide when you eat, they serve you your food. They decide when you have to go to gym, when you're allowed to go and play basketball.

ML: [laughs] That seems to be like a little rite of passage they think is so important.

F: Mmm! Mmm, mmm. . . . You know the experience is the same, but I'm not quite, I'm too much in trauma I mean I'm fuckin', you know my folks said I was like running this entire ward. You know, I was controlling everything that was happening.

ML: Yeah.

F: He [the doctor] said: they would *call* me when I was on call *begging* me to let them give you more pain killers! And he said well, you didn't manage to get me, he said. I just told him – simple. They didn't believe that you're trying your best. Give him a saline injection. [laughs] So . . . what I discovered, I mean, okay, for a while I was sheltered, because I was with my comrades, my family, a lot of, you know – they would *understand*, have a general understanding of oppression, and, and rights and equality and so on. And so I was sheltered for a while. I also had my brain.

ML: They were kind of advocates in a way.

F: Advocates, but supportive, like you know, ja, you know. "This is bullshit. Why are people, you know people shouldn't do that and you know, that's wrong and" . . . but . . . when you are being repressed, okay, people have a fuckin' agenda on you. And it's a conscious agenda. When you're being oppressed people are fucking with you and they don't even know it.

Francois' memories of detention and rehabilitation were "completely similar," and sometimes it is difficult to identify which experience he is referring to, detention or in-hospital rehabilitation. In previous chapters I explained some of the histories of institutions (Chapter Two), and discussed the impact of such institutions in the creation of disability identity (Chapter Three and Chapter Four). Their relevance surfaces again in relation to processes of appropriation, or possible readings of texts to broaden or encourage a new mode of being. The text is not remade, but responded to (see Ricoeur 1981).

Ontological security can be influenced by other people, able-bodied or disabled. In institutions such as the hospital where Francois and others spent so much time, able-bodied ideology is perpetuated, and can even be encouraged because of a familiarity of once being able-bodied. An able-bodied self may be preserved or exist in tension with other self-components for years. Pieter provides an example of shifting selves in his narrative, the torque of able-bodied and disabled identities surfacing and shifting. He does not accept his disability, yet he is not trying to be able-bodied, existing somewhere in between. His narrative is inconsistent with the interpretation of his wheelchair:

> The first few years I felt . . . awkward, sometimes embarrassed. And people saw me the way I was. "You're not changed?" and I said, "No – hang on a second, this wheelchair can command attention." This wheelchair can open doors. It's going to do it and I now exploit . . . the opportunities that this wheelchair allows me. If people feel awkward in the chair that's too bad. They must remain feeling awkward. No, it's not "too bad" – I would like them not to feel awkward – but, in terms of a business negotiation tool, being in a wheelchair is a very strong tool. In terms of a debt-collecting tool, it's a very strong tool.

In this passage, Pieter, on the one hand conveys that his wheelchair gives him access and advantage to participate in business exchanges, and on the other hand wants acceptance regardless of the wheelchair. After long discussions about disability, I asked Pieter if he would rather be able-bodied:

P: Would I rather be, would I rather be able-bodied? Yes.

ML: Would you?

P: Clearly.

ML: Why?

P: Do I – am I striving to be able-bodied? No. Would I rather be able-bodied? Yes – I want to be, I want to have the functions that I was born to have. I would like to have retained them.

ML: Mmm.

P: I was born to be able-bodied, but I was born able-bodied.

ML: And so was I.

P: I've lost some critical functions.

ML: Sure.

P: Sure. I, I, if you gave me the choice to have them back . . . I'll take them with pleasure. I'll take them without even blinking an eyelid – but, I live the life of a – no, I don't live the life of a quadriplegic 'cause according to the book it's shocking rough, I don't, I live a wonderful life. I . . . I have no problem. I, I live a normal life.

ML: You have an extraordinary life.

P: I, my disab – it's doesn't, I don't consciously, I . . . look and say I'm, I've got a disability. I seldom use the word "disabled" 'cause it's not a disablement here. I'm not disabled. Um, and the day I become disabled – oh I dread that day. But I live with this disability, but I, I often consciously don't realize it. You just go about your day and your wheelchair has just become part of me. It is my, my, my mobility. Um, it's detached occasionally to get into the boot and when I go for a swim or whatever, but when I get out I need my chair, I'll need to get to the next place. Um, so . . . ja, I don't consciously think about "okay, walk again, walk again". I don't. It doesn't cross my mind at all. It's enough – today, tomorrow, the next day. I will think a lot about that because I'm in a medical, spinal cord injured conference.

You know what – disability – disability, disability is an attitude. Or "disabled", the word "disabled" – it's actually just a person's attitude. The able-bodied person or mine. That able-bodied person could make me disabled or my input. It's not a tangible thing anymore.

ML: It can come from within, or from, outside

P: Ja. It's not a tangible thing anymore. The wheelchair doesn't mean "oh, disabled." The wheelchair is, it's the thing I use to get from A to B. Usually you use your legs. Your hearing aids, that assists you to hear. That's your assistive device. It doesn't mean that you're hard of hearing. The hearing aid means you can hear.

ML: Well, no, it doesn't – hearing aids aren't that effective. I mean I, ja, I have the auditory perception disorder. They're not, you don't hear like you used to.

P: Okay.

ML: With the hearing aids.

P: Someone with hearing aids. I don't say, "they're deaf" or "they're hard of hearing." I say they can hear. Someone with a cane, they can see.

ML: But the moment I take this out, you see this is the part where I get so hung up on is – you know I take these out before I even take off my shoes. I'm just more comfortable, pretty much deaf.

P: Yeah.

ML: You know. Um, but . . . it's a much deeper thing than that.

P: Ja, ah, it can be, it can be very difficult. To become able-bodied again. There would be lot of people that would, that wouldn't allow me to, um. I don't think that's such a good thing, um, to have gotten myself into that position.

ML: I would really freak out if I, if I could hear like normal people. That would freak me out and I don't want it.

P: Ja, ja, no. I'm telling you, if you gave me the option, I will want to be able-bodied. That's it. But – it doesn't mean I don't want to be disabled. It's, to have a disability. I, I don't even notice my disability, ah, a lot of the time. I sometimes I could . . . ja, ja, ja – I notice my personality. My personality, the way I behave, is, I, I challenge myself on my behavior, more than anything else . . . than my physical attributes. Why wouldn't I remain calm, why didn't I make that decision? I'm changing the way I behave everyday, the decisions I make. And I know a lot of people would just challenge their disability everyday. They don't

> have time for that, actually. Don't have the time. And you know something Martha, think about it, if maybe it's because you're so busy in the sector and so am I, that we just get so deep into it and it keeps us away from challenging our, our, our . . .

Disability and its associated meanings have multiplied. Pieter's narrative perhaps shifted the most dynamically and dramatically of all the participants. He uses many of the changed meanings of disability, disability as an attitude, for example, but must place himself in multiple contexts. He is white, Afrikaner, quadriplegic, in the sector, and other contexts. A disability identity surfaces when needed. His sense of self is informed by a disability identity, and perhaps other identities and contexts, but generally remains conflicted. In addition, people have been portrayed differently. There is a want or preservation of able-bodied knowledge, but that knowledge is not always suitable or accurate.

Learning the intimacy of ones disability is a progression for most people, where disability's lessons are taught given his or her own timeline or learning curve. Though the next chapter discusses the fusion of multiple identities and contexts, the point here is to illustrate some of the ways participants are influenced by experience and can exist in tension with previous knowledge. Semiotics can help sort out the qualities of experience in narratives. De Certeau refers to 'style,' a linguistic structure that exists on a symbolic level (1984:100). The symbolic level concerns "an individual's fundamental way of being in the world" (de Certeau 1984:100). The qualities of a symbol are unmotivated or arbitrary, "having no obvious connection to the idea it represents except through convention, what we take for granted" (Tomaselli 1996:31). This is similar to Giddens' use of ontology. In de Certeau's view, style connotes a singular (1984:100). 'Use,' on the other hand, defines social phenomena through communication as fact (de Certeau

1984:100). While style and use both contribute to "ways of operating," style is processed on symbolic terms and use refers to elements of a 'code' (de Certeau 1994:100). Codes are basically frameworks where signs make sense. Therefore, a style of use is a way of being and a way of operating, according to de Certeau (1984:100).

Sipho came to terms with his blindness by relearning his environment and relationships, he was disabled by being shot by security police while engaging in political activity in the township on the eve of the 1976 Soweto uprising. He also participated in the Truth and Reconciliation Commission (TRC) by giving a public testimony of his experience, which to only an extent was healing. He had come to terms with his blindness prior to his TRC experience, but understands that his lifecourse was greatly changed. I asked Sipho if there has been change for people with disabilities since the dispensation and the TRC. Here he refers to his TRC experience:

S: I don't think that much has been, has changed. You know, disabled people were not treated differently from other people, you know.

ML Mmm.

S: Yeah, we, in actual fact what the TRC has done, especially in the case of reparations and so forth, it means they've just made an *overall* you know, an overall

ML: Blanket, sort of . . .

S: Yeah, yeah. Kind of reparation you know?

ML: Ja.

S: They didn't look at who is disabled in what way, what do you need, blahblahblah, you know I mean it's one of the things that I would say, the, the, the, the, the TRC could not look at.

ML: Mmm. Mmm.

S: Yeah. I mean . . .

ML: Because they asked people, but people responded in many different ways about what they thought they needed.

S: Yes. I mean, for me for instance I told them that I needed a big house, I told them that I mean I would afford, I would afford a big house that okay my kids would have, study rooms and so forth.

ML: Yesss.

S: It was *if* I was normal, because I would work for that. It would be very easy for me to get a job *that I wanted.*

ML: Yeah. Yeah. You would have finished school, you would have

S: I had to finish school and do *whatever* what I wanted to. You know. I would have a car, drive it myself, take my kids wherever I want. You know. I would build them a house that they need, you know. You know. I mean such things.

ML: I mean what did you see yourself doing?

S: Hmm?

ML: What did you see yourself doing if you know if you hadn't become, if you hadn't become blind?

S: I wanted to be a teacher.

ML: Teacher.

S: Yes. I wanted to be a teacher. It was, I mean, I was a very good narrator, in actual fact.

ML: [chuckles] I can see that! Yeah!

S: [laughs] Yeah. So, I, you know even, even, even after, after, I mean during my matric, we used to, we formed study groups where one would go and prepare something.

ML: Ah yes.

S: You know and then teach it, to, to, to, to the group, you know.

ML: Yes.

S: They preferred me.

ML: [chuckles]

S: Yeah. I used to go and prepare – especially with history. I used to prepare

ML: Oh is that your subject?

S: Yeah, yeah, I was very good in history. Yes. Very, very good.

ML: Oh that's great.

S: Yeah. And biology.

Sipho does not think the perceptions of people with disabilities have changed give the wider events and changes in South Africa. In his perspective, the TRC did not treat people with disabilities differently, but perhaps should have. After more discussion about South Africa in general, he is just okay with how life has changed for everyone, like he is okay with his blindness. His experience conveys a metonymy or evokes a whole through connection (Wilden 1987:198). Metonymy uses one signified to stand for another signified in direct or close relation. Metonyms are based on indexical relationships between the signfieds rather than symbolic and iconic qualities as with metaphors. Another way to interpret this example is to say that Sipho's ways of knowing disability and the political situation have become connected in a more or less equally weighted manner.

For Francois, the experience of detention and rehabilitation are "completely similar," and as noted above, seem the same experience. Of all the participants, I spent the most time recording conversations with Francois. Hours of tape were recorded in restaurants, coffeehouses, at my cottage, the commune where he lives, in cars on the way to meetings, and other places. I have known Francois since 1998 and although he can be very astute and cogent about what is happening to him in the personal-is-political sense, he remains conflicted at times with his disability. There is more to his life story. He was once asked to give a lecture to 120 occupational therapy students at Chris Hani Baragwanath Hospital. He purposely leaves his crutches in his car. Once he is in front of the students he asks the lecturer in charge to go to his car to fetch them. While she is gone he explains to the students that he was at a club the previous night and he needs a volunteer. One student tiptoes to him and he instructs her to stand up with her arms out in front of her. She does and he leaps out of his wheelchair and into her arms and says "Last night I was dancing." After our laughter he tells me "And like, the initial miracle shock comes over." He went on to explain to the class that for a long time it was the occupational therapists and other rehabilitation specialists that inhibited him. "I said I spent a whole year of my life *mainly* learning how to ultimately walk on one crutch. Until I realised this is not my ambition in life." He said it is because the occupational therapist did not teach him the proper way to use a chair that he can now dance. Through this presentation a student whispered to a fellow student, "I wonder at what level his [spinal] break is" as though he was not there. He responds:

> I was facing the other way and I *spun* around and I stared at her. And I said, "Of what possible use to you is that information?" And she drew herself up, put her shoulders back, assumed a bit of height, and said, "It's medical." And I thought "You had your chance." And I was still thinking what I was going to say. And then I just looked her up and down, and up and down and then while I'm thinking. And then I just fastened on her breasts and said, "Yeah. It's about as medical as your bra size."

In one way, Francois understands how special disability knowledge and experience is, but in another way, grieves. The following story of Francois' demonstrates to able-bodied people that "help" can come in repressive forms.

F: . . . being left in the airplane for 20 minutes, and then somebody starts to push me from the [wheel] chair, [so I] grabbed the guy's arm, twisted it, and the only judo move I know, and dropped the fucker to the floor.

ML: [laughs]

F: And I felt quite bad. This is quite an old guy. And then he's lying there and he's just looking up at me, or kneeling there looking up at me and saying, "I was only trying to help." And you saw all the people, you know, crowded airport, all the people looking you know, with a look on their face like "fucking ungrateful crip."

ML: Yeahhh.

F: But I had anticipated that. And I immediately yelled extremely loud "I thought I was being mugged!"

ML: [laughs]

F: This is somewhat energy consuming and could get dangerous. And I *finally* worked out a way of doing this less violently. So I say I really appreciate that you're trying to help . . . but let me put it to you. If I saw that your zip was down on your trousers and I said nothing to you, came *right* up to you - and then at this point some action is needed - you lunge with your hand towards their crotch

ML: [laughs]

F: and I just pulled it up [demonstrating the motion of zipping up].

ML: [laughs]

F: The guy says, "No, no, no! No, no, no, no, no!" He was, "Mustn't do that! No!" I said, "But, but I'm trying to help. I'm just trying to help." He said, "No! No, no, no!" I said, "But I want to help!"

F and ML: [laughs]

F: He said, "No, no, no!"

F and ML: [laugh]

F: They guy says, "What would you like me to do?" I say, "You must ask me first." "Ahhhh!"

Much of Francois' narrative is devoted to such stories about making the able-bodied understand. He is a great translator through the use of metonmy, stimulating the indexical, or the existential relationship of the phenomenon depicted, the direct connection of the signified. His narratives include many examples of metonymy, evoking a whole thorough connection (see Wilden 1987:198). To me, a disabled person, Francois' stories have metonyms, but he translates them effectively to able-bodied people who would have taken the meanings as metaphor. The essence of a metaphor is in understanding experience in terms of another (Lakoff and Johnson 1980:5; see also Chandler 2001). Metaphors express the unfamiliar or tenor in terms of the familiar, the familiar being the vehicle with which to express the unfamiliar. Sipho's narrative also conveys metonymy, but applies it to himself and he has resolved some issues connected to his disability to an extent. For Francois, this has not happened to such an extent.

Pieter's shifting narrative of being okay with his disability to wanting to be able-bodied to not noticing his disability is an example of knowing his disability well, having the 'style' perhaps, but he also has had experience of able-bodied knowledge that he harnesses. The relatedness of style to things symbolic is not casual. De Certeau asserts that the symbolic "connotes" a singular (1984:100). Further, this is similar to Ewing's ideas of shifting selves and illusion of wholeness. Metaphors express abstraction via more well-defined models or examples. In Pieter's case, the well-defined model was once stable, but through his experience of living with disability he is sorting this shaky ground, over and over.

As will be explained in the next chapter, the narrations of other participants conveyed a sense of greater ease with their disability than did Sipho, Francois, and Pieter. The reasons for this are in the metonymic quality of their narratives. Metonyms stand for things where they are regarded as belonging, in an ontological sense. As a trope, a metonym is a word or phrase substituted for another in which it is closely related. An example is "Soweto changed the political landscape." Soweto, referring to the 1976 uprising, substitutes the place for the event. Such substitutions are important when looking at narratives as a whole. Is the experience of disability expressed in terms of something very closely related (metonym) or understood as resembling something else? Is disability the same as the experience under apartheid, or is it similar (metaphor) to the experience of apartheid? This is important because it demonstrates the reaches of oppression, the fight against repression, and the nature of meaning. Metonyms are said to reference indexical relationships, where the connection is not arbitrary, but rather draws attention to the thing to which it refers. An example is a weathervane indicating wind direction (Tomaselli 1996:30). There is a cause and effect relationship. A metaphor stimulates indexical and symbolic relationships. The symbolic relationship in metaphors is not motivated, but arbitrary, and there is not obvious connection to the idea it represents except through taken for granted convention (Tomaselli 1996:31). These modes of relationships emphasize the users' context. Although some semioticians may argue that my application of semiotic tools is too general, not appropriate, or not analytically correct, semiotics is nonetheless helpful. Whatever the application, semiotics has helped me recognize the depths of meanings in narratives and their critical practice.

WORLDS AND IDENTITY

Ontological security can be fostered in a variety of ways, such as Sipho's and Francois' hospital and rehabilitation experiences. But influences to ontological security can also lead to an embodied social suffering, and disability identity as a way out.

Participants' experiences in schools for the deaf provide a good example of institutions wanting to "help," and even provide a lifelong cohort, "Deaf community," or alternative family of sorts. Emma, who grew up in a school for the deaf, explains how she was controlled by the hearing for most of her life. Once she graduated, she took a job in sign language development, though she was taught signing was bad:

E: *My* identity as a Deaf person was a bit shaky, at the time. I wasn't sure about sign language or when I worked there as a sign language development officer. And my boss was a hearing person and *he* was the one to teach me. A *hearing person*, to teach me, to accept myself. He always teased me because I tried very hard to be like uh, how can I say, you know, accepting hearing culture, things like that. And he taught me many things. And that is what brought out my Deaf identity. And I have to thank him for that. At the time I didn't really understand how and what the connection was between sign language and English. I didn't really understand it and at the same time I did my Masters in linguistics so that's how I came to understand that sign language is a separate language from any spoken language. So, and ja, that really brought out my identity.

ML: That was an empowering experience for you then.

E: Ja. In a way, ja. Ja. And I think people need to learn to accept themselves. I grew up in the oralist mode and you know I was taken by my parents to speech therapy, etcetera and then one day I just got a motto: I was born deaf, stayed deaf, and I will *die* deaf. And I accepted that. So I'm a Deaf activist now. People look at me and they think I'm funny or I'm this or that. You know in the past I'd get so upset about it, but you know if they look at me funny, it's their problem. I'm fine with myself. Those who either grew up in the oral method or hard of hearing, if they can just accept themselves. Then if they want to go into the deaf world, let them go. If they want to go into the hearing world, then go.

Lindiwe had an experience similar to Emma's in that it took other people to explain that sign language was her language. In addition, she travels hearing and deaf worlds. An added component involves the reasons for her deafness, but it became secondary to her current feelings and objectives.

> I did ask my mother and I asked some of my aunts why I was deaf because they are very, . . . stories in the family. My auntie told me that I became deaf because I was always very clever in hearing school. I was always number one in my class.

> And my friends weren't very clever, you know, they were perhaps number nine and number ten. They [Lindiwe's aunties] believe that their mothers bewitched me. So that I couldn't be number one anymore. So they could take my place in school. And you know they go to *sangomas* and people believe these kind of things.[45] My mother said you were just ill, you know. You fell ill, that's it. So I don't know really what to believe. I'm Deaf, you see. I don't need to investigate the reason for it. I am Deaf. [. . .] I accept it and I'm happy to be Deaf. I have a language which is sign language. I'm happy.

Like other people with disabilities, Deaf people understand accessibility is dependent upon perceptions of the able-bodied. I asked Lindiwe and Justice if deafness is a disability, as they are aware of the wider Deaf movement's ideas about deafness not being a disability. Globally there is a movement for "Deaf culture." This means several things. In the United States, the tensions within the Deaf community are based on whether people embrace or reject sign language, and whether they identify themselves as Deaf, deaf, hard of hearing, or hearing impaired. It has been my experience in the United States that the Deaf community does not accept me as I am not prelingually deaf and sign language is not my primary method of communication. In some Deaf communities I will always be an outsider for these reasons. In South Africa, however, these distinctions were not an issue. I would sign and learn local signs and signs in SASL. But people's underlying treatment of me was based on experience of hearing loss and the feelings of exclusion. The method of communication had little to do with acceptance, but the fact that I embraced my disability was important. These issues were explicitly discussed, but the Deaf in South Africa have other defining criteria. Lindiwe's response to whether deafness is a disability:

> I think it's both. Um, a bit of both. I personally, if I'm with deaf people out there, in meetings and when we have a conversations, I am not disabled. But once I am with hearing people in the social environment, yes, I'm disabled. Because of the communication barrier. But today, I have a sign language interpreter, I don't feel

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[45] A *sangoma* is a diviner. There are also *inyangas*, or healers.

> disabled because we can all understand one another. So it's a bit of both: disabled and what, not disabled. So I don't really know what answer to give you. I think a bit of both.

Justice, who is involved with the deaf in Gauteng, says there are a variety of ideas about deafness and disability. His response was that yes, deafness is a disability because of the unfair treatment they experience, especially in terms of employment and education. For many of the Deaf participants embracing sign language means claiming their deafness. The situation of language medium for education, oralism, sign language, total communication, or other methods, though, impacted the lives of the Deaf. Parents are conflicted on how to handle their deaf children and often want them to go to oralist schools because they do not know other methods exist, or they have difficulty coming to terms with their child's deafness, wanting them to be productive adults through lip reading and voicing. The control of hearing teachers and parents inculcated the idea that sign language was bad. When Emma thinks of the deaf school experience she thinks of oralism. Several issues collide in her narrative: hard of hearing and deaf distinctions, and treatment by oralist teachers.

> All my life when I grew up, it was in the school for the deaf. . . . And what I have seen is that deaf or hard of hearing people who come to the school a little late from a hearing school – the others would love teasing them. And that's awful! I mean it's not nice the way in which they do that. If the deaf person accepts sign language fully, then it's fine. Same with the hard of hearing. Deaf people seem to always assume that hard of hearing people are a little more intelligent or clever because they can hear so they think that people who can hear something should have more knowledge. . . . Then we look at the hard of hearing children. The majority of them *control* the deaf. Because they speak well. The teachers obviously sweet-talk them. And I see a very interesting thing: many hard of hearing children are not bright. Their language skills are appalling. I mean because they hear half and they see half signs, they don't really have a defined identity. Most of them, when they finish school, they can either choose whether they want to go into the hearing world or into the deaf world. Some still just hang around between the two. And those who choose to socialize with the deaf and be part of the hearing world, I see they are fine. Those who go into the hearing

> world always tend to come back, whether it takes ten or twenty years they come back . . . crawling. Those who hang around in between the two worlds certainly do not belong in the Deaf world.

These "worlds," in adulthood, become more visible and deaf individuals have made heavy decisions concerning their family and relationships. They often have to traverse many realms. Justice explains that he lost his hearing at a young age and was taken to a hospital with a crèche for deaf children.

J: So they took me there and I learned the basics of sign language. The following year I moved to primary school for the deaf. From there it was a new environment. But this is how I learned sign language. But, at home, there is no one family member who is fluent in sign language. I can speak a bit with them, sign and speak.

ML: But do you have almost like a larger family in Deaf culture?

J: I can say they're both. Because I can move in both worlds, the hearing and the deaf world.

Maneuvering the deaf and hearing worlds with more deft and security, however, came with understanding sign language as their language. Justice explains that although he did learn sign language earlier than many of his deaf peers, it was not until high school that he defined himself as Deaf. He saw that deaf people were being forced to choose and study certain subjects and that they did not have a choice. Justice and his colleagues came together to object to this and as a group still work towards Deaf rights as adults. They are a group of friends with a bond based on teaching each other sign language and questioning the authority of teachers, and later, deaf organizations. This group of black Deaf people thinks of themselves as black Deaf intellectuals and has maintained a network of friendship and advocacy.

Race is sorted in a unique way because of the nature of a somewhat closed community or the "d/Deaf world."

ML: Have things changed for deaf people since the end of apartheid?

L: I think, you know, yes. We, it has change, because I think our problem is that many hearing parents of deaf people control them still. Like for example, again you know at the time it was apartheid in this country. We had some against all the black and white children got together, deaf children, and they used to communicate although their parents would watch them and say, "You're not allowed to." But I think many things have changed for the deaf in South Africa.

Similarly, Emma answered:

> My view is the Deaf community and the problems *we* encounter in terms of race is influenced by the hearing community. I mean the deaf people come from all different linguistic communities, right, so they come together in a school for the deaf. And they'll say, "Ja, we're all deaf. We are the same." But still they have that racism issue because of the influences from the outside. Many deaf people won't agree with me and don't agree with me, but . . ..

And:

> My experience with my white English community was strongly oral, oralist approach, so you know they had one sign for different things. I go to the black community and I can see they have *so* many different signs. They're illiterate! But they use proper sign language, correct facial expressions, right syntax – everything. But after apartheid, you know, the white community got on par with that, especially the young kids, the children. Not the older deaf – please, not them. Certainly not the white or the black deaf; but I look at the children and I see they have really developed. But I think overall the teachers have never been able to sign. It was the older deaf children in the school who would teach the younger ones the signs. So that goes for all schools and have always.

Defending the Deaf way becomes an exercise in self-representation and identity, and at the same time is punctuated by the ever-present "race issue." The specialness of the Deaf way is defended because of control by the hearing and their racist attitude. An assumed wanting of unity or common understanding of deaf ways is inhibited by those in control. Advocating language rights, the Deaf who were interviewed maintain that SASL is an African language that does not just belong to the deaf, but to hearing people as well. They do not just want a perceptual change in thinking about sign language, as some alluded that the deaf are suspicious beings because of the nature of sign language being primarily visual to the able-bodied, but they want SASL to belong to everybody.

DISCUSSION:
DO TYPE AND AGE MATTER?

In Chapter One I stressed that there is a need to include people with a variety of ages of disability onset and disability types in this study. Now I state that the age of onset and disability types do not factor heavily or at all in the South African experience of disability identity, at least among the participants in this study. This is vital. Disability identity, as a social construct, is similar to other identities, such as gender and ethnicity, and needs to given the same weight because all identities exist in relationship to contemporary structures of power. Just as women were generally excluded from early ethnography, the disabled were but continue to be ignored by anthropologists. I stressed age of disability onset and disability type in the research design because those social scientists focused on disability insist that disability type matters. That the age and type does not figure significantly to these participants or that they achieved the same insights is exciting and significant because it shows that those criteria do not limit disabled peoples potential to understand disability socially and politically, and importantly, to act collectively. It strengthens the argument that the political changes in South Africa were far reaching and that the movement could harness that discourse.

I problematize disability type because of the unequal treatment by social scientists to disability type and their deficiency in possibly extending that argument to other disability types or exploring whether disability could be an area of identity formation. Deafness has been intriguing to anthropologists, perhaps because of the 'invisible' nature of the disability, the public but secretive beauty of signed languages, the close cohort communities the deaf and their families create, or how the lack of hearing is socially isolating. The ironic twist of anthropological studies on deafness is that it is not elaborated in medical nor disability discourses. Deaf people are somehow *sui generis*. Becker (1983) uses a life course perspective, interviewing old deaf people who essentially created a cohort with fellow students from their deaf residential school and maintaining those relationships throughout their lives. But what about those people who are not prelingually deaf? Groce's 1985 ethnography is the product of historical and genetic research. For approximately 200 years a high prevalence of hereditary deafness on the relatively isolated island of Martha's Vineyard represented an important and unique case: the deaf were not referred to as "the deaf". Hearing people were bilingual in English and Island sign language, adjusting the disabling environment for the integration of deaf people and their families. One of Groce's 80 year-old hearing informants remembers her thoughts as a girl: "Oh, . . . those people weren't handicapped. They were just deaf" (Groce 1985:5). What about the people with other disabilities on Martha's Vineyard at the time? Preston's 1994 ethnography on CODAs is yet another perspective, but he is more cunning in his abilities to find a widely-held perception in American Deaf communities that deafness is "not disabled."

Considering the age of disability onset was purposeful because of the differences in experience with institutional and other loci of power. As I stated previously, people disabled at a birth or a young age had critical life choices made for them and often existed in segregated places and spaces. Those disabled as teenagers or adults had to reevaluate their lives and conclude that segregated places were unacceptable. I was concerned that perhaps people born with disabilities or disabled at an early age were sheltered to the point of near total social seclusion. I was also concerned that people disabled as teenagers or adults would dominate the leadership of the movement organizations because of their previous able-bodied knowledge. I am relieved this is not the case.

CHAPTER SIX

FINDING ACCESSIBILITY, FINDING RECONCILIATION

This chapter, as the end of Part Two, concludes the discussion on selves and identity. To summarize Chapter Four and Chapter Five, identity is a signifying practice, but so too are selves. Disability identity, like other identities such as race and gender, pursues political goals, and is based on an expanded definition of accessibility that includes the removal of physical, social, economic, political, and other barriers for meaningful participation in society. As I have often repeated, "South Africans have multiple identities in common contexts, and common identities in multiple contexts" (Thornton 1996:150). Disability identity was initiated when the disability rights movement began questioning and rejecting the individual perspective of disability as tragedy, and engaged with the larger struggle for human rights, most prominently in the revolutionary context of the early 1990s. Participants came to understand their disabilities through various identities and discourses. Their self or selves shift in response to context, and can exist in tension or fusion, from one conveyed memory or experience to another. In one sense, the struggle for disability identity is explained as no different from, similar to, nothing to do with, or informed by the struggle against apartheid. In another sense, a disabled identity is accepted into the shuffle of selves, rejecting a dominant discourse of disability as Othering.

The previous chapter included excerpts of narratives where experience, self, and identity surfaced and oscillated, where selves shifted and multiple identities were thought of or referenced. Pieter's narratives were one such example. However, a greater number of participants marry the experience of disability and other identities into a united philosophy, where disability, regardless of the age of onset or disability type, brought not only a new perspective, but a philosophy about society and how it should work. Only two participants rejected their disability not because of a lack of understanding the political nature of disability, but because accessibility was not embraced by people who by example should. For the majority of the participants, however, this united or closely related perspective of disability and other identities is something of a liberation philosophy. This last section reiterates how social movements concerning disability can engage other social forces, and argues that participation can foster identity formation. The South African disability rights movement pushed for the representation of disabled people at a time of transition and democratization, when core concepts like citizenship were redefined. The link between accessibility and human rights is discussed below in terms of the South African Truth and Reconciliation Commission. The relationships of participation, identity, selves, and philosophy are extended to discern how participants made sense of human rights at various points in their narrative telling.

SELVES AND IDENTITY IN DISABILITY AND LIBERATION

While the disability rights movement participated in events leading to the transition to democracy and put disability on the national agenda, one important event did "nothing" for the disabled according to participants. The Truth and Reconciliation Commission (TRC) provided a space for public memory and public discourse (Hamber and Wilson 1999) with the added implications of displaying a public transfer of power and justification of a new moral order (Minow 2000). As a recovering of history for the majority of people who suffered the apartheid regime, the efforts to make the TRC hearing public was a partially healing event. Truth commissions, however, can have the effect of a grand narrative effort to place atrocities in the past or as a monument of history (Fabri 1995; Minow 2000). Although narrative and memory are individually and collectively important, the ardent desire for change through the mechanism of truth commissions can mediate the realities of those victimized. Recalling Sipho's story from the previous chapter, his experience was like everyone else's, but hampered the political gravity.

The Human Rights Violations Committee (HRVC; one of the three TRC committees) hearings were often televised or broadcast on radio and captured representations of the disabled through this process. As an example of large-scale official recording of human rights violations, the public broadcast of HRVC hearings was also a display of victims and survivors. What may not be emphasized enough is that apartheid created a disabled population. Acknowledging pain and loss of social actors is a political act (Ramphele 1997:101; see also Das 1997 and 2000) and although the TRC was successful in this to an extent, the disabled still seem portrayed as belonging to a welfare sector. There are many potential outcomes of the portrayal of the disabled in countries in conflict or transition. Soldiers disabled in Nicaragua assumed new roles due to their political importance as symbols of the revolution (Bruun 1995:197). Sandinista war heroes and disabled Contra soldiers ultimately became symbols and were used in terms of propaganda yet they gained new status and further normalized the disabled body (Bruun 1995). The unit of government in Afghanistan responsible for the disabled is the Ministry of Martyrs and Disabled. People with physical disabilities from political and armed conflict gained attention and a medical professional approach to disability was aggressively perused for the war injured at the expense of provisions for other disabled people (Ministry of Martyrs and Disabled 2003). Overwhelmingly, participants believe that the TRC had nothing to do with disability. In one way, the testimonies of the disabled in the TRC perpetuate an individual model of disability as tragedy. Participants responded that they, themselves, needed to be the ones who educate and demonstrate through daily practice what disability is all about.

Again, accessibility to the disabled participants in this study means acceptance, inclusion, and fulfillment of rights. But accessibility also weighed heavily in the responses of a few participants who expressed a desire to be able-bodied. This scenario was described with stories that would break off into other topics. For example, Queen described a play she saw and relates it to her experience, connecting past and present emotions to convey the tenor of the similarities:

Q: You know, that is a play which tells you of the ordinary person that was in the struggle. Because somehow now you know some of us are not even recognised because we didn't go to exile or we were not jailed or what have you, but as far as you were black you were part of the struggle because they were also for battles you were fighting. As I'm telling you now that *I* was raided at two o`clock in the morning simply because I was applying for a visa to have Zimbabwe – a *disabled* Zimbabwean to come to South Africa! And I, you know, the, as a black person I started exactly as any other black person with my disability. But that doesn't mean much because you know I didn't march, I didn't go and *toyi-toyi* and, that is the play in which is actually exposing some such things so . . ..[46]

ML: But you still felt part of the struggle.

Q: I didn't have an option! I was black! I didn't have an option. I was black. I slept on a dog mattress in a white house you know, and a dog blanket next to a cold stove so you realize that these people weren't even that well off and their dog could go into the bedroom with them. And it was because of my pigmentation.

ML: Yeah, yeah.

Q: You see.

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[46] *Toyi-toyi* is a protest dance and was often practiced during marches and demonstrations during the 1980s. Van Schalkwyk's (1994) research found that *toyi-toying* is a reclaiming of the right to occupy public space and a way to participate in civil society.

Queen does not believe much has changed in South Africa since the end of apartheid. Her blindness should not have mattered, in her opinion, to the resistance movement. Her past experiences in trying to introduce TABBA and engage with some resistance leaders during the 1970s were not taken seriously. Further, she was caught up in the disability politics and organizational tensions when SHAP was in the process of defining and proposing how DPSA should work.

Ben is another participant whose frustrations with accessibility make him wish to be able-bodied. Although shot by security police in Soweto in the 1980s, he does not see his disability as political, but something that "more or less just happened," and that was a fact of life in the township. Ben says he is living "with it, I'm understanding it," about his disability. Although he is successful, he says he has internalized these feelings of displacement and that his success as a person with a disability is not acceptance. Both Queen and Ben are certainly aware of their disabilities, and reject their perceived and real unfair treatment. This, indeed, was an illusion of wholeness (Ewing 1990) to me. I was very surprised to see a rejection of disability despite their long-term involvement and good arguments on repression and oppression. On reading and re-reading narratives and fieldnotes, I did find that their selves shifted in unique ways. The passage of Queen's (above) locates or roots her rejection of her own disability to the unfairness and injustices of being black and seeing little change in the country.

As meaning can change, it can also linger or grasp, have temporary uses or be recycled. In Chapter Three I indicated that DPSA was a message, itself, of the disability rights movement and that participants have held on to that message and participants are now critical of that organization because although rights have been won, the attachment of message and medium remains and the organization is looked to for action. The life of that meaning remains and has not changed dramatically. Another example of a meaning being used, maintained, recycled, or differently applied is with the DEAFSA march, held on February 7, 2003 in all provinces. Their demands were for SASL to be recognized and implemented as an official language in the education of deaf students, that SASL become the official medium of instruction in all schools for the deaf, that all teachers of the Deaf receive proper SASL training, and that the Department of Education accept responsibility for developing SASL learning materials. The organizers in each province delivered these demands in a memorandum to their respective Department of Education. Education in SASL is believed to be a human right to Deaf South Africans. Some participants in the march made the connection of the 1976 Soweto uprising, carrying boards that said "Forced Oral Medium of Instruction Equals Soweto Uprising." This comparison was readily understood. Deaf people and people with other disabilities attended this march, myself included.

Meanings can also become secondary to experience and gained knowledge, being replaced by new understanding. The narratives of people who accept their disability did not devote much time to their early experiences of disability in their lives, regardless of disability type or age of onset. These aspects became secondary to an understanding or meaning of rights and accessibility, or included disability in their inventory of selves in a dialectical and positive way. Lindiwe's example, included in the previous chapter, told how her family took her to a *sangoma*, and how her mother said she became ill. But though involvement with the Deaf community and understanding sign language most of all she is able to say, "I'm Deaf, you see. I don't need to investigate the reason for it. [. .

.] I accept it and I'm happy to be Deaf. I have a language which is sign language. I'm happy." Although selves and identities are signifying practices, this example shows how identity is a socio-emotional need (Shaw 1994) and politically motivated. Selves, in their narratives, were not an illusion of wholeness but a comprehensive understanding. Inaccessibility is a source of frustration, but becomes empowering for self-representation. Thandi says, "But being a disabled person has taught me many things. To be assertive, to know who I am and to know what I want in life, you know." Another reported:

> Actually, I always say to people you know I realized something. Before I became disabled, I wasn't so fast in learning things but when I became a person with a, I learned a lot of things, I learned a lot of you know environment, people, structure, and whatever, and whatever.

Further, those who include disability in their selves used it positively to reinforce their personhood with little doubt. Some participants equated their disability with their gender. For example they agreed that they were as much disabled as they were female. Participants also compared disability identity both implicitly and explicitly to tenets of Black Consciousness. Tisetso, for example, had a quote from Steven Biko printed on a sheet of paper and taped to her wall. It says, "The basic tenet of Black Consciousness is that Blacks must reject value systems that reduce their dignity." I asked her if the disabled are finding a voice through such influences. Her response was:

> Yeah, I mean to a large extent it's about identifying with the philosophy. Um . . . and I think . . . for me it's more for as a black person, um, than a disabled person I think that maybe to, to identify with it. And certainly the principle that he, he talks about certainly applied to you know, to any grouping that is you know is under an oppressive system which is what disability is all about. I think that's how I separated you know when I say um identifying with it as a black person that's under South Africa and racial discrimination but as a disabled person it's more broad and general as you were saying anywhere in the world. Because anywhere in the world disabled people are oppressed you know so it is an oppressive system, but it need not only be *just* for South Africans, um system with its history. It's a more generous thing.

Adeela, active in both the women's movement and the disability rights movement, takes the same philosophy and applies it to her life:

> Firstly at the individual level in terms of how do, how do I engage or how do I allow society to engage *me* as a disabled woman, is that firstly I don't allow society or any individual in society to engage me in an undermining way. I will not tolerate that. Um, and people pick that up, that you know, that they're not going to get anywhere of trying to undermine me anyway. Um and you've constantly got to assert yourself. You know and let them know this is what's acceptable and this is what's not acceptable.

This is not metaphorical. Disability and gender are a united entity in this passage. Tisetso's passage about Black Consciousness is not as metaphorical but makes a close comparison to race, disability, and inequalities experienced globally. The following passage has a metonymic quality, where one word or phrase is substituted for another to which it is closely related.

> Never say I'll never sit in a wheelchair. No, I'm not going to put a ramp. Provide. It's something which has to be there. We do exist and we've been in existence, it's just that the previous eh government did not recognize us. We've got abilities.

The experience of being black and disabled is closely related in the sentence "We do exist and we've been in existence, it's just that the previous government did not recognize us." The message conveyed is that both black people and disabled people were not recognized by the apartheid government. I remember when I was first in South Africa and never heard people say the word "apartheid." It was conveyed as "then," "before," "the previous government," "before the dispensation," "used to be," or "before elections." That was in 1998. In 2000, a few people spoke the word. During my last trip I realized more people were saying the word in conversations: "My daughter was born during apartheid," or "I lived in Orlando East during apartheid."

Adella describes such processes of appropriation and making new meaning elegantly and succinctly. Adella and other participants have gained a holistic understanding through such experience that is empowering and accountable to acting in a rights-based democracy.

> As South Africans you know we've got to unlearn our own racism, and everything that's been taught in terms of our difference and looking at difference first and classifying and judging people on the basis of their difference. So it's about you know you've got to de-label yourself, right, and de-label how you view the world is going, and so on. So on that level, the whole issue around valuing and managing diversity is an important issue. And looking back at our achievements over these ten years, uh we're probably the country that has achieved the greatest amount of progress in terms of disability over the shortest period of time. And you know it's very progressive stuff ranging from our constitution which is considered the most progressive in the world, to a range of legislation. We've got a very enabling environment here that you know outlaws discrimination on the basis of disability.

DISCUSSION:
ACHIEVING DIGNITY

There are participants in this section whose stories appears elsewhere in this dissertation, specifically in Chapter Four. There, they were telling stories about their fight for recognition and voicing their frustrations of being treated as objects. Participants questioned assumptions of a different mental capacity, as in their ability to learn English or calculate math equations, and such queries are essentially demonstrations of signified meanings that are appropriations or remaking of texts also critical to the success of a rights-based, democratic post-apartheid South Africa. In Chapter Four, participants were telling stories with a beginning and end about an experience or confrontation. But the portions of narratives in this chapter were taken from points in the narratives where participants gave a comprehensive statement on their status as disabled.

It was a story of the lesson learned, or the philosophy drawn from experience. These stories have no end, but are sustaining in their promise for change.

As I stated in Chapter One, anthropologists are concerned with meanings. Conflict takes place in meanings (Escobar 1992:408; citing Melucci 1988) and movements take place in fields of meaning (Burdick 1995:369). The organizational and strategic components of social movement organizations essentially confront social forces. It cannot be assumed that a given social group develops an identity first and then engages in strategic action (Canel 1997:202). It was through the process of interaction with other social forces that developed disability identity, where participants became involved in the appropriation of new meaning. This everyday practice, where the examples in Chapter Four are but a few, sustains the movement. It is achieved dignity and an exercise of human rights.

PART III

CHAPTER SEVEN

CONCLUSION

One of the goals of this dissertation was to show how disability is organized and defined in the context of democratization and human rights in South Africa, a purposefully broad topic. South Africans are celebrating eleven years of democracy at the time of writing. The disability rights movement, by engaging with the ANC, worked and continues to works for the absorption of the disabled into the discourse of democracy in the new South Africa. Indeed, the end of apartheid was instrumental in the introduction and implementation of a social model of disability. Both the OSDP and INDS work toward the implementation of the social model of disability. In practice, however, there is a real concern that disability is last on the national agenda. That is, although race targets are coming close to being met, gender lags behind and disability may become addressed if any energy or resources are left. According to a recent report, 83 percent of government departments do not have disability policies and those that were found to integrate or include the disabled were not translatable to strategies or programs that seek to integrate the disabled into society (Research Dynamics South Africa and Office on the Status of Disabled Persons 2000:vi). This is but one problem identified in the disability sector and movement. Neglect of disability in government departments becomes personal and contributes to answering both the above goal and the second goal of this dissertation: identifying and describing the multiple ways disabled South Africans identify with their disability toward an understanding of difference or political identity.

Apartheid created a difference in the experiences of disability. Where the white experience of disability had been influenced by medicine and welfare through special schools and institutions sponsored by the state, the black experience of disability was and is characterized through being the target of structural violence, including the maintenance of poverty. What they have in common is living under able-bodied ideology. But the process of understanding disability socially and politically is dependent on multiple factors for these participants. Chapter Three described how the weakened apartheid state and the disability rights movement pursued engagement with the ANC, helping elevate disability as difference. Though social movements can provide a space for the practices of the movement's message, identity can develop in the process of interaction with other social forces (Canel 1997:202). Although many of the movement's goals were achieved, the meaning of disability as a social and political identity needs to continue at the level of social integration (Canel 1997:199). Including disability in the new South African constitution, government representation in the form of disabled members of parliament, the Office on the Status of Disabled Persons located in the Office of the Presidency, and the White Paper on an Integrated National Disability Strategy are achieved goals, but widespread understanding of disability as seen by disability activists is not fully actualized. This is evidenced by the continued struggle of disabled activists, the descriptions of two types of disability in the township (those who participate in society and those who live behind closed doors), lifecourse achievements expressed as desired for all disabled persons rather than common experience, the worlds of disability, and struggles in everyday life. Therefore, while medicine does play a role in the lives of the disabled, experiences with the institution can be empowering or inhibiting (as described in Chapter Five), and it is only one contributor to participants' understanding of disability.

The persistent and exigent theme of accessibility in the narratives of participants points to the ways the disabled are subjugated in multiple ways. Accessibility, as demonstrated in Chapter Three and Chapter Four, comes to mean acceptance, inclusion, and fulfillment of rights. Chapter Five and Chapter Six introduced 'self' and finding the nature of selves, whether disability shifted or existed in tension with other identities, was also critical to wider social change. Such research is better geared to assess the potential impacts of implementing a social model of disability, a goal of the global disability rights movement. Disabled South Africans continue to learn about their disability. On the one hand, the disabled manage their disability in ways similar to that of other identities. On the other hand, they fight with that knowledge and experience or it exists in tension and secondary or inferior to other identities held.

This dissertation makes five contributions and they are discussed below. The first contribution is the recognition of disability as a potential site for identity creation. Medical anthropology is appraised in terms of the potential to misrepresent or alienate people with disabilities. Second, although a social suffering perspective attempts to bridge issues in medical anthropology and psychological anthropology, a feature I welcome, it was not appropriate for this research without significant changes. The danger of the social suffering perspective is in its assumption of repression in the aftermath of social forces. The participants in this study are or have been actively engaged in a movement, creating and maintaining spaces for new meaning to their realities and pushing for change. This discussion is presented below under *Social*

Suffering vs. Social Justice. Third, *The Body/Embodiment Debate*, provides a family history of sorts to the social suffering perspective. Disability identity questions whether either medical anthropology or psychological anthropology is needed for the study of disability, and the debate is given below. Fourth, the importance of semiotics in the analysis of this study contributes to a modified social suffering approach. I used conceptual tools such as metonymy and appropriation to aid in understanding the nature of meaning which was critical to this work. Fifth, disability is a human rights issue and every research endeavor must include people with disabilities in their research.

Medical Anthropology and Identity

The standard dichotomy of 'illness' and 'disease' ignores disability. Indeed, if "*Disease* refers to a malfunction of biological and/or psychological processes, while the term *illness* refers to the psychosocial experience and meaning of perceived disease" (Kleinman 1980:72; original emphasis), disability is something else. Words like 'chronic' and 'permanent,' and phrases like 'the outcome of illness' and 'those who don't get well' are used to describe disability (Estroff 1993). Disability has been left behind because it fits into the far reaches of illness experience yet is qualitatively different to the extent of exclusion from this axiom. Perhaps people with disabilities do not fit well into a research design, foiling the projection of data about them to the general population.

The majority of medical anthropologists focusing on 'illness' fail to recognize that people in their research sample may not see themselves as such, but rather consider themselves 'disabled' and part of a much wider community of disabled people. For example, people identified with multiple sclerosis may be labeled as 'ill' by medical professionals, but to themselves and to segments of the disabled community they are often viewed as 'disabled.' Regardless, of whether or not the people they interview are comfortable with this identity, medical anthropologists must recognize the potential for chronicity [defined by Estroff (1993) as the merging of identity with diagnosis] or adherence to a disability identity. Perhaps a lot of people with disabilities exist in between these categories.

In another respect, medical anthropology concerns itself with health and well-being. In the 1990s medical anthropologists began in more earnest to investigate the components of well-being. Bolton (1995) has found misuse in explanatory models used by medical anthropologists. He maintains that the products for analyses from such methods illustrate an over-reliance on text for interpretation to the extent that they discard the emotional and cognitive rules involved in the process and production of such ethnographic data. Braithwaite (1990) takes this argument a step further by locating the strategies involved by people with emergent disabilities and identifying how they navigate able-bodied discourse as a rich communicative space. As opposed to the mere description of symptoms and the nature of the doctor-patient relationship, Taussig's (1980) example is one of how medicine can jeopardize patient self-understanding. Helander (1995) accurately finds how anthropologists misrepresent people with disabilities. He critically explains that disabilities cannot be treated generally and their definitions become largely useless because they focus on a single or limited type of disability (such as disfigurement or paralysis). The experiences and personal meanings of disability in everyday life were better served by seeing disability as a potential site for identity formation. In the discussion to Chapter Five, I stated that the age and type did not figure significantly to participants and that they achieved the same insights. This is exciting and significant because it shows that those criteria do not limit disabled peoples potential to understand disability socially and politically, and importantly, to act collectively. The corporeal bantustan was not successful in keeping these participants down and dependent.

Social Suffering vs. Social Struggle: Everyday Subjugation and Collective Action

This dissertation also challenges the social suffering perspective in anthropology. "Everyday violence" (cf. Scheper-Hughes 1992) has spurred interest in the workings of violence and has evolved into the study of "social suffering" (cf. Das 2000; Kleinman, Das, Lock 1996, 1997). Social suffering as an approach attempts to collapse the dichotomies of individual and social levels of analysis, representation and experience, and identifies the connectivity of state and institutional power to everyday life. In this way, suffering can be seen as at once collective and individual. Farmer (1992, 1997), Ramphele (1997), Scheper-Hughes (1992, 1998), and Taussig (1987), for example, understand violence and social suffering as embodied. They examine violence as a complex construct with contradictory, ambiguous, unpredictable, and unexpected aspects. The social suffering perspective, inspired by everyday accounts of subjugation and with gained experiences by anthropologists using a social suffering perspective, contributes to the literature on social justice, but in a peculiar way. As both critical and interpretive, a social suffering perspective could use the concept of hegemony to explain social suffering and highlight how people may not be able to advocate for change (e.g. Gramsci 1971; Williams 1977, 1980). In this way, 'embodiement' seems similar to hegemony. But, appropriation of symbols that once oppressed can become "co-opted in rebellion as a source of identity," as Nordstrom and Martin note (1992:6; West 1988:23; Williams

1980:40). Nordstrom and Martin observe that the concept of hegemony is "a more fluid vision of the way power interacts with culture, not a simplistic model in which economic elites plot to control their world" (1992:6). Further, influenced by Foucaultian concepts of power and discourse, ethnographies became a collection of micro-analyses of power and everyday resistance, and, perceived as unorganized or non-collective, the anthropologist overlooking collective struggles for social justice (Burdick 1995:361). In other words:

> When resistance is confined to the level of cultural expression the task of specifying the nature and form of oppression is often left to the anthropologist – who, inspired with a cultural spirit – discerns the hidden meaning behind the informant's statements and practices. In contrast, when informants begin to organize consciously, they specify their own understanding of structures of domination and employ tactics that respond to local circumstances. [Nordstrom and Martin 1992:7]

A social suffering perspective that attempts to draw a circle around experiences and expressions in terms of discourse and calls it embodiment misses or is not appropriate to the realities of participants in this study because participants are engaged in a process of politicizing a disability identity in the context of transition, democratization, and post-apartheid South Africa. Theories of embodiment focus on how bodily experience can mediate the ways in which people grasp and understand objects and sites of meaning production (Csordas 1990), hence an emphasis on discourse. Given this emphasis on meaning production, theories of embodiment further study of culture and the self (Csordas 1990). Theories of embodiment emphasize the phenomenology of perception, ontology, and semiotics (Merleau-Ponty 1962) as tools to find meaning and change in meaning. But theories of embodiment, to me, and for use in a social suffering perspective, come to emphasize the phenomenology of perception, ontology, and semiotics as tools to find meaning and change in meaning *perhaps resulting from not only the body but also wider sociocultural forces.*

The lens of social suffering is one way of negotiating the body-embodiment debate (discussed below). Each approach involves basing analyses in empirical research, yet beginning with different units of analysis. Anthropologists using a social suffering perspective seem to focus on the ground of embodiment, using semiotics implicitly. Nevertheless, social suffering as an approach no longer seems to be in a liminal space in between medical and psychological, but may become the property of one or the other as anthropologists redefine, write, and publish.

The Body/Embodiment Debate

Anthropologists utilizing a social suffering approach have been influenced by their backgrounds in medical anthropology and psychological anthropology. In recent years, distinguishing between the two sub-disciplines has become difficult for several reasons. One reason for such overlap is the common aims to represent human suffering as it pertains to the body, experience, and inequality. Some of this confusion is also owed to the far-reaching impact of Western Cartesian science on the development of each sub-discipline (Lock and Scheper-Hughes 1990; Suárez-Orozco 1994). I agree with Good (1992:190) in his observation of the irony of anthropologists denying their support to the mind-body dichotomy yet using “different forms of analysis of conditions such as diabetes, on the one hand, and schizophrenia or depression, on the other.” The works of both medical anthropology and psychological anthropology are successful in illustrating power, coercion, domination, and structural inequalities; however, each sub-discipline seems to hold onto different strands of "interpretation." It seems medical anthropologists have spent more effort in developing theories of the body while psychological anthropologists have focused on embodiment. Lock and Scheper-Hughes (in various combinations and publications) and Good (1994) problematize the body and bodies and begin to find meaning. Some of these 'bodies' become conceptual lenses for understanding experience (the body–self of the individual body, the social body as a natural symbol) and have made contributions to interpretive anthropology (DiGiacomo 1992). Theories of embodiment are qualitatively different in that they focus on how bodily experience can mediate the ways in which people grasp and understand objects and sites of meaning production (Csordas 1990). Csordas' paradigm of embodiment is based in psychological anthropology and leans strongly in the direction of phenemonology (1990:5). "This approach to embodiment begins from the methodological postulate that the body is not an *object* to be studied in relation to culture, but is to be considered as the *subject* of culture, or in other words as the existential ground of culture" (Csordas 1990:5). Given this emphasis on meaning production, theories of embodiment further study of culture and the self (Csordas 1990). Theories of embodiment emphasize the phenomenology of perception, ontology, and semiotics (Merleau-Ponty 1962) as tools to find meaning and change in meaning, perhaps resulting from not only the body but also wider sociocultural forces.

The common footing for these anthropological interests may be with a critical-interpretive approach, but epistemological underpinnings of body and body knowledge are generally split by sub-discipline or teeter in between in a creative space. This distinction goes beyond representation of the body: this distinction forges different theories of sociocultural dimensions of power. An approach incorporating semiotics can uncover how meaning, experience, and emotion can be inseparable from hegemony in not owning the narratives of informants but rather through the wider discursive practice. This wider discursive space is vital because although the social context of memory and experience outweighs narrative telling, it is through narrative that meanings can be seen as appropriated. As a way of generating meaning, memories are grounded in response to historical contexts and become incorporated into ways of knowing.

Conceptual Tools in Semiotics

With a more developed understanding of semiotics, anthropologists using a social suffering perspective can more accurately use semiotic conventions or tropes beyond 'metaphor.' Lock and Scheper-Hughes define the task of critical-interpretive medical anthropology as "first, to describe the variety of metaphorical (conscious and unconscious) about the body and associated narratives and then to show the social, political and individual uses to which these conceptions are applied in practice" (1990:49-50). Although social suffering has expanded on a critical-interpretive approach, anthropologists sometimes use metaphor in its literary sense, to get to the tenor of seemingly unrelated descriptions of reality, the unfamiliar expressed in terms of the familiar. I used this writing convention in Chapter Two, with corporeal bantustans. In Chapter Five and Chapter Six I analyzed narratives with attention to modes of relationships, or how participants characterized their experience of disability. In these ways semiotics can be used more for analysis than writing, being more accurate to participant's interpretations than to those of the anthropologist.

Research and Human Rights

Given the above explanations for greater attention to identity I am also influenced by an African perspective to human rights. As stated in the introduction, anthropologists have contributed to the efforts of human rights through cross-cultural research and monitoring (Messer 1993:221). I, too, am dedicated to the exploration and adoption of an inclusive concept of rights that, as Farmer suggests (2005), conceptualizes pathologies of power. But why do anthropologists continue to ignore disability? Disability and disability identity has the potential to become its own sub-discipline in anthropology, rather than a subsection of medical anthropology. Look what it has to offer – an abused and underrepresented minority that is exotic and 'other'! Understanding the sliding scale of illness and disability avoids the trap of anthropologists using Western conceptualizations of institutionalized or informal healing systems and focuses more on experience, change, and knowledge. Accessibility is, after all, what all identities demand. Better yet, disability must be included in any human research endeavor.

In the "soft sciences," disability is slowly being adopted in history, sociology, media studies, literature, and the arts as a legitimate topic of study. Disability studies as a field has contributed to this growth with the establishment of an organization (Society for Disability Studies), academic programs and courses, journals and other publications, and conferences. There needs, however, to be a stronger push for disability's inclusion into the "hard sciences," (e.g., statistics, biology, engineering, and the like) to integrate disability and lessons of difference into their theories and practice. Disability, when conceptualized as outside "normal," has played a role in teaching about physiological difference, but it needs to be transferred into humanistic reality, perhaps to find answers to why there is such variation in human biology rather than to the ends of "fixing" disabled bodies. Research in sciences such as economics, business, and biology can include disability. Simi Linton, in her book *Claiming Disability* (1998), makes an observation that lives at the forefront of my mind as I critique any research ever since I first read it. To paraphrase, how can researchers whose studies do not include people with disabilities in their samples claim that their findings are generalizable to the wider population, especially when people with disabilities are often thought of as the world's largest minority group (Linton 1998)? Instructors and professors of university courses on sampling, research design, or quantitative methods can teach students entering the research field to include disabled people, or students using pre-existing data sets to statistically equalize the balance. Or would this skew data too much? Including a representative sample of disabled people in research sampling might challenge some theories in science that researchers may not be willing to give up. As a human rights issue, efforts need to be made by researchers not to perpetuate able-bodied ideology.

GLOBAL DISABILITY RIGHTS

Disability is not acted upon as a political identity in the wider international disability rights movement. The international disability rights movement is the voice of the North and takes a narrow approach to social change. It also fails to engage with big development and civil society in meaningful ways. This is recognizable to disabled South Africans active in their movement as they have experience of a revolutionary context in which to direct change. They have been able to engage in dominant discourse, evidenced through their perusal of political parties in the early 1990s, participation in constitutional negotiations (CODESA), the RDP, and other landmarks to democracy.

Two current developments illustrate how disability works globally. Although it was off to a weak start, the African Decade of Persons with Disabilities (1999-2009) started as an initiative of the African Union and is currently in the process of making the movement accountable to all people with disabilities and the conditions that both perpetuate poverty and inhibit growth (African Union N.d.). The goal is to facilitate DPOs and government in an inclusive dialogue for the betterment of civil society, one that is inclusive of the disabled. Participants in the African Decade recognize that the essential infrastructure, DPOs and development organizations, already exists, but is not used to maximize political power. Another development, the proposed UN Convention on a Comprehensive and Integral Convention to Promote and Protect the Rights and Dignity of Persons with Disability, has been receiving a stimulated discussion from Africa as a continent. The United Nations General Assembly, resolution 56/168 of 19 December 2001, established an Ad Hoc Committee

> to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development. [United Nations 2001:electronic document]

The African Regional Consultative Conference held in Johannesburg in May 2003 was a meeting of representatives of the disability sectors of various African countries where these two topics (the African Decade and the proposed UN convention) were specific topics or goals of the conference. Though the various countries were at different stages of development as far as national disability strategies, all agreed that the global movement did not represent them or recognize the relationship between disability and poverty. Further, there was consensus about the need for a separate convention for the disabled, rather than simply integrating disability into existing conventions. Here, too, the impact of UN conventions were said to be failing Africa.

The weakness of the international disability rights movement is underscored by a lack of understanding of disability as a political identity. This dissertation identified disability as a potential location of identity, and how disability identity was created and used in everyday life. Further, this dissertation described how disability as a human rights issue was mobilized and forged a social model of disability, as demonstrated by South Africa's disability rights movement. As a whole, the history and workings of the South African disability rights movement provides an important model for other countries to learn how to articulate and mobilize for rights. The model may not be appropriate to all countries, but should serve as an example of what can be accomplished.

FUTURE DIRECTIONS

I asked every research participant what they thought this dissertation could do to contribute to the movement, or how the information could be made more useful to disabled South Africans. Some responded that whatever is done they would like a copy and that whatever form the information took it should be made available in accessible formats (e.g., Braille, audio tape, additional languages, and the like). Some thought about it and contacted me later with ideas after their interviews. Others want OSDP to have a copy and perhaps other relevant government departments should have a summary too. Towards the end of fieldwork the idea of a movement discussion document arose in an interview. After more discussion with participants, this seems to be one appropriate solution, and perhaps a helpful tool to spark a dialogue on a common agenda that was identified as a current need of the movement. Therefore, this dissertation will evolve, with the consultation of available participants, into a movement discussion document. The dissertation as it appears for my degree requirements will also be distributed to those who want a copy.

This dissertation is important to able-bodied readers as a "future direction" because they are only that way, able-bodied, temporarily.

APPENDIX A

DISABILITY IDENTITY AND COMMUNITY FORMATION IN SOUTH AFRICA: A HUMAN RIGHTS ISSUE

Department of Anthropology
Michigan State University

You are being asked to participate in a study examining the experiences of disability in everyday life. Your opinion will be asked about people with disabilities, and if you have a disability, how your life changed because of it. Concerns about disability as experienced by you, family members or others are aims of this interview. The information given to the researcher, Martha Laclave, will be used for completion of a doctoral degree in medical anthropology.

Approximately 30 minutes to 1 hour of your time will be needed to participate in this study.

Participation in this study is voluntary. You are free to decline, ask questions, or omit anything you are uncomfortable with or do not understand at any time.

All information given to the researcher is confidential; your name will not be released to anyone and will not be published. You may request a copy of the research findings.

If you have any questions about this study, please contact the investigator:

Martha M. Laclave
Phone: 083-672-9900
Email: mlaclave@mweb.co.za or laclavem@msu.edu

If you have questions about your rights as a human subject of research, please contact:

Peter Vasilenko
University Committee on Research Involving Human Subjects
202 Olds Hall
Michigan State University
East Lansing, MI 48823
USA
Email: ecrihs@msu.edu
Tel: +01 517-355-2180
Fax: +01 517-353-2976

My advisor, Dr Judy Pugh, may also be contacted:

Department of Anthropology

Michigan State University
East Lansing, MI 48823
USA
Tel: +01 517-353-9634

The nature and general purpose of the research procedure and the known risks involved have been explained to me by Martha Laclave.

I consent to the explained purpose and may withdraw from participating in this study at any time.

Signature: ______________________________

Date: ______________________

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