Why Shouldn't We Be Angry:
Values of the Chicago Disability Rights Movement
In the Words of M. Ervin

BY
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THESIS
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This thesis is dedicated to my parents, who have provided me with so much support throughout my process for it, and to my friend, William Hawke IV, who was instrumental in helping with its conceptualization and the organization of its ideas.
ACKNOWLEDGMENTS

I would like to thank the members of my thesis committee - Carrie Sandahl, Joy Hammel, and Robin Jones - for their support throughout my research and writing process. Dr. Sandahl excelled in her capacity as my advisor, and without her efforts I would never have even made the acquaintance of Mike Ervin. Speaking of Mr. Ervin, no list of acknowledgments for this thesis could be complete without acknowledging the legacy of activist work that he and my other interviewee, Susan Nussbaum, have created and that inspired this thesis from the very beginning. Thank you, Mike and Susan, for your interview time, for your words, for your patience, and for your openness.

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>CHAPTER</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. INTRODUCTION ..................................................................................</td>
<td>1</td>
</tr>
<tr>
<td>A. Description of Scope of Project ...............................................</td>
<td>1</td>
</tr>
<tr>
<td>B. Literature Review ........................................................................</td>
<td>6</td>
</tr>
<tr>
<td>1. Primary sources: Ervin’s writings ............................................</td>
<td>6</td>
</tr>
<tr>
<td>2. Secondary sources: The values of disability culture ....................</td>
<td>9</td>
</tr>
<tr>
<td>3. Secondary sources: Methodology ................................................</td>
<td>12</td>
</tr>
<tr>
<td>C. Methodology ..................................................................................</td>
<td>15</td>
</tr>
<tr>
<td>D. Conclusion ....................................................................................</td>
<td>19</td>
</tr>
<tr>
<td>II. INTRODUCING SEVEN VALUES FOR THE EARLY CHICAGO MOVEMENT ..........</td>
<td>20</td>
</tr>
<tr>
<td>A. Introduction ..................................................................................</td>
<td>20</td>
</tr>
<tr>
<td>B. Personal Connection .....................................................................</td>
<td>21</td>
</tr>
<tr>
<td>C. Interdependence ..........................................................................</td>
<td>25</td>
</tr>
<tr>
<td>D. Acceptance of Human Difference ...............................................</td>
<td>30</td>
</tr>
<tr>
<td>E. Human Community .........................................................................</td>
<td>34</td>
</tr>
<tr>
<td>F. Tolerance for Lack of Resolution .............................................</td>
<td>38</td>
</tr>
<tr>
<td>G. Self-Determination .....................................................................</td>
<td>42</td>
</tr>
<tr>
<td>H. Disability Humor .........................................................................</td>
<td>48</td>
</tr>
<tr>
<td>I. Conclusion ....................................................................................</td>
<td>52</td>
</tr>
<tr>
<td>III. COMPLICATING THE VALUES OF THE EARLY CHICAGO MOVEMENT ..........</td>
<td>54</td>
</tr>
<tr>
<td>A. Introduction ..................................................................................</td>
<td>54</td>
</tr>
<tr>
<td>B. PERSONAL CONNECTION BRINGS JOY... But Does It Also Bring Responsibility?</td>
<td>56</td>
</tr>
<tr>
<td>C. HUMOR IS HUMAN... But Not Everyone Gets the Joke? .....................</td>
<td>58</td>
</tr>
<tr>
<td>D. WE HAVE RIGHTS... But Are They the Same as Those of the Nondisabled?</td>
<td>60</td>
</tr>
<tr>
<td>E. POWER IS GOOD... But Who Gets to Wield It? .................................</td>
<td>64</td>
</tr>
<tr>
<td>F. ANGER IS A TOOL...But Might It Be a Dangerous One? ....................</td>
<td>67</td>
</tr>
<tr>
<td>G. PEOPLE WANT JUSTICE... But Can They Ever Get It? ......................</td>
<td>69</td>
</tr>
<tr>
<td>H. THE SYSTEM IS RIGGED... So Maybe Independence Is the Way to Go? ....</td>
<td>71</td>
</tr>
<tr>
<td>I. Conclusion ....................................................................................</td>
<td>75</td>
</tr>
<tr>
<td>IV. CONCLUSION ....................................................................................</td>
<td>76</td>
</tr>
<tr>
<td>APPENDICES ........................................................................................</td>
<td>81</td>
</tr>
<tr>
<td>APPENDIX A .......................................................................................</td>
<td>82</td>
</tr>
<tr>
<td>APPENDIX B .......................................................................................</td>
<td>83</td>
</tr>
<tr>
<td>CHAPTER</td>
<td>PAGE</td>
</tr>
<tr>
<td>----------------------</td>
<td>------</td>
</tr>
<tr>
<td>CITED LITERATURE</td>
<td>85</td>
</tr>
<tr>
<td>VITA</td>
<td>88</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>TABLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. ERVIN PIECES SELECTED FOR ANALYSIS</td>
<td>7</td>
</tr>
<tr>
<td>II. NATURALIZED BELIEFS FOR THE MOVEMENT VALUES</td>
<td>53</td>
</tr>
<tr>
<td>III. COMPLICATIONS CORRESPONDING TO BELIEFS AND VALUES</td>
<td>77</td>
</tr>
</tbody>
</table>
SUMMARY

In writing this thesis, I used critical discourse analysis techniques to examine the themes present in 21 short pieces of writing from 1980-2000 and three transcripts (each approximately 30 pages in length) of oral history interviews conducted this year with local activists. I conducted this analysis to tease out information about the values present in the disability rights movement in Chicago at the end of the twentieth century. I propose that a naturalized belief undergirded each of seven values present in the movement at that time, and that these unspoken assumptions supported not only those values, but also the interests of those within the movement who wielded power. I also propose that these beliefs presented ideological complications for the followers of the movement, due to systemic inconsistencies (conflicts between the values), but that these inconsistencies represented the system's attempt to become better able to face variegated social challenges.
I. INTRODUCTION

A. **Description of Scope of Project**

   While working through my courses for UIC’s Disability and Human Development program, I noticed that several of the texts selected by my instructors held up the story of Ed Roberts and the Berkeley Center for Independent Living as central to the United States’ disability rights movement’s history, and that those texts told the stories of local victories (and defeats) in other regions of the country less frequently. Roberts undoubtedly pioneered the movement, and landmark national legislative victories such as Section 504 and the Americans with Disabilities Act need to be discussed in the curriculum. However, regional and local histories deserve attention as well.

   The history of the disability rights movement in Illinois at the end of the twentieth century remains unpublished, inaccessible both in book format and online. I discovered this gap in the historical record while performing research for a previous paper for a specific class in this Master’s program. I quickly learned that if I wanted information about past disability rights activism in Chicago, I would need to turn to primary source documents, that secondary sources simply did not exist. I also learned that any interview material I wanted from the senior leaders of groups active at that time, such as ADAPT (at that time, the acronym for Americans Disabled for Accessible Public Transportation; ADAPT has since retooled its focus, and is now Americans Disabled for Attendant Programs Today), I would need to collect that material myself. My professor for that class observed that such a process was outside of the scope of the original assignment, but not outside the scope of a thesis.
Over the course of my next semester of the program, I undertook some data collection and organization for a pivotal activist from ADAPT’s Chicago chapter during the 1980s and 1990s, Michael (more commonly known as “Mike”) Ervin. In addition to participating in many direct actions, Ervin promoted disability rights by writing prolifically as a journalist during those years, publishing hundreds of articles and editorials in magazines such as Chicago Enterprise and New Mobility, and also newspapers such as the Chicago Tribune and the Southtown Economist. In fact, for much of that time Ervin published a weekly column in the Southtown Economist/Daily Southtown newspaper, called “Access to Life,” which chronicled the frustrations and advances of local disability rights struggles. “Access to Life” also shared Ervin’s reactions, grounded in his radical perspective, to a variety of news items of national significance.

Ervin had approached one of my professors, Dr. Carrie Sandahl, in search of a student who could help him prepare the body of his work for publication in an anthology. He was looking for suggestions on which pieces had held up best over the passage of time and should be included in the anthology, and for a thematic framework to organize the pieces selected. Dr. Sandahl selected me due to my undergraduate background in literature and theatre arts. Over the course of the semester that followed, Ervin allowed me to come to his home and take magazines and binders full of newspaper clippings from his personal archives to a local coffee shop. For each of the hundreds of pieces of writing I read, I decided whether or not in my estimation it made for good anthology material, and I also took notes regarding what themes were present, so that pieces that bore a common message could be grouped together. When I was finished with the works Ervin had kept at his home, I worked my way systematically through the pieces of
writing that had been preserved in the special collection of Ervin’s work at the Newberry Library, still analyzing for themes present and evaluating each piece’s contribution to the whole. I used a preliminary set of results from this work as a final project for Dr. Sandahl’s class. The sweeping overview it gave me of more than twenty years of the Chicago disability rights movement was irreplaceable.

By examining the topics Ervin covered in his newspaper articles, we can flesh out what issues concerned the movement at different points during the 20-year arc from 1980 to 2000 that I consider to be the movement’s early years. To make a sweeping generalization, over the course of these twenty years, the Chicago disability rights movement’s emphasis shifted from the “micro” to the “macro.” For example, one of the earliest pieces of writing that I read by Ervin, “Climbing too high,” examined the phenomenon of the Supercrip who climbs mountains (1981). This phenomenon affects the self-image and self-perception of the run-of-the-mill disabled person\(^1\), and self-image/self-perception are problems experienced by individual psyches through personal experience – “micro” problems, so to speak. But in the latter half of the 1980s, Ervin began to shift away from articles like “Climbing too high” in order to cover the struggle for accessible public transportation in Chicago, and later the national push to get legislative support for the ADA. The passage of the ADA caused the movement to shift priorities again, and in the 1990s Ervin started writing more about health insurance, funding issues, and other public policies, as well as the importance of protecting the ADA through judicial rulings like Olmstead.

\(^1\) This thesis will use the terms “the disabled” and “disabled person” more frequently than person-first language. I made this choice in terminology because I believe in disablement as a social process, as opposed to disabilities being qualities inherent to individuals and therefore identical to impairments.
In addition to this periodical material, Ervin also produced some fiction writing, in the form of short stories, a collection of skits titled *The Plucky and Spunky Show* (in collaboration with Susan Nussbaum), and a play titled *The History of Bowling* which theaters as far from Chicago as Alaska have since produced. The Newberry Library has archived a special collection of Ervin's works.

Despite these accomplishments, Ervin did not gain widespread notoriety outside of the disability rights movement during the 1980s or 1990s. I believe this relative obscurity makes his work an ideal focus for critical analysis in order to learn more about the Chicago movement. If Ervin had achieved celebrity status, his writing would have been filtered to a much greater extent through a public persona and the desire for the gratification of personal attention. Instead, Ervin, free to keep his focus on the movement's issues and struggles, has used his columns and fiction as a platform to express his social and political viewpoint, without feeling the need to stay in the good graces of the masses (or even the more mainstream component of the disability rights movement). He has said unpopular things and has made radical arguments without a panderer's fears. This means that, more so than many authors, Ervin has transmitted the movement's radical priorities and progressive values. This brings us to my thesis' central question: What can be deduced about the *cultural values of the disability rights movement in Chicago between 1980 and 2000 from the words of Mike Ervin, both then and now*?

In order to answer this question, I will analyze the thematic content and ideological stances present in a selected set of newspaper and magazine articles published by Mike Ervin in the specified timeframe. I will relate these themes and
stances to seven values that have been noted as generally present in U.S. disability culture: personal connection, interdependence, acceptance of human difference, human community, tolerance for lack of resolution, self-determination, and disability humor. I base this list of seven values not only on previous writings by academic authors (specifically Paul Longmore and Carol Gill), but on interviews I have conducted with Ervin and Nussbaum, in which these two activists independently confirmed which of the values that I had discovered in academic discussion were actually relevant to the Chicago movement specifically. I fervently hope that, while I am grounded academically in literary analysis and social science, and do not personally identify as a “historian”, this thesis can still help to fill the gap in the historical record regarding disability rights activism in the Midwest. Perhaps looking at the historical material through the lenses that I have access to can provide some useful insight in this interdisciplinary field of Disability Studies.

I have deliberately limited this paper in scope, fixing it both in terms of timeframe (1980-2000 CE) and geography (Chicago). I have done so with an eye on the constraints of a Master's thesis, as opposed to those that would be present for a doctoral dissertation or a full-length book. My timeframe begins with the year that Ervin first became active in the movement (according to self-assessment in his interview), and centers around the year of the ADA's passage, an event which both of my interviewees assessed as extremely significant for the movement. The history of the disability rights movement in Illinois could easily fill a book; this particular piece of it will make for a good beginning to documenting and analyzing the larger history. The main contribution this thesis will make to the field will be to document a specific historical facet of disability
culture that few analysts have explored previously. I propose that we can deduce from Ervin's words that the cultural values of Chicago's early disability rights movement were undergirded by unspoken, naturalized beliefs that served the interest of the movement's activist leaders. Furthermore, these values can be arranged in a sequence which evolved out of complications encountered by members of the movement who tried to put the values into practice and therefore experienced conflict with the greater system of values in place in the United States at the end of the twentieth century.

B. **Literature Review**

1. **Primary sources: Ervin's writings**

   In the course of my preparation for this thesis, I have read more than 600 pieces of Ervin's writing, preserved in either his personal archive or the Newberry Library's special collection dedicated to his work. I have selected 21 pieces as the most fruitful for analysis of seven values of the Chicago movement.
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<thead>
<tr>
<th>VALUE</th>
<th>ERVIN PIECES SELECTED FOR ANALYSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>personal connection</td>
<td>&quot;Anna&quot; (1999)</td>
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<tr>
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<td>&quot;Folklore&quot; (1982)</td>
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<td>&quot;Why Me&quot; (1990)</td>
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<td>interdependence</td>
<td>&quot;Deficient in no way&quot; (2000)</td>
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<td>&quot;Erasing the E-Word&quot; (1997)</td>
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<td>&quot;Uncle Tom’s Condo&quot; (1982)</td>
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<tr>
<td>acceptance of human</td>
<td>&quot;Disabled kids having fun in a circle of friends&quot; (1994)</td>
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<td>difference</td>
<td>&quot;Double Barrier&quot; (1994)</td>
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<td>&quot;Spreading it on thick on the South Lawn&quot; (1990)</td>
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<td>&quot;A short, unrevised history of the holiday&quot; (1991)</td>
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<td>&quot;Today's kids don't know whom to hate&quot; (1990)</td>
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<tr>
<td>tolerance for lack of</td>
<td>&quot;Beware the Brahmins&quot; (1997)</td>
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<tr>
<td>resolution</td>
<td>&quot;A close encounter of the best kind&quot; (1990)</td>
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<td></td>
<td>&quot;Here comes trouble&quot; (1995)</td>
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<td>self-determination</td>
<td>&quot;Activists Decide to Do It Themselves&quot; (1989)</td>
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<td></td>
<td>&quot;Bustin' Out&quot; (1994)</td>
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<td>&quot;We all scream for our ice-cream freedoms&quot; (1993)</td>
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<tr>
<td>disability humor</td>
<td>&quot;Blessed Are the Butt-Wipers&quot; (1997)</td>
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<td></td>
<td>&quot;Funny Is as Funny Does&quot; (1998)</td>
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<td></td>
<td>&quot;Offensiveness is in the eye of the beholder&quot; (1990)</td>
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With the exception of "Why Me", which tells of the inner struggles of a frustrated wheelchair user, Ervin originally published each of the pieces listed above as a newspaper or magazine article. Ervin released "Anna" shortly after the death of his first wife, Anna Stonum, and in it he explains his thoughts on love and loss. "Folklore" warns the reader of predation and manipulation based on visual impairment. The most recently published piece that I will use for my analysis, "Deficient in no way"

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2 Taken from The Plucky and Spunky Show, a collection of skits first performed in 1990. The Plucky and Spunky Show was never published, but is available for review at the Newberry Library.
demonstrates how a disability consciousness can bring hope to members of the community who previously felt powerless. "Erasing the E-Word" reclaims the disparaged concept of entitlement. "Uncle Tom's Condo" dissects the desire to direct all disability-related funding toward cure. "Disabled kids having fun in a circle of friends" brings the question of integration or segregation of disabled children to the fore. "Double Barrier" directly addresses the status of Latinos in the disability rights movement. "Spreading it on thick on the South Lawn" gives Ervin's thoughts on the ADA at the time of its signing. "Beware the Brahmins" explores the ways in which power corrupts its holder, and why those who hold power should therefore not be trusted. "Activists Decide to Do It Themselves" details the founding of Access Living's limited equity housing co-operative, KHOSO. "Bustin' Out" relates the story of one nursing home resident's struggle for independent housing. "Blessed Are the Butt-Wipers" confronts the supposed indignity of receiving help with personal hygiene. "Funny Is As Funny Does" explains why the disabled need to be able to laugh at themselves. "Offensiveness is in the eye of the beholder" speaks out against censorship. Not all of the pieces I will use are ostensibly about disability; "The Japanese internment" tells a story of WWII-era history, "A short, unrevised history of the holiday" gives Ervin's take on the Columbus Day controversy, "Today's kids don't know whom to hate" speaks to the complexity of post-Cold War international politics, "We all scream for our ice-cream freedoms" satirizes the process and techniques of activism and protest, "Here comes trouble" profiles a Chicago activist who dealt more with local class-based struggles than with disability rights, and "A close encounter of the best kind" looks at humanity's place in the cosmos. However, all of the pieces in question express
the values present in Ervin's perspective, sometimes explicitly, sometimes in a more subtle, sophisticated, or complicated fashion. My thesis will analyze the ways in which these pieces express these values, demonstrate the sometimes unexpected ways in which the values interrelate, and characterize the perspective of the Chicago disability rights movement.

2. **Secondary sources: The values of disability culture**

In order to determine what concepts I would be asking Ervin and Nussbaum about in their interviews, I attempted to determine from literature in the field what values disability theorists have previously ascribed to disability culture during the era of the publications I will analyze. Few published authors have attempted to concretely and explicitly define disability culture's values. Most of those who do, simply quote or make passing references back to the four values set out by Longmore in his essay "The Second Phase: From Disability Rights to Disability Culture" (1995). In this essay Longmore contrasted those values with those of mainstream U.S. culture: “not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community” (para. 35). My thesis will not only give examples of these four core values (self-determination, interdependence, personal connection, human community) that can be found in Ervin's writing, but also demonstrate the interconnections and relationships between those values (for example: the tension perceived by Ervin between the concepts of self-determination and interdependence, which he addressed explicitly in interview).
Another scholar who has researched the values of disability culture extensively and thoroughly is Dr. Carol Gill. In 1991, Gill elucidated this list of values:

1) An acceptance of human differences (e.g., physical, functional, racial, intellectual, economic/class).

2) A matter-of-fact orientation toward helping; an acceptance of human vulnerability and interdependence as part of life.

3) A tolerance for lack of resolution, for dealing with the unpredictable and living with unknowns or less-than-desired outcomes.

4) Disability humor - the ability to laugh at the oppressor and our own situations, to find something absurdly hilarious in almost anything, however dire.

5) Skill in managing multiple problems, systems, technology and assistants.

6) A sophisticated future orientation; an ability to construct complex plans taking into account multiple contingencies and realistically anticipated obstacles.

7) A carefully honed capacity for closure in interpersonal communication; the ability to read others' attitudes and conflicts in order to sort out, fill in the gaps and grasp the latent meaning in contradictory social messages.

8) A flexible, adaptive approach to tasks; a creativity stimulated by both limited resources and experience with untraditional modes of operating.

Proponents of disability culture have disseminated variations on this list of values in a variety of contexts. For example, I found a very similar list in the 2006 keynote speech given by Kemp to the Rehabilitation Engineering & Assistive Technology Society of North America. Echoes of Gill’s analysis can also be found in Petra Kupper’s anchor essay, “Disability Culture.” Kuppers relies on Gill when writing about the culture’s history, the sites where it has crystallized, impairment groups that have formed subcultures, and ways in which the culture is currently expanding.
In interviewing Ervin and Nussbaum, I asked about these values as well as the four listed by Longmore. Most yielded useful and thought-provoking responses, but a few do not appear to have held especially important places in the Chicago movement's value system and I therefore will not analyze them at length in this thesis. I will note that an argument can be made that further values for the culture, while not explicitly stated, are implicitly present in the culture's writings and that I could derive those values myself through more original analysis, but my thesis will clearly demonstrate that there is sufficiently complex material for examination in the seven values that I have selected: personal connection, interdependence, acceptance of human difference, human community, tolerance for lack of resolution, self-determination, and disability humor.

While performing my literature review, I should discern the ways in which the values of the Chicago disability rights movement have been distinct from the concepts present in mainstream U.S. social policy towards people with disabilities. Turnbull et. Al (2001) derived a list of eighteen concepts and values found in disability policy, through a review of policy literature, statutes, and case law, paired with a participatory action research committee made up of consumers, policymakers, and researchers. These concepts were: antidiscrimination, individualized and appropriate services, classification, capacity-based services, empowerment/participatory decision-making, service coordination and collaboration, protection from harm, liberty, autonomy, privacy and confidentiality, integration, productivity and contribution, family integrity and unity, family centeredness, cultural responsiveness, accountability, professional and system capacity-building, prevention and amelioration (135). In my interviews of Ervin and Nussbaum, I inquired into their perception of mainstream policy concepts, and their
responses did provide me with additional evidence regarding the presence of the seven
disability culture values listed above; however, Ervin and Nussbaum also conveyed
uncertainty regarding the nature of the term "policy," and I ultimately decided that I could
not use this broad line of questioning for the sort of tight focus I wanted for my thesis.
Therefore I will not discuss Turnbull’s list of concepts at length in the following chapters.

3. **Secondary sources: Methodology**

   My methodological readings for this thesis chiefly aided my efforts in
constructing and shaping my interviews of Ervin and Nussbaum. I first read Hahn's
“Attitudes Toward Disabilities: A Research Note on Activists with Disabilities” (2001)
which focuses on issues of mistrust between the disability activism community and the
academic research community, with interest, believing that these issues might surface
during my interviews with Ervin and Nussbaum and that it would be best to deal with
them directly. In his article, Hahn asserts that his status as an ADAPT “insider” helped
him to gain internally valid responses to his survey questions about the activists'
attitudes toward their disabilities (42). I believe this speaks to the potential value of my
preexisting professional connection with Ervin through prior classwork, in opposition to
anyone who might question the effect of that connection on the validity of the responses
I would get to my interview questions.

   I then turned to the discipline of oral history, using the principles and guidelines of
the third chapter ("Conducting Interviews") of Ritchie’s text *Doing Oral History: A
Practical Guide* to prepare my questions lists. Ritchie discusses numerous practical
issues such as the optimal length of an oral history interview, the degree to which such
an interview should be structured as opposed to an improvised conversation, how to
elicit fresh and unrehearsed stories, how to handle topics that require sensitivity and discretion, how to ensure the interviewee's responses go beyond the perfunctory, and how to sequence questions to ensure rich responses. Eventually I concluded that while I liked many of the epistemological underpinnings of the field of oral history, I wanted to use the information gained through my interviews to shape and supplement my analysis of Ervin's writings, not as the primary focus of the thesis, and that therefore oral history techniques would not be sufficient for me.

For me, the answer to the question of where to find sound methodology for analysis of both the Ervin and Nussbaum interviews, and Ervin's writing, lay in the field of discourse analysis. Like disability studies, discourse analysis crosses disciplinary boundaries, tugging on the threads of anthropology, linguistics, philosophy, and sociology in the academic tapestry. The specific types of discourse analysis that have inspired the analysis I will perform in this thesis are pragmatics (which draws upon philosophy) and critical discourse analysis (which draws upon critical theory). Cameron introduced me to these methodologies in her text *Working with Spoken Discourse*, in which she also discussed other discourse analysis techniques, such as the ethnography of communication (which draws upon anthropology, and I found useful to a limited extent) and conversation analysis (which draws upon sociolinguistics, and which I ultimately found unsuited for my purposes).

Cameron persuaded me of the value of abandoning standard grammatical conventions in favor of a transcription coding system. I eventually adopted a simplified version of DuBois' system, which comes from pragmatics, as reproduced in Schiffrin, to code my transcripts (see Appendix A). I used the DuBois coding system to remind
myself that I had collected this information in a different, more extemporaneous way, and therefore it might reveal more thought processing and information structuring than Ervin’s more polished material. I took the time to incorporate the coding into producing my transcripts because I thought it would provide a more authentic and accurate account of my interviews of Ervin and Nussbaum. The nuances made evident simply by using line breaks to indicate pauses fascinated me and I deduced that the longer lines of text frequently corresponded to thoughts that had become rote, no longer requiring extemporaneous structuring. Schiffrin also provided me with additional information about the ethnography of communication and pragmatics approaches to discourse analysis.

For this thesis, I will use the views and perspective of Lemke as found in Textual Politics: Discourse and Social Dynamics to flesh out the critical discourse analysis techniques which can be found in Cameron. Lemke challenges his reader, stating "If we want to ask how a particular discourse functions ideologically, we need to look with both the broader and the narrower view of ideology. We need to see how the discourse is situated in the social and political relations of various communities and their interests vis-a-vis one another, and we need to ask specifically what it says about its subject that somehow works to the profit of a dominant social group" (12). This challenge, along with other subversive concepts in Lemke's text, helped to inspire me to go beyond simple interpretations of Ervin's text, to produce a more nuanced and complex view of the Chicago movement, in which the tension between certain values of the movement echoes tension between different groups of people involved with the movement.

C. **Methodology**
I used multiple interpretive methods to draw my conclusions for this thesis. I viewed the personal connection I made to Ervin not as a stumbling block to objectivity, but as a bridge that provided me with heightened understanding. This attitude is quite typical for those engaged in qualitative study; as Patton notes, “The inquirer gets close to the people under study through physical proximity for a period of time as well as through development of closeness in the social sense of shared experience, empathy, and confidentiality” (48). The first stage of research for this thesis involved extensive archival readings, in both Ervin's private archive and the Newberry Library special collection of his publications, to gain familiarity with Ervin's body of work and general philosophy. I was extremely fortunate to have been able to establish a strong level of trust with Ervin, and this trust gave me access to information that could not have been gained any other way. While I did not consciously shape my analysis around this additional information, it would be foolish to assert that it was not a factor in my process. The second stage of research entailed semi-structured interviews of Ervin and his collaborator, Susan Nussbaum, conducted under a rudimentary oral history framework, to learn more about the Chicago disability rights movement in the 1980s and 1990s and the ways in which that movement's values aligned with those I had discovered through my literature as characterizing disability culture. I then transcribed the recordings of these interviews using a simplification of DuBois’ conventions (taken from the discipline of pragmatics). In the third and final stage of research I performed close reading, using discourse analysis techniques (specifically pragmatics and critical discourse analysis), of a specific subset of publications, selected on the basis of relevancy, to discover
examples of the disability culture values that had come out in the interviews with Ervin and Nussbaum.

Not all of the readers of this thesis may be familiar with the foundations of the field of discourse analysis, particularly the disciplines of pragmatics and critical discourse analysis. My own understanding of the field is far from expert, but certain principles elucidated in Cameron have proved indispensable to me in conducting my analysis for this thesis. The first of these principles is that discourse analysis is less about collecting facts than about studying interpretive processes (14). The conclusions that I come to in this thesis are subjective and subject to dialogue, debate, even refutation. The second principle that I used is that language use is an intersubjective process. Cameron writes that "We speak with the voice of our communities . . . A voice that is wholly individual runs the risk of being incomprehensible" (15). I also believe that in order for even the most banal text to serve its communicative purpose, those who receive its words must draw upon a great deal of general knowledge and contextual information (13). Another principle of discourse analysis that helped me to analyze Ervin’s words is that speech is a form of action. When we say something, we also do something (69). Note that to perform discourse analysis, the analyzer must pay attention not merely to what is said, but how it is said. This will give additional insight into the way the sayer understands things (3). This principle also informed my use of the DuBois conventions.

I found the subfield of pragmatics helpful in interpreting my material. According to pragmatics, when people interact, four maxims of cooperation are in force:
1. Quantity: each person’s contribution should be as informative as is required for the current purposes of the exchange, and not more informative than is required.

2. Quality: each person should not say what that person believes to be false, or for which that person lacks adequate evidence.

3. Relation: each person’s contribution should be relevant.

4. Manner: each person should avoid obscurity of expression and ambiguity, and be brief and orderly. (75)

These maxims can be flouted (communicative technique meant to be noticed) or violated (communicative technique not meant to be noticed). Flouting a maxim will result in a receiver looking for implicatures - something the communicator cannot or will not say directly, but expects the receiver to infer. It is also the only circumstance in which receivers will look for said implicatures (78).

I also made use of critical discourse analysis when writing this thesis. Critical discourse analysis is a transformative discipline, in which it is assumed that reality is constructed, but frequently naturalized - presented not as the outcome of social practices that might be questioned or challenged, but as simply "the way things are," which obscures the fact that that the way things are is not inevitable, unchangeable, or impartial, but rather results from particular actions and serves particular interests (123). This idea of naturalized beliefs is central to my analysis for this thesis. Naturalized beliefs perpetuate a culture’s understanding of the way the world should work. One of my starting assumptions was that, since proponents of disability culture assert that it is different from the mainstream, nondisabled culture, logically it should have its own set of
naturalized beliefs, separate and perhaps counter to those of mainstream culture. I also assumed from the beginning that there would be internal challenges to those naturalized beliefs, coming from a faction within the movement interested in a horizontal, rather than vertical, distribution of power. Practitioners of critical discourse analysis assert that the choices communicators make when talking or writing about reality are ideologically patterned, naturalizing particular social arrangements and serving particular interests. These choices are not consciously an issue to most language-users on most occasions, and can be lexical or grammatical (124). A more controversial critical discourse analysis assertion is that which is naturalized in discourse tends to be the common-sense beliefs of dominant groups, which may be presupposed in discourse rather than openly stated (126). Now, in order to perform critical discourse analysis, the analyzer must pay attention not only to surface linguistic features (such as what is said and how it is said, see above) but also to what is not said, but is indirectly hinted at or presupposed as obvious (128). The critical discourse analysis process has two steps:

1. Find a regular pattern in a particular set of text or set of texts. This can be a pattern of lexis, of grammar, of modes of address, of intertextual relationships, etc.

2. Propose an interpretation of the pattern which is an account of its meaning and ideological significance. (137)

Lastly, I note that critical discourse analysis deals with questions of power, and in order to look systematically for the workings of power in discourse, a practitioner of critical
discourse analysis looks systematically for evidence of resistance to power, because
the two very often go together.

D. **Conclusion**

I have heard many say that “history is written by the winners.” I would like to think
that the story of Chicago's disability rights movement is more of a tale of victory than
one of defeat, that despite frustrations and setbacks, budget cuts and roadblocks, we
still have the ability to say who we are and where we have come from. This thesis gives
me the chance to make my first real contribution to the movement. I do not intend to
squander that chance.
II. INTRODUCING SEVEN VALUES FOR THE EARLY CHICAGO MOVEMENT

A. Introduction

From the values enumerated by Gill and Longmore as the values of disability culture, a subset of seven emerged in my interviews of Ervin and Nussbaum as important to the disability rights movement in Chicago: personal connection, human community, acceptance of human difference, interdependence, self-determination, disability humor, and tolerance for lack of resolution. These existed as a system and a sequence of interrelated concepts. A person with a disability fortunate enough to discover disability culture usually does so first through personal connection with peers (Kemp writes, "Typically, cultural phenomena are transmitted down through families, as lore and legend, and at places of worship. Our disability culture is transmitted from one of us to another, peer to peer" (197)). These peers transmit the core value of disability culture, interdependence, which allows the person with the disability to better accept differences between people and widens his or her understanding of what constitutes human community. In time, the struggles that must be fought in order to gain incremental change in the living conditions of people with disabilities, if the disabled person chooses to fight them, call for a tolerance for lack of resolution and a high value placed on self-determination. Lastly, disability humor can serve as both a balm and a weapon in those struggles. The points that I will make to shape my analysis of the presence of these values in Ervin's writings from the historical era in question come directly from the retrospectives given by Ervin and Nussbaum in their respective interviews.
B. **Personal Connection**

with uh ^especially^ a group like adapt uh that's basically the glue
that's basically what holds it together that's where a lot of the passion comes from
it's almost like um
playing harder for your team
uh you know uh than
than you would in an individual sport um
because well you want
your teammates to uh succeed you want them to be proud of you you want them to
to feel
good too you want them to win too
so you work harder
because it's a team than you might if you if you were just by yourself

(Ervin interview transcript, 23)

Ervin actually gave the preceding quote as part of a response for a question about
"human community," but I would argue that this results from the tight link between these
two values and their easy conflation. A "team" is a smaller unit than a community, and
the connections made by members of a team are personal in nature. Ervin
demonstrated the link between personal connection and human community neatly
when asked in his second interview about the significance of travel in his life:

it's harder to uh dismiss a group of people
like when you when you've been to a country like i've been to cuba and i've been to
germany and
and if i hear about something happening in cuba it kind of catches my ear more than if
it's happening in chile or something like that because
i feel like oh i've been there maybe i know somebody and it and it matters more to me
just because um i think i wonder if this guy who i met in cuba is affected by this
that kind of thing
so i think the more that you see the harder it is to fall into the traps of
i don't like this group of people
it's easier to not like them if you've never met any of them and never lived where they
live

(Second Ervin transcript, p. 4)

In this quote, Ervin's personal connection to "this guy who i met in cuba" becomes
magnified and transformed into hypothetical concern for "a group of people" over
"something happening in cuba" - the human community that the "guy" represents.

The importance of making personal connection through direct interaction, as
opposed to abstract appreciation, also came through in the list of names Ervin gave
when asked about sources of inspiration for his activism; with the exception of Saul
Alinsky and Mike Royko, names he has given in previously published interviews, Ervin
preferred to list people that he has known in direct capacity, rather than public figures:

Nussbaum, Kent Jones, Jim Charlton, Margaret Fromer, Marca Bristo, and other local
activists, including Ervin's wives, Anna Stonum (now deceased) and Rahnee Patrick
(second interview with Ervin, transcript page 12). In the early days of the Chicago
disability rights movement, activists such as Ervin and Nussbaum connected personally
at Access Living, Chicago's Center for Independent Living, inspired by the
"Berkeleyites", as Nussbaum refers to Ed Roberts' Berkeley activists (Nussbaum
interview transcript, p. 2). Ervin explains,

> i think access living coming made that possible
> because it gave people a place to gather
> a place of common interest
> where they found each other accidentally
> and then um and then uh
> everything sort of branched out from there

(Second Ervin transcript, p. 22-23)

Speaking about a specific connection rather than as a generalization, when asked how
she originally met Ervin, Nussbaum first guessed that it had happened through Access
Living, although she did posit a few other possibilities:

> L: (0) okay um
> so how did you first get to know mike ervin
> S: i don't remember [really i]
> L: [@@]
> S: i'm sure it was through= organizing
> uh /maybe he came to access living/
> maybe i just met him at a
> i don't even remember if we called it adapt then
> i guess we did
> um=
> i really don't remember /
> maybe i met him on a ^medicar^ we had these
> these medica– paratransit [vehicles that we]
> L: [mhmm]
> S: were given to
> not "given" you know
> to be
> transported if we were so lucky as to have a job
> L: 'right'
These possible locations for the beginning of Ervin and Nussbaum’s friendship emphasize that their disabilities could serve to provide them with a common understanding and interests - a reason to connect. This emphasis gets repeated in Ervin’s writing.

The *Achievement* newsletter\(^3\) published a piece entitled “Folklore” in 1982, making it one of the earliest pieces by Ervin that I will analyze in this thesis. It tells the story of Rosie, a visually impaired teacher at the narrator’s high school, and her courtship by a nondisabled man who pretends to have a mobility impairment. Believing himself unobserved, the man drops his deception to get his wheelchair over a curb; a third party observer informs Rosie.

According to the rumor machine, Rosie gave Ed an ultimatum: be out of my life permanently when I get home tonight or I’ll turn you in. (What would they have charged him with? Impersonating a para?) That night and every night after that, Rosie returned to walking home accompanied only by her white cane. It was another two years before I saw Ed again. It was in a shopping mall. I saw him but he didn’t see me. He was back in the wheelchair. And walking along beside him was another blind woman. (4)

This ending marks the tale as a warning regarding the predatory tendencies of the nondisabled, rather than a moral victory for Rosie.

A second piece of writing that deals extensively with personal connection is “Why Me”, which relates a dialogue between the characters of Wheelchair Woman, frustrated because she has spilled Chinese food and can’t clean it up without rolling her wheelchair through it first, and a disembodied Voice who viciously ridicules her. Only

\(^3\) Now no longer in print; according to correspondence with Newberry Library staff, its audience was people with disabilities, and its sponsoring organization has evolved into the Achievement Disabled Action Group.
calling an unspecified person on the telephone and promising physical intimacy to that person silences the Voice:

WW: . . . I gotta get out of here.
Voice: It'll be okay. It's just like being inside only it's outside.
WW dials phone. VOICE sings "Strangers in the Night".
WW: (on phone) Hi, it's me. Wanna do something? I don't know. I could come over and we could order out.
Voice: Fool.
WW: Or we could go out, eat, movie, grope, kiss, you know. (pause) Yes, with tongues. Okay, I'll pick you up. I'm on my way. Bye. (hangs up) What'm I gonna do about the mess?
NO ANSWER

Ervin and Nussbaum took great pains to humanize Wheelchair Woman; despite her lack of a name, she has the detailed quirks of an individual, and her loneliness, while palpable, is expressed irreverently enough to never be pathetic.

In 1999, *New Mobility* magazine, marketed to wheelchair users, published the third piece of Ervin's writing I shall analyze for its focus on the value of personal connection, after the death of Anna Stonum. Titled simply "Anna", the piece brings together five humorous anecdotes in a timeframe stretching from Stonum and Ervin's first meeting in 1983, until 1998, their eleventh year of marriage. By sharing his memories of a very tender relationship, Ervin reaches out to the reader, and muses,

I've had a very soft life, almost completely tragedy-free to this point. Joy has been much more predominant and the gift of Anna's deep and unconditional love is the main reason why. If the wrenching misery of losing that love is the price we pay, I'd do it again a thousand times. It's a brutal price indeed, but it's still very much a bargain.

This is Ervin's core message, present in all three pieces, regarding this value: *loss is the price of attempting genuine personal connection, but is not as great as the joy that it brings.* "Folklore" emphasizes the loss component of this message, but in Rosie's case the loss comes at her own choosing because she prefers no connection at all over one that is not genuine. In "Why Me," Wheelchair Woman loses the Voice, again at her own choosing, and is momentarily disoriented by this loss, going so far as to continue talking to the Voice for a line of the script, but soon reorients and rolls her wheelchair through
the Chinese food ("Metaphor for my life." (5)) to pick up the person she has called.

Despite the fact that Ervin wrote the piece while experiencing more personally intense loss, "Anna" truly celebrates the joy of his relationship, giving that joy more weight and strength than the power of Stonum’s death.

Critical discourse analysis, however, requires that I take the next step beyond making this message explicit. I must ask what common-sense belief held by the dominant group gets naturalized here. Because I am proposing these as the values of the Chicago disability rights movement, I must look at the dominant group within that movement - which, as Ervin assessed retrospectively in his interview, were

/should i say more privileged people\ /i guess/  
uh.. being uh  
i think those were where the agenda tended to come from because the people  
and i don't mean this as a put down it's just how it was  
the people who uh f- founded the movement who ran the centers *were* the most privileged as a rule disabled folks  
they were the ones that had *educations*  
they were the ones that had nice *résumés*  
they were the ones that had ah  
ah were able to to hold *down* full-time jobs  
and things like that  
(Ervin interview transcript, p. 4)

What common-sense belief of this group gets naturalized in Ervin's message about personal connection? I propose that Ervin's message naturalizes a belief best summed up as PERSONAL CONNECTION BRINGS JOY, and with good reason - if members of disability culture and the disability rights movement did not believe that personal connection brought joy, the movement would lose its “glue” (to borrow the term Ervin used in his interview). It would not hold together, and the dominant group within that movement would not be able to organize the community.

C. Interdependence

Many have cast interdependence as the central value of disability culture. The only value listed by both Gill and Longmore as typifying that culture, interdependence is
often juxtaposed to contrast against the mainstream U.S. cultural value of independence. When asked about interdependence in his interview, Ervin made this contrast quite sharp:

independence more implies this myth of i can take care of myself just you know do this and
like just put a curb cut there and i'm fine
as opposed to um i need a lot of support in these ways
in that way i'm @just like everybody else@
and when i get support i can contribute just like other people do
and that's more of an interdependent way of looking at things
(second Ervin transcript, p. 24)

Calling independence a ‘myth’ could be quite incendiary in some circles, radical enough as it were, but in the present day Ervin and Nussbaum take the next step, portraying interdependence as a universal feature of human society, meaning that it should be valued more strongly than independence by the nondisabled as well:

independence implies that anybody does anything on their own
that that we don't all rely on thousands of other people even if we don't leave the house
we still rely on thousands of other people every day
and um
and that somehow our the way we rely on people is is different
or somehow less worthy or something to be ashamed of
when in fact it's the basic inescapable center of everybody's life
(Ervin interview transcript, p. 21)

every human being needs
e-- all the other human beings in their.. orbit
in order to survive
it's just natural
and yet
independence is what's held high in on a pedestal in this country w--
it's ^so^ valued
it's ^so^ stressed
i know it was stressed in my /family a great deal/
i don't think we ever understood..
that it was a ^dangerous^ thing to ^prize^
so !highly!
(Nussbaum interview transcript, p. 23)

This assertion, that interdependence is a universal principle that should be embraced by the nondisabled as well as the disabled, radicalizes simple acts that involve caring for someone else’s needs. The centrality of interdependence as a value of the Chicago
disability rights movement entails it surfacing in unexpected places, such as publications that deal explicitly with the question of cure.

Like "Folklore", "Uncle Tom's Condo" was published in *Achievement* magazine in 1982, an early year of Ervin's involvement in the movement. Borrowing from imagery used in the Black civil rights movement earlier in the twentieth century⁴, the article warns the reader about the Spinal Cord Society, a group dedicated to redirecting funding away from access and rehabilitation for people with disabilities, towards cure research focused on the spinal cord. "Cure everyone, the mother said, and we won't need any access or rehab programs" (4). Ervin takes the SCS' message apart, pointing out how it excludes categories of impairment, and then makes his own point:

> I won't be foolish enough to say that we will never be able to repair and regenerate the spine. But I am absolutely certain that there will never be a world without disabled people. So what do we do until that miraculous day of cure that may never come for most and will never come for all? Uncle Tom wouldn't worry about that. He's got his, just like Marie Antoinette. He's rationalized it all so well that such dirty thoughts can't survive in the sterility of his intellectual condo. (4)

Ervin’s perspective is typical of that held by believers of the social model of disability, in which people are disabled, not by their impairments, but by the methods society constructs to exclude them. Three decades later, Nussbaum would describe this model aptly and succinctly in her interview with me, saying,

> our inability to do and believe certain things was not because we were intrinsically just unable

L: mm

S: but because that um it was the system itself that was disabling us

(Nussbaum interview transcript, p. 21)

⁴ Ervin was not the first author to draw upon this particular image in a disability culture context. As early as 1969, scholars were observing that “Uncle Tom and Tiny Tim are brothers under the skin (Kriegel 1).
This social model distinction between inability/impairment and disability sets the stage for Ervin's scathing words towards the SCS' position. His certainty that “there will never be a world without disabled people” also begins to hint towards another value of the movement, the tolerance for lack of resolution.

In 1997, Ervin published a short, biting satire titled "Erasing the E-Word," in which he sardonically framed an entitlement program for personal attendant care in a disabled person's home as a "home security system" pitched by a salesman on television - presumably because it would prevent that person from institutionalization in a nursing home. Unfortunately, Ervin soon reveals this "home security system" as the dream of "an inmate at the Jesse Helms Institute for the Politically Insane," sentenced for "the crime of feeling a sense of entitlement" (62). The inmate knows the Institute's punishment: re-education through crossword puzzles. "Soon I would again realize the central patriotic principle that makes America great: No one deserves a damn thing" (62).

The Chicago Sun-Times published an even shorter piece by Ervin, "Deficient in no way," in the Commentary section of a 2000 issue. Here, Ervin returns to the question of cure. He begins by mentioning Anna, stating "Had either of us not had a disability, we never would have met. This in itself would be enough reason for me to be grateful that I was born with the disability I have lived with for more than 40 years" (page not given). He proceeds to amplify that personal connection through the larger community of people with disabilities before reacting to Christopher Reeve and Dennis Byrne's call for cure:

I don't know whether to laugh or cry. I want to laugh because the notion that the only source of hope we ever can have is the hope of someday walking is so absurd. I want to cry because I get so frustrated when I think of how many other people with
disabilities buy into that nonsense. I think of all the newly disabled people in hospitals and rehab centers who pour all their energy and concentration into walking. Meanwhile, life passes them by. It delays the day when they realize that they can still be proud, satisfied, important, talented people whether they ever take another step or not. This is the day when real hope returns. My greatest source of hope is that the disability rights movement will continue to shatter barriers so thoroughly that even insulated elitists like Byrne won’t be able to avoid contact with us. And then, when someone tries to say that the only way people with disabilities can be happy is to become someone else, everyone will see how silly that is. (page not given)

There is a surface call for acceptance of human difference here, certainly - but might other values, such as interdependence, be present as well?

The closing line of "Erasing the E-Word" - that in the U.S., no one deserves anything - provides the key for analysis. This obvious exaggeration challenges the reader to ask the question, “What do I deserve?”, for which Ervin had already provided an answer earlier in the article: "I could sleep well at night, knowing that little could harm me! Isn't that what we all want, I said to myself? Is this not the American dream?" (62) I have heard “the American Dream” defined different ways by different people; usually this definition involves prosperity, rather than security - but is not the desire for security at the heart of the desire for prosperity? Perhaps Ervin's sums up the nature of “the American Dream” more accurately than he first appears to do. Ervin argues that people have a right to a sense of security - to be in their own homes, as themselves, not required to become someone else. This right can only be made manifest through acts of interdependence, that "basic inescapable center of everybody's life", because remember, as Ervin understands life, we all “rely on thousands of other people even if we don't leave the house.” The naturalized, common sense assumption here is the existence of human rights, that WE HAVE RIGHTS. This assumption serves the interests of the dominant group within the movement by eliminating the need for justification for a demand of that which the movement claims as a “right”. No further
defenses need be given if the person receiving the demand agrees that it is, indeed, the
demander's "right."

D. **Acceptance of Human Difference**

i think the basic concept especially early on
with five oh four and the um the
architectural barriers law in the sixties
i think the basic concept was um
uh
<Q if you do this for them they will succeed
uh they can succeed in our world Q>
sort of an assimilationist type of thing
um the a.d.a.'s a little more uh comp– a little more
requires more active accommodation it drags the private sector into it
and uh things like that so it's
it's not quite
it's never been sort of we don't have to do anything just get out of the way
and they'll and they'll thrive but I think
the things we've asked the laws of
haven't been the things that they've sought to achieve

(ERVIN interview transcript, p. 11-2)

According to the perspective Ervin expresses in this quote, if the things that the laws
sought to achieve were "an assimilationist type of thing", it follows that "the things we've
asked the laws of" - the real goals of the disability rights movement - were *not*
assimilation. The word "assimilationist" in this quote is a particularly interesting choice
on Ervin's part; "assimilation" in its relevant modern sense (according to dictionary.com,
"to bring into conformity with the customs, attitudes, etc., of a group, nation, or the like")
is derived from the Latin word *assimilatus*, which according to Harper meant "feigned,
pretended, fictitious." Conformity can be feigned, but human difference is real, and the
Chicago disability rights movement valued its acceptance. Nussbaum spoke with pride
on the subject of diversity within the movement:

one of the great things about the disability rights movement is
that disabled people
"contain" such an array of
minorities and...
um=

L: you can [you can drop into the group from anywhere you know]

S: [you know orientations]
yeah..
u=m..
and that was very valuable for a lot of people including *me* and it was m– very *pleasurable*

(Nussbaum interview transcript, p. 17-8)

If human difference could be accepted within the movement's disability culture, perhaps the difference between members of that culture and the nondisabled could be accepted too - on both sides of the divide. The rarity of that acceptance can be seen in popular organizations devoted to curing disability, which Ervin has no patience for:

i never cared anything for groups like the muscular dystrophy association even when they would have things like talk groups because even though i never went to one my im*press*ion was XXXX all they were was people that wanted to get together and talk about when they're going to be cured which was of no interest to me

i did write something early on about um people who were cure who were i still they still drive me nuts the /miami project types/ still drive me nuts the ones that are just absolutely laser focused on cure and put everything else aside for that i wrote some stuff early on where i *might* have been just a *little* harsh on em but they still make me nuts (second Ervin transcript, p. 8, 11)

Ervin most likely refers to "Uncle Tom's Condo" here, which I examined in the previous section of this thesis for its take on the value of interdependence. For this value, I prefer to look at three pieces written in the first half of the 1990s.

The Southtown Economist column "Spreading it on thick on the South Lawn" recounts a selection of memorable details from Ervin's attendance of the signing of the Americans with Disabilities Act at the White House, published shortly after the event took place. Ervin opens the piece by expressing ambivalence about attending the event. The details that he mentions confirm radical leftist notions regarding the nature of U.S. culture (the Marine Corps band signaling militarism, Vice President Quayle not receiving applause and not knowing how to handle an encounter with someone with no arms, the hollow nature of speech rhetoric, parallels between Democrat behavior and Republican behavior), with one significant exception:

"Let the shameful wall of exclusion finally come tumbling down," Bush said, and he sat down to sign the act. At that moment, I realized something I never knew before.
George Bush is left-handed! What does that say about the superficiality of our sound bite culture and how it keeps us from really getting to know each other? What does that say about the right-brain theory? (B2)

I am not sure precisely to what extent Ervin intentionally participated in "sound bite culture" when writing this piece, but the use of the phrase “spreading it on thick” in the piece's title certainly cues the reader in to the presence of irony in what follows, and by not expounding at all on the significance of the details he relates, Ervin leaves himself open to charges of superficiality here.

A few years after publishing "Spreading it on thick on the South Lawn", in 1994, Ervin tackled the question of segregation vs. integration of disabled children in an ostensibly neutral article for the *Chicago Tribune*, called "Disabled kids having fun in a circle of friends." The article uses the local chapter, called a "circle" by its participants, of a national organization called Winners on Wheels, open only to "youth in wheelchairs", as the focal point for its discussion of this issue.

Because membership in WOW is open only to children who use wheelchairs and not kids with other - or no - disabilities, it runs counter to philosophies behind the movement to fully integrate kids with disabilities in schools and life's other arenas. Advocates of inclusive education, like those who pushed for racial desegregation, argue that separate is inherently unequal and that the only way people with and without disabilities will truly learn to value and respect each other is to routinely live and work together.

Says Gill: "If people with disabilities choose to get together, that's a community. But if they're told that's where they need to be by authority figures, then the message they can get is, 'I'm not like other people.' And from there it's a short step to thinking 'I'm not fully human.'" (13)

I refer to this article as "ostensibly neutral" because, while Ervin does not state his perspective on this issue explicitly in the same manner he would in an "Access to Life" column, or use his trademark biting humor, he definitely has a take on this issue, and makes it subtly known. Ervin carefully uses rhetorical questions in this article and by leaving them unanswered, guides the reader to contest them in the negative. Because the answers come only through inference on the part of the reader, the text gives the appearance of neutrality, while still conveying a pro-integration, anti-WOW position.
Later that year, writing again for the Chicago Tribune, Ervin published an article titled "Double barrier", about the Pilsen chapter of Fiesta Educativa, a disability rights organization for Latino families: "a grass roots special education advocacy group that understood their cultural and language needs" (3). In this article, members of Fiesta Educativa struggle and succeed against private and public school officials who care more about controlling children with disabilities than educating them, and the power that results from self-advocacy spreads outward from them: "Once a disconcerted and relatively powerless lone warrior, Vazquez is now savvy enough to be organizing a group of other Hispanic parents of neglected special education kids" (3). Ervin speaks more directly in this article about the dangers of segregating the disabled than he did in "Disabled kids having fun in a circle of friends", by relating the tale of "Lilia, a Pilsen mother whose learning disabled son was farmed out to a private segregated school for kids with disabilities by his public school district. One day Lilia dropped in the private school and found her son in a corner strapped to a chair" (3).

When first examined, the messages of these three pieces of writing do not seem to cohere well. However, upon closer inspection, it becomes apparent that Ervin's central thought regarding acceptance of human difference in all three cases is that acceptance of the subjugated by the dominated is necessary for the subjugated to gain power. This naturalizes the belief that POWER IS GOOD, and this belief serves the interests of the dominant group within the Chicago disability rights group very handily in that it provides them with a raison d'être. If the members of the movement did not believe that power is desirable, their leaders would have nothing to fight for, nothing to achieve, no function. The movement would disintegrate, arguably more quickly than it
would if its members did not believe in joy from personal connection. It is important to note that the power sought by the Chicago disability rights movement was not (in at least most cases) the power to dominate and subjugate others, but instead the power to make choices. The values of self-determination and acceptance of human difference can be seen as imbricated in the movement’s culture, through the naturalized belief that POWER IS GOOD.

E. **Human Community**

when they
when they find
the community and get active
it's just sort of like a big dose of hope that they hadn't had before
or in a different form in a more realistic uh form

(Ervin second interview transcript, p. 26)

Ervin spoke of the community's potential to create hope when asked about the possibility of disability getting transformed from a deficit into a source of pride, a concept that had surfaced in Nussbaum's interview (Nussbaum interview transcript, p. 23). This exchange of concepts, in which a question about disability received an answer about community, points to the fact that a community has formed around disability. The members of this community have more in common than the presence of disabling conditions. They also share certain basic needs that must be filled if they are to participate in society:

(H) one thing i always liked about adapt is the way that they um..
decide what's important
and they look at it as sort of as hierarchy of
(H) what does someone need first
so=
we probably did it a little backwards with starting with public transit
@&
but @nevertheless that's where we started@
but what is what do you need first
you need a place to live
you need uh people to help you with whatever it is you need help with in that place
where you live
ahum but unless you want to stay in your !home! all day then you need public transit
ahum and you need a decent a "basic" income of some kind
\um but that com- can come through social security to some degree\
\um you need a basic income of some kind
you need to be able to get around
so
the most uh at least in the city is public transit is the first
the first link in that chain
then when you get somewhere you need to be able to get in
the buildings or the places or the whatever that you are
when you're in there you need to access whatever it is that's available in there

(Ervin second interview transcript, p. 22)

Ervin enumerates these needs as housing, personal assistance with "whatever it is you need help with", transportation, income, accessible infrastructure. While the tasks required of the personal assistants, and the features of accessibility, may be somewhat different, the needs described by Ervin do not differ in essence from the needs of the nondisabled in contemporary society. The community of the disabled becomes one part of the human community.

Nussbaum concurs, but does so by pointing out that the medical model is

part of the framework
part of this vast framework of systems
that
many people are oppressed under and by
and uh i
i'm an anticapitalist so i
i see that as
the s- systemic um
structures or realities or whatever that we have to deal with
we can do things and fight for things that.. will..
incrementally
ahum help us to..
enjoy more freedom
and pull more people out of
oppose-- you know powerful situations
but
we will never
until we unite with all sorts of other movements
in my opinion
be able to...
come
you know do battle! with those systems
<X and these whole system X>
until..
there's more of a i think developed political consciousness

(Nussbaum interview transcript, p. 13-14)

In this view, a common enemy ("the capitalist system to be frank" (p. 15)) has the potential to unite people, more than shared needs. This tension in the development of a sense of human community, between the possibility of doing so on the basis of common
traits and the expediency of doing so on the basis of a common enemy - between defining the "us" by what it is for, and defining the "us" by what it is against - resurfaces in Ervin's writings.

Published in 1981 in the Chicago Sun-Times, "The Japanese internment" features a shared byline with Norma Sosa and exposes a heinous and shameful action by the US government during World War Two: the forceful confinement of 120,000 Japanese Americans, none of whom "was ever charged or tried for any acts of espionage or criminal activity" in "relocation centers," paired with the confiscation of their assets (1).

"Nothing can ever replace the loss of our freedom and dignity," Helen explained, "but we lost something else of value that can be replaced. I would like for the government to admit that it was unjust. I want to see them take some kind of strong action so that it could never happen to any group under any circumstances." (5)

The article was published nine days before a federal executive commission met at Northeastern University to explore "the wartime experiences of Chicago area residents of Japanese ancestry" (4). The commission considered plans for "individual reparations of $25,000, endowment of a foundation to benefit the Japanese-American community, and an education project designed to prevent a repeat of the episode" (4).

Almost ten years later, Ervin wrote a column for his "Access to Life" feature in the Southtown Economist, titled "Today's kids don't know whom to hate." In this column, Ervin uses humor to point out the complexity of post-Cold War international politics, in which the dictator one should hate today gets replaced with a new enemy tomorrow. In mock indignation, Ervin decries this situation:

Having a central bad guy is the primary glue that bonds a generation together. If you can't reach consensus on whom to hate, how are you ever going to agree on anything else? How are you going to have any collective identity or self-esteem? . . . Pretty soon kids will stop believing in the concept of hate. Convinced that true, lasting hate is just an illusion, they'll decide not to hate anyone anymore. Then where will we be? (B2)
I would argue that the word "generation" in the preceding quote stands in the place of "community", that a generation is in fact a specific type of human community and that Ervin knew the organizing principle he had described gets used by many different types of community (Ervin cues this awareness to the reader in the phrase "any collective identity"). I would also argue that Ervin's point about hate can be applied with equal ease to a broader and less pointed human emotion: anger.

Ervin revisited the concept of anger dividing people into communities in another Southtown Economist column, "A short, unrevised history of the holiday," which examines the controversy over the historical figure of Christopher Columbus, and over the holiday that bears his name. Ervin acknowledges that "Revisionist historians say Columbus was an Indian-slaughtering slavemonger," but points out, "If it hadn't been for him, we wouldn't get the day off" (B2). Also, if Columbus hadn't done it, someone else would have.

Whether Columbus was a slave-driving Indian killer or not, someone else would have done it if not him. As soon as the next guy came ashore and felt awe-inspired by the endless possibilities of this breathtaking new paradise, the same thought would have occurred to him. A day off is a day off is a day off. It just seems un-American to lobby against having a day off. (B2)

Ervin has stated on more than one occasion that humor comes from exposing truth. In this case, the humor in Ervin’s writing comes from the seeming triviality of a day off from work, weighed against the slaughter and enslavement of an indigenous people. But I say "seeming" because, in the practical existence of current, living members of U.S. society, a day off from work is highly prized, and could be seen as a victory against the common enemy of, as Nussbaum would say, the capitalist system (to be frank).

In each of these three pieces of writing, Ervin sympathizes with the common citizen in the struggle of interplaying social forces: the historical Japanese Americans.
who lost assets and freedom due to ethnicity, the consumers of U.S. media whose sense of nationalism gets inflated when they are made aware of the existence of an opposing political force, the workers who must choose between expressing disapproval of genocide and their day off from exploitation. The identities of the enemy are interchangeable; the anger, as Ervin clearly expresses, serves to provide a collective identity - which can then be manipulated by elite power-brokers.

Ervin's core message regarding human community, expressed in all three pieces, is that the easiest way to create a sense of community is to target that which makes the members of the community angry. This message is built upon the foundation of the naturalized belief that ANGER IS A TOOL. This belief serves the interests of the dominant group within the movement by allowing them to access a deep well of energy in the minds and hearts of the movement's members, and focus that energy towards the movement's goals.

F. Tolerance for Lack of Resolution

It seems appropriate to begin a discussion of the value of tolerance for lack of resolution where Ervin began: with Alinsky's guide, Rules for Radicals.

M: . . . so i just started reading the book rules for radicals i think i read it i don't remember how i came across it i think i
L: (0) the alinsky book
M: yeah saul alinsky book i think i read an article in the reader about it and decided to read it and i remember sitting under my mother's tree in the backyard reading it and really thinking wow this is the kind of thing that i like to do
this is the kind of thing that i um this this makes sense to me you know this kind of approach and uh
    and then i heard about people forming adapt locally (Ervin transcript, p. 7-8)

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5 Readers concerned by the implications of the message that ANGER IS A TOOL may desire clarification as to the type of anger in question (just as the message POWER IS GOOD requires a measure of clarification). I would say the type of anger deemed useful by the movement would be the type of anger that unites people against injustice and inspires direct action.
Alinsky speaks quite eloquently of his tolerance for lack of resolution in a section of *Rules for Radicals* called Class Distinctions:

> If we think of the struggle as a climb up a mountain, then we must visualize a mountain with no top. We see a top, but when we finally reach it, the overcast rises and we find ourselves merely on a bluff. The mountain continues on up. Now we see the "real" top ahead of us, and strive for it, only to find we've reached another bluff, the top still above us. And so it goes on, interminably. Knowing that the mountain has no top, that it is a perpetual quest from plateau to plateau, the question arises, "Why the struggle, the conflict, the heartbreak, the danger, the sacrifice. Why the constant climb?" Our answer is the same as that which a real mountain climber gives when he is asked why he does what he does. "Because it's there." Because life is there ahead of you and either one tests oneself in its challenges or huddles in the valleys in a dreamless day-to-day existence whose only purpose is the preservation of an illusory security and safety. The latter is what the vast majority of people choose to do, fearing the adventure into the unknown. Paradoxically, they give up the dream of what may lie ahead on the heights of tomorrow for a perpetual nightmare: an endless succession of days fearing the loss of a tenuous security . . . At times we do fall back and become discouraged, but it is not that we are making no progress. Simply, this is the very nature of life: that it is a climb, and that the resolution of each issue in turn creates other issues, born of plights which are unimaginable today. The pursuit of happiness is neverending; happiness lies in the pursuit. (19-20)

Alinsky may not have had the Chicago disability rights movement still on its way in mind when he wrote of "the struggle," but Ervin and other members of the Chicago movement embraced the sentiment behind his words.

In 1990, a few weeks after "We all scream for our ice-cream freedoms" hit the newsstand, Ervin published another column in the Southtown Economist called "A close encounter of the best kind." By far the grandest in scale of the pieces I have selected for this analysis, "A close encounter of the best kind" relates a private moment Ervin shared with the cosmos at three in the morning on the deck of a ferry in the Gulf of California. Ervin then reflects on the sort of big-picture perspective dwelled upon by "guys who are too smart for their own drawers, guys like Carl Sagan and Stephen Hawking and Albert Einstein," which Ervin claims should depress them but actually brings them inner peace. "Sagan will sit up there grinning like a stoned cat and say things like 'Someday, BILLIONS and BILLIONS of years from now, our sun will burn out and the Earth will become a lifeless glacier.' Look at his eyes, wide with wonderment.
The man is either a sadist or the essence of mental health." (B2) This paradox of elation over humanity's lack of importance in the universe fascinates Ervin, and he did not think that he would share in it until he experienced it himself when struck by the cosmos on that deck at three in the morning.

So what was scaring me most as I sat on the deck was that I wasn't more scared. This confrontation with God was not like they said it would be in Sunday school. There was all the sobering humility but none of the soothing harp music. I spoke, and no one spoke back. But yet I was smiling and feeling a satisfaction. It was not unsettling but peaceful. I still haven't figured it all out yet. (B2)

Ervin does not specify in the column why he had traveled through the Gulf of California. Perhaps, given the emotional content of the column, such details of context seemed ephemeral when composing it.

In 1995, Ervin published a profile of a local community organizer, Shel Trapp, in the Chicago Tribune, titling the article "Here comes trouble." Like Alinsky's "struggle," Trapp's geared his activity not towards disability rights, but against oppression anywhere, anytime. At the time that Ervin composed the profile, Trapp had been organizing communities for nearly thirty years (1). He had begun a career as a Methodist minister, but ended that career when his week of jail time for desegregation work in Alabama led his church superior to tell him "Shel, if you keep doing these kinds of things, you're never going to get a suburban church" (3).

What keeps Trapp going is an irrepresible, restless anger. "I wake up in the morning and I'm angry. I'm angry that people are getting screwed over by other people. There isn't a helluva lot that doesn't make me angry," he says. . . Trapp feels he's lived out the gospel according to Trapp more as an organizer than he ever did as a minister. That gospel is: "We're put on this earth not to screw each other." (1-3)

Trapp was not what Ervin would call “a guy too smart for his own drawers.” Instead of focusing on what would happen to the sun “BILLIONS and BILLIONS of years from now,” he believed in "people power" (3).
Ervin has had his own beliefs about people power. In 1997, he published an article in *New Mobility* which he titled "Beware the Brahmins." This article brings the Colorado Collective for Medical Decisions (CCMD) to the attention of the reader, relaying that "CCMD has proudly published a set of proposed guidelines outlining who should receive life-saving cardiopulmonary resuscitation and who should not. And the guidelines say that administering CPR should be 'unusual' if it is known 'that the patient had significant physical or mental impairments prior to the cardiac arrest.'" (65) Ervin compares the treatment of a disabled person under these guidelines to the treatment of a *panchama* (untouchable) under "the ancient caste system of India - outlawed not all that long ago" (64).

The whole point of being a Brahmin is to be able to rig the game. Do you really think the caste system was invented by some poor panchama who said to himself, "I think I'll start a social order where I am scorned and ostracized and my station in life is to sweep up behind the elephants?" No, you can be sure that if there is a civilization on earth where the revered elite consists only of men named Felix who have three noses, the one who developed the concept was a man named Felix who had three noses. The elite are always self-appointed. (64-65)

Ervin then proceeds to appoint himself to the elite, and decree his own set of CPR guidelines.

I say we get it all and they get nothing. It makes sense. They obviously see life, or at least our lives, as one big tragedy. I think life is a gas. So why prolong their misery? Why squander precious resources? Why waste a rare fine wine on someone with a stone palette? Under my guidelines, the CCMD Brahmins are in big trouble, because there is only one human condition that is so tragic and debilitating, so alarmingly contagious, that it's probably beyond hope. Acute narcissism. (65)

All three of these pieces express the same tolerance for lack of resolution described by Alinsky in his confrontation of the mountain with no top. In “A close encounter of the best kind,” that resolution would take the form of a human sense of moral justice having a presence in the cosmos, a human God; but when Ervin speaks, no one speaks back. In “Here comes trouble” and "Beware the Brahmins,” the resolution would take the form of the end of oppression, of people not screwing each
other (to borrow a phrase from Trapp) and of the end of caste systems; but nothing can
be accomplished except a reversal, in which the Brahmins are killed and panchamas
prosper (because narcissism is a human condition beyond hope). Therefore, the
underlying message Ervin presents regarding the value of tolerance for lack of
resolution is that the human desire for justice will never be satisfied, which naturalizes
the belief that PEOPLE WANT JUSTICE. Once naturalized, this belief gives the
dominant group within the movement a perpetual purpose and justifies its existence. As
long as people want justice, the dominant group's work is fundamentally necessary.

G. **Self-Determination**

at that time all the big
sort of @“disease” organizations@ like
united cerebral @“palsy” and all those groups
were *extremely* straight and
uh
had no clue about
disabled people having *agency* of any kind or um
actually
having au– uh
being able to in many cases be /autonomous human beings\ that live /in the world/

L: @@

S: um [so]

L: [I’m laughing] because it just seems so naïve you know

S: y=eh it was real bad back then
      i mean
      it
      was
      unbelievable
      (Nussbaum interview transcript, p. 4)

This quote from Nussbaum, in which she introduces the concepts of agency and
autonomy, which nest closely with self-determination, came out in her discussion of the
size of the early Chicago movement and the composition of its struggles. Nussbaum
believes self-determination was very important in the early days. Her understanding of
its significance connects to her understanding of the social model:

L: . . . can you talk about
how the value of self determination was
present or absent in the movement at that time
S: um I think,
we began to identify ways
that we didn't have s-
that power um..
we began to name things and
really see them in
uh action in our lives and
inst– uh i think we cleared up for ourselves
that um
our inability to
do and believe certain things
was
not because we were
intrinsicly
just
unable

L: mm

S: but because
that
um
it was the system itself that was disabling us (Nussbaum interview transcript, p. 21)

Ervin agrees that self-determination was important to the early movement.

/consumer control could be another word for it/
but i mean that's why we want to get on the bus because we wanted to be have more
control over our own lives
so that was a strong
yeah i would say that that was a strong uh value and theme at the time
(Ervin interview transcript, p. 20)

In fact, Ervin holds out self-determination as the reason why Access Living served as
such an attractive focal point and gathering place for the activists of the era:

this seemed like something different like a place that um..
people were more in charge of the disabled
folks were more in charge of i hadn't really seen
a group
of that
size and potential that had disabled folks in charge of it
there were student groups on campus and things like that so it wasn't a com/plete/ly
foreign concept but
it was the most promising thing that i had seen that disabled folks were in charge of
and uh so that's why i was attracted to it (Ervin interview transcript, p. 8)

The desire for self-determination manifested in multiple items on the agenda of activists
in the 1980s and 1990s, from the presence of the disabled in media representations. . .

instead of having the
a.b.’s always defining and
^acting as^ and all that
nondisabled people ^directing^ plays with
disabled characters and people ^writing^ plays
that knew nothing about disability
[using those characters]

L: [in which it's just a symbol]

S: yeah

L: [disability as a symbol]

S: [a- that]
   a symbol and and other. . . 
   'horrible things'. . .
   uh
   mike and i had a consciousness obviously of
   the need
   to use e–
   ourselves
   in these productions. . .
   (Nussbaum interview transcript, p. 10)

. . . to the use of street action protests in addition to lawsuits. . .

had we just let the lawyers decide they probably would have told us not to do any
actions because it might hurt the lawsuit
i think we would have lost the lawsuit you know
XXXX hadn't done actions or we wouldn't have
it wouldn't have held the same
we might not have lost it
but i think that it wouldn't have been as effective
had we not uh done actions with it  (second Ervin transcript, p. 25)

..to the protracted, involved struggle with the CTA to turn Chicago's bus fleet accessible.

it never had occurred to me that i could even that i even *should* ride a bus
even though i lived on a street where a bus went by every day
i just never even considered it an option
part of that was probably
my lifestyle as a child we were not
we were not upper class people but we were
middle class people who always had a car and lived in a neighborhood where people
always drove
so part of that was tran–
public transportation was never part of our life but it never
occurred to me
a that i should ride a bus and b that there would be a problem riding a bus until
*this* started happening
so i was almost like <Q give em an inch and they take a mile Q> i started getting
around more and more
but then i started getting very !frustrated!
cause it was @nine to five on weekends@
it was like
elev–
seven in the morning til eight o'clock at night during the week
ah, it was call in advance maybe get a ride maybe not
maybe go straight to where you're going maybe not
maybe spend an hour on the bus
maybe wait an hour before they show up it was
for anybody with anything other than a discretionary life it was
it was it was !crazy! it was just it became insulting after a while
and i felt insulted having to ah
call and and ah ask permission
for things like that and i started to really think about
how m- how inferior my transportation was to other people's
and i had a van and i had friends that drove me around and my mom drove me around
uh so i got around a fair amount you know there was a nice lady in my house
but this was the on--
i realized now that i could travel independently which i'd never done before
cause i never drove
a car
and so really to go anywhere i always needed someone else
um
so anyway i just the idea of
of traveling independently     (Ervin interview transcript, p. 7)

Correspondingly, finding examples of this value in Ervin's body of work presented no challenge.

In 1989, Ervin published an article in "The Neighborhood Works," the policy journal of the Center for Neighborhood Technology, a "creative think-and-do-tank" that currently "works across disciplines and issues, including transportation and community development, energy, water, and climate change" (cnt.org). Titled "Activists Decide to Do It Themselves," the article gives the background on, and details of, a plan for Access Living clients to form a limited equity not-for-profit accessible housing cooperative called KHOSO (20). The designers of KHOSO intended for it to spark hope among the 700 people on Access Living's waiting list for affordable, accessible housing.

There's no way we can meet the demand. But what we can do is perpetuate the idea of empowering people to have the skills to build and run their own buildings. Disabled people have proven themselves to be capable of tremendous achievements. So it's perfectly realistic to think we can do something this difficult. (20)

One of the most important elements of KHOSO as conceptualized in this article was "true empowerment through control of resources, since the residents [made] all decisions regarding the building" (20).

Ervin has never believed that certain topics should be considered off-limits, in need of protection from satire (as I will soon detail in the context of the value of disability humor). Why should his own activities, and those of his activists friends, not feel the heat of the fire? Ervin brings activism under scrutiny arguably most successfully in his
1993 Daily Southtown (then-recently renamed from the Southtown Economist) column "We all scream for our ice-cream freedoms." According to the column (published in the summer month of August) a group of "out-of-school teenagers . . . hot, bored and ravenous" felt motivated to protest Baskin-Robbins' withholding of their favorite ice cream flavor, Quarterback Crunch (C2). "This was yet another example of ivory-tower corporate executives deciding what's best for a constituency they are hopelessly out of touch with," Ervin proclaims, mixing academic, corporate, and political imagery in his description of the social elite.

The Baskin-Robbins brass would surely have seen it coming had any of them retained a clue of what it was like to be a bored teen or if they had ever allowed a bored teen to penetrate their inner sanctum. Perhaps they need a bored-teen advisory committee. And I also can now clearly see the profound inspiration behind the sign "Freedom to Decide." That, more than anything else, is what this story is about. What a farce it is to live in a land with over 650 flavors of ice cream when no more than 60 or so are made available at a time. It just goes to show how there will never be true freedom of choice until the people, not the capitalists, control the means of distribution. (C2)

I must point out that the hilarity of this column derives from the idea of perceiving ice cream, which most people would think of as a quintessential luxury good, as a right. This is an attack, albeit one made through laughter, on the priorities of activist movements in general, and the disability rights movement specifically, implying that those setting the priorities are self-absorbed ("bored teens" frequently depicted in U.S. culture as self-absorbed) (C2).

The deep significance of self-determination for members of the movement in the life arena of housing also comes through in a 1994 article Ervin published in the Chicago Reader, "Bustin' Out." Instead of describing the situation using statistics, this article uses the technique of the specific story of a forty-year-old wheelchair user given

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6 The original source for this column was a piece of newsprint. Newspapers frequently designate their section paginations with a combination of letters and numbers. "C2" in this context indicates that the column was found on page 2 of section C.
the pseudonym "Willie," who feels the need to dissemble to ensure he succeeds at moving out of a nursing home, to illustrate and personalize the desperation of many in Willie's situation.

Maybe they couldn't do much about it but threaten and tell him he'll come crawling back some day. But who knows? A destitute guy like him, an ex-convict and all, is a valuable commodity for a place like this. Every month he's here the nursing home gets a check from the state for his room and board. And he's easy money, in the sense that he doesn't need any help. He can dress and feed and do everything else for himself, and his mind isn't orbiting Mars. He wound up here because he was fresh out of prison, disabled, and broke, and didn't have anywhere else to go. (8)

Willie manages to leave with his stuff, escaping to "a one-bedroom cube, about 500 square feet," with a lounge chair for a bed, a sectional couch, a manual typewriter, a boom-box radio, and a window with a view of a children's ballpark and the city skyline. Willie finds these assets more than sufficient, in comparison to the life he knew in the nursing home. The article ends with a quote from Willie that has challenging implications regarding self-determination: "'This is God,' he says, grinning with satisfaction. 'God put me here' "(22).

How can we synthesize the messages of "Activists Decide to Do It Themselves" and "Bustin' Out," which both deal the distribution of a truly scant resource and choosing the "least worst" option from a limited set, none of which can fulfill the desires of the chooser, with the message of "We all scream for our ice-cream freedoms," in which the activists demand the right to 650 flavors of ice cream? We can remember how Ervin prefaced his discussion about the shared needs that draw disabled people into the human community. "we probably did it a little backwards with starting with public transit," Ervin says with a laugh, "but @nevertheless that's where we started@" (Ervin transcript p.22). "We all scream for our ice-cream freedoms" came from a shift in the movement, a realization that the prioritization of accessible infrastructure in the 1980s had not addressed more deeply rooted problems of social inequity that "Activists Decide
to Do It Themselves" had started to address in the context of progressives and "Bustin' Out" attempted to bring to the attention of the nondisabled. In the early 1990s, Ervin's consciousness changed. He saw that people with disabilities (as Cameron says about a different subjugated group) "do not have to play the game - as we have seen, some explicitly refuse to do so - but refusing to play is not the same as being able to change the rules so that the game itself is played differently by everyone" (169). This is, in fact, Ervin's core message regarding self-determination: *true freedom of choice involves more options than society will give you.* This seems to handily naturalize the concept of thought-based hegemony, in which oppressors are able to control what options the oppressed pursue by structuring the systems of thought of the oppressed so that the options undesirable to the oppressors do not even occur to the oppressed as possibilities. A less abstract and intellectual way of phrasing this naturalized message might be THE SYSTEM HAS BEEN RIGGED, which serves the interest of the dominant group within the disability rights movement because it has the potential to absolve the dominant group of responsibility for certain types of failure of the dominant group’s initiatives. If those initiatives were to lack vision, the leaders could claim that their ability to envision a better way had been limited by their involvement in the social system, even if that involvement had occurred by force.

H. **Disability Humor**

really what the basis of the humor is is just exposing a truth about someone (Ervin interview transcript, p. 28)

i use it as a way to get at the truth (second Ervin transcript, p. 9)

Ervin’s truth, the truth of the values of the Chicago disability rights movement, poses a threat to those who wield power over others. Approaching it in a somewhat oblique
way, through humor, can bring this truth home in a way that is more difficult for the power wielders to fight. Nussbaum points to this in a general way when she observes,

> i think
> it
> gives
> one
> or a movement its
> sense of identity you know
> and its...
> humor it can be so subversive  (Nussbaum interview transcript, p. 25)

Again Ervin makes a connection between his writings and the philosophy of Alinsky, as the origin of his understanding and use of humor.

> alinsky was very very big on that
> very
> one of his main things was that you have to have fun
> and if people aren't having fun they're not going to come to the meeting
> or if they are they're not going to be coming back..
> i mean that's the way you keep people
> involved is if they're having fun
> and when they win
> they have fun
> and when they uh when they
> when they're together and succeeding
> and enjoying each other and feeling like they have power /they have !fun!/ and uh
> so
> so i always thought that it was an an incredibly important thing to have
> i always...
> i was not at ^all^ uncomfortable with with uh ridicule..
> alinsky said that ahum
> if you're laughing at somebody it's hard to be afraid of them
> i mean you ^can^ be afraid of them
> but but um if you if if
> if you're laughing at someone at least for that moment you're not afraid of them or you couldn't
> your fear couldn't \keep you from laughing at them\}
> and so um that it can be
> very disarming if it's done right
> it can be
> something that people it's very hard to defend themselves
> (Ervin interview transcript, p. 26-8)

It would seem that Ervin's disarming sense of humor served him a little too well in the first decade of his involvement with the Chicago movement. At the start of the 1990s, he felt the need to explain himself.

Ervin published "Offensiveness is in the eye of the beholder" in his Southtown Economist column in 1990. Inspired by the specific instance of outcry against two
public sculptures at the Cermak Plaza shopping center in Berwyn, it targets censorship as a culturally destructive and arbitrary act.

I've talked to both the mall owner and the artist in the past, and I can't see where either intends to mock Berwyn. My interpretation of the artist's main purpose was that she's trying to get us not to look at everything so literally. Anyone who can teach us that lesson is doing us a favor. But even if their purpose was to mock, ridicule, it is their right. If the people don't like it, they should exercise their right to mock back. (B2)

Ervin does not deal with the question of the artwork’s funding source in this article; he focuses on the question of subjectivity of aesthetic appreciation.

Years later, Ervin wrote an article that could easily draw fire to him when it comes to that question, called "Blessed Are the Butt-Wipers." Published in *New Mobility* in 1997, this article begins with a quote from the founder of the Michigan Hemlock Society regarding the indignity and injury to pride of needing assistance with personal hygiene, particularly regarding feces. Ervin retorts by amending the Christian beatitudes to include "the butt-wipers," and then goes a step further by bluntly admitting that he needs their services - as do others, he points out, such as Stephen Hawking. "I'm sure the good professor would agree that wiping time is not the dreaded submission to humiliation a lot of people think it is. In fact, there is often a very special kinship between wiper and wipee. It can be quite spiritual" (52). Ervin drives his point home by telling an anecdote about a specific friend of his, who helped him by cleaning animal excrement out of the ridges of his wheelchair tires, with whom he feels this spiritual kinship. If all people could deal with unsavory aspects of life as pragmatically, Ervin proposes, the world would be a much better place.

Even among other folks with disabilities, us wipees have second-class status. I think one of the biggest problems with our movement (no pun intended) is that there are not enough wipees in leadership positions. If I were on the board of an independent living center and we were hiring a director, I would pitch the resume and ask one multiple-choice question: Have you ever a) had your butt wiped, b) wiped someone else's, c) none of the above? If the answer is C, you need to go back and spend some time in the trenches. (52)
While "Blessed Are the Butt-Wipers" does not use the same satire techniques present in
some of the other articles I have analyzed, such as "Erasing the E-Word" or "We all
scream for our ice cream freedoms," its frank, head-on confrontation of a topic that most
people treat squeamishly will provoke at least a nervous titter, if not a belly-laugh, from
most readers.

The year after the publication of "Blessed Are the Butt-Wipers", Ervin produced
another article for New Mobility, "Funny is as Funny Does." This article addresses the
subject of media and artistic representations of people with disabilities. Ervin objects to
those who would censor those representations to ensure that they are all positive and
flattering, on the grounds that such representations are not honest. In this quote from
that article, he begins by relying on personal connection with the audience to make his
point, and then broadens out to his general principle:

> When Anna and I drop something important like our keys on the floor, the flies on the
> wall must split a gut watching us devise ways to pick them up. Well maybe if we tie a
> rope to the handle of the bucket and then drag the bucket on its side across the floor
> we can scoop up the keys and raise the bucket by the rope up to our level. Or maybe
> if we detach the hose from the vacuum and inhale real hard on one end we can suck
> the keys up the hose and catch them with our teeth. At one point in time, when the
disability movement was first emerging, it was probably necessary to above all be
dignified. So it was probably also necessary to be strict about the kind of jokes that
were told about us. But I think it's safe to ease up now . . . gaining the power to define
ourselves and our culture means developing a sense of humor. Part of claiming status
as a fully dimensional human being is to satirize and be satirized. (50)

Note the retrospective analysis beginning to coalesce! Ervin writes about "when the
movement was first emerging" as a separate time with different priorities, As noted in
the Introduction, this shift in priorities can be seen by examining Ervin’s choice of writing
topics. When the movement was first emerging, it was about personal experience and
the problems experienced by individuals, but later the push for systemic solutions to
problems experienced by society as a whole intensified.
"Funny is as Funny Does" states explicitly what "Offensiveness is in the eye of the beholder" attempts to express when it talks about the right to mock, and what "Blessed Are the Butt-Wipers" demonstrates in action: *Fully-dimensional human beings satirize and are satirized*. This naturalizes the common-sense assumption that humor is innate to human nature, rather than a social construct. This assumption can be summed up as HUMOR IS HUMAN. The answer to the question of how this serves the interest of the dominant group with the movement at the time should be obvious, given Ervin's discussion of Alinsky's take on humor. If HUMOR IS HUMAN, opponents of the movement who attempt to stop its use as a subversive political tool run the risk of accusations of dehumanization of the disabled, opening themselves up to dehumanization as well.

1. **Conclusion**

   The value of critical discourse analysis, and the critical theory paradigm upon which it rests, is that it gives an opportunity to defrock the emperor of his imaginary clothes, to name and claim that which seems too obvious to need stating, to undo the rigging of the system for at least a moment. To summarize the conclusions of the analysis given in this chapter,
TABLE II

<table>
<thead>
<tr>
<th>VALUE</th>
<th>NATURALIZED BELIEF</th>
</tr>
</thead>
<tbody>
<tr>
<td>personal connection</td>
<td>PERSONAL CONNECTION BRINGS JOY</td>
</tr>
<tr>
<td>interdependence</td>
<td>WE HAVE RIGHTS</td>
</tr>
<tr>
<td>acceptance of human difference</td>
<td>POWER IS GOOD</td>
</tr>
<tr>
<td>human community</td>
<td>ANGER IS A TOOL</td>
</tr>
<tr>
<td>tolerance for lack of resolution</td>
<td>PEOPLE WANT JUSTICE</td>
</tr>
<tr>
<td>self-determination</td>
<td>THE SYSTEM HAS BEEN RIGGED</td>
</tr>
<tr>
<td>disability humor</td>
<td>HUMOR IS HUMAN</td>
</tr>
</tbody>
</table>

This begs the question, could members of the disability rights movement in Chicago in the 1980s and 1990s have found these naturalized beliefs that their values rested upon problematic? As one possible answer to this question, Chapter II of this thesis complicates the values of the movement.
III. COMPLICATING THE VALUES OF THE EARLY CHICAGO MOVEMENT

A. Introduction

I have demonstrated that each of the movement’s seven values, which I claimed formed a system and sequence, could be linked to an undergirding naturalized belief. I will now show how this system of values, although it can be entered at any point, does indeed operate in a sequence, based on an interplay of belief and external complication necessary for the movement's sustainability. The most convenient place to enter the sequence is with an external complication, “value placed on independence.” Starting there, the connections between naturalized beliefs and complications read like this:

- The value placed on independence leads to a demand of
- WE HAVE RIGHTS, but the complex nature of those rights leads members into
- wondering about what differences really exist between the disabled and the nondisabled, which splits and divides the movement until the members remember their common goal of
- POWER IS GOOD, and this authorizes the existence of
- a privileged subgroup within the movement, who teach the members that
- ANGER IS A TOOL, but this ignores the fact that anger is felt to be dangerous and controversial by many, so
- this belief conflicts with a previously asserted value, and this conflict can only be resolved through the belief that
PEOPLE WANT JUSTICE, but this frustrates some members because
the goal is unattainable due to the evolving nature of oppression, which leads
those members to conclude that
THE SYSTEM IS RIGGED, and this creates a desire to place value upon
independence. See first point in sequence.

Note that only five beliefs and five complications take part in this sequence, even though
I discussed seven values in the preceding chapter. I have removed the values of
“personal connection” and “disability humor” from the sequence. Not that the members
of the movement did not experience complications of these values; rather, I have
removed them because the naturalized beliefs revealed in my analysis of these two
values in the preceding chapter were self-reflexive. The naturalized belief for “personal
connection” was PERSONAL CONNECTION BRINGS JOY, and the naturalized belief
for “disability humor” was HUMOR IS HUMAN. In both cases, the belief about the value
helps to define the value itself, whereas with the other five values, the belief about the
value connects the value to another concept (for example, the naturalized belief about
“acceptance is human difference”, POWER IS GOOD, connects the value to the
concept of “power”). Because the beliefs about personal connection and disability
humor are self-reflexive in this way, they do not contribute to the larger sequence; they
form ends unto themselves. Let us therefore examine their complications first.

B. PERSONAL CONNECTION BRINGS JOY… But Does It Also Bring
Responsibility?
As I demonstrated in Chapter I, Ervin believes personal connection to be extremely valuable, both to him and to the movement. Only when he recollected a moment of crisis, encountered in his early days of facilitating a peer support group at Access Living, did the problematic aspect of this value stand out in sharp relief:

there was a young woman with cerebral palsy
and she was married to a "man" with cerebral palsy
and this guy had a habit of being domineering and abusive to her
i don't know if he was ever physically abusive but he would /yell at her and everything/
and he didn't like to let her
he didn't like to be "away" from her
so
we debated about
he wanted to join the group
and she did
so we debated about whether to let him in
and we let him in but we also said that
if at any point she said that she didn't want him in there that he had to leave
he started acting up and we told him he had to leave
and then he got angry and stood up and said
<Q uh come on we're leaving Q> to "her"
but she didn't want to leave
and then she like grabs my arm and starts crying i'm like oh god this guy's going to punch me or something (second Ervin transcript, p. 6)

Note that at no point in this story does Ervin explicitly state that he considered his personal connection to the couple in question burdensome. However, at the height of their crisis - when the husband demands that the woman leave with him and she makes a physical connection to Ervin by grabbing his arm - he does state that his primary concern is for his own physical safety ("i'm like oh god this guy's going to punch me or something"). It seems logical to conclude that, in that moment at least, he had wished that the woman had not attempted to make that type of connection to him. This aspect of personal connection, in which it is experienced as a responsibility instead of a joy, gets discussed infrequently in Ervin's writing. Recall, the message in Ervin's writings from which we can derive PERSONAL CONNECTION BRINGS JOY is that loss is the price of attempting genuine personal connection, but is not as great as the joy that it brings; the sort of loss that Ervin described in a piece such as "Anna" has more to do
with losing the source of the connection, than feeling burdened with too much responsibility while the connection still exists.

However, in "Why Me", Ervin's collaborative effort with Nussbaum, the downside of connecting with other people does get explored. When the character of the Voice is not busying itself with making flip and derisive comments to Wheelchair Woman in response to her defenses, it attacks her for not trying harder to maintain a social life:

Voice: Seeing anyone these days?
WW: Yeah, I'm seeing a couple people.
Voice: Don't kid a kidder.
WW: Things didn't work out.
Voice: Men are pigs.
WW: Why are men such pigs?
Voice: It's an economic determinism thing, you know, like you live in a patriarchal society and you got a situation where the men are pigs. You know, you should go on Love Connection. They only see your head on the video. They wouldn't see the rest of you 'til it's too late. (3)

In this quote, the Voice, which clearly externalizes part of Wheelchair Woman's interior monologue, mocks her for relying on a social/political answer to problems she is experiencing in her personal life, and through a sarcastic reference to Love Connection, challenges her to instead admit that she fears her mobility impairment has made her undesirable. Eventually, the Voice needles Wheelchair Woman too far, and Wheelchair Woman snaps back:

WW: Just stop nagging me about my relationships. I have friends, I go out, I see men, they don't care about the wheelchair, I'm doing fine. It's amazing how fine I am. Considering all the ridiculous trivia I have to deal with every second like broken wheelchair parts and idiot strangers saying "hi there" and Jerry Lewis is still alive.
Voice: The French love him. Parlez vous francais?
WW: I spend half of my life doing all the stuff I need to do to survive and the other half pretending I'm just like regular people. Like it takes me an hour just to get dressed. That's just getting dressed. What is that - like five minutes a sock? (pause) Of course nothing pisses me off more than someone who cuts me extra slack for being disabled. Those patronizing head patters. Someone oughta lock those people up.
Voice: You're so well-adjusted. What's your secret?
WW: Sorry, I forgot, being well-adjusted is in. I'm supposed to overcome my disability, like how on TV they're always "overcoming" - like these days all crips have to either ski or hang-glide. I'm supposed to go rappelling off Mt. Everest in my wheelchair to realize my full crip potential. It's pathetic. You gotta be Supercrip. You gotta be a segment on That's Incredible.
Voice: That's incredible.
WW: Oh, shut up.
Voice: That's why you don't have a date. You're the rudest handicapped person I've ever met. (cheerfully) Oh well, what should we girls talk about? I know! Why don't you go out more? (4)
Ultimately, Wheelchair Woman decides that personal connection is worth it; she calls someone, silencing the Voice, and leaves her apartment to meet up with the person she has called. However, if she did not experience personal connection as a responsibility at all, if the value had no complication, she would not need the Voice's "nagging" as impetus to make that phone call. The Voice pushes her to connect when withdrawal would conserve emotional energy. This push would not be necessary if personal connection brought only joy and no complication.

C. **HUMOR IS HUMAN . . . But Not Everyone Gets the Joke?**

M: . . . i usually! try to use it to humanize people and that doesn't necessarily mean that i'm building them up it could be that i'm knocking them down humanizing em by knocking em down uh= somebody who i think is trying to get away with being.. something.. that um you know somebody who's being oppressive or bullyish or a big shot trying to act like they're um more important than other people um so i think if you ^take a shot^ at them and and uh you aren't dehumanizing them i think you're bringing them back to earth and um the ^opposite someone you would think is buried if you use humor to to strengthen them to build them up then i think that that's humanizing them

(Second Ervin transcript, p. 9)

The question of "What is human nature?" has proved intensely slippery and difficult to answer in philosophical dialogue. To what extent is there such a thing as an essential human nature, and to what extent is "human nature" determined by the considerer's position, in terms of era, geography, social strata, etc.? How much of "nature" is really made up of culture, and how can the answer to that question ever be known definitively, given that the knower is not separate from the knower's culture? The answers to these questions will not be found here; Ervin certainly did not attempt to write about them, or discuss them in his interviews. The quote above, however, makes evident that he does believe in the moral principle that all human beings have equal worth, equal fundamental importance, be they "big shot" or "buried." The easiest way to determine
whether or not two things have equal worth is to evaluate them upon the basis of a common essence; otherwise, one runs the risk described in the old adage about comparing apples to oranges. It therefore follows that, if Ervin believes that humor is a tool with which he can "humanize" people, by either "bringing them back to earth" or using the humor "to strengthen them to build them up", he also believes that there is a fundamental essence to humanity.

This essence, Ervin claims in "Funny is as Funny Does", has multiple dimensions to it, and one of those dimensions is humor - as I cited in chapter I, he explicitly asserts, "Part of claiming status as a fully dimensional human being is to satirize and be satirized. Because the more you get to know about people the funnier they are" (50). But then why do so many people, both disabled and nondisabled, have a problem with disability humor - and why did even more people have a problem with it in the early days of the movement?

L: I was wondering if you could talk a little bit about like how that sense of humor played out eh in other ah with other people in the movement ahum in the in the eighties and in the nineties
M: Yeah um I think it there was a lot less acceptance of it back then than there is now (Ervin interview transcript, p. 26)

S: . . . we were having auditions for history of bowling and I remember we had a bunch of good actors come in and I couldn't find anyone for the lead guy role and um they had these impressive resumes but they were so careful in their in their auditions to um sort of keep a=H I can't describe it they just didn't understand that the guy was had a sense of humor
L: mm
To answer these questions thoroughly might require a thesis expressly dedicated to no other purpose than exploring the nature of humor (both disability and non-disability related) and the nature of humans. For the purposes of this chapter, it will have to suffice to raise them, and note that perhaps disability humor and human nature connect in ways that are less expected, and more sophisticated, than the naturalized belief HUMOR IS HUMAN allows for.

D. **WE HAVE RIGHTS . . . But Are They the Same as Those of the Nondisabled?**

The more
*polite* organizations
however had a I'm okay you're okay type of approach
you know I'm not that different from you
and I think adapt had more of a I'm! different from you
and uh
and and that's a !good! thing
type of approach
I think others were more into minimizing
differences than um
than uh
um t- exploring them and cultivating them
(Ervin interview transcript, p. 15)
priorities have tended to be
especially early on
um eas- eas- easy stuff
/relatively/ easy stuff
that um...
you sort of model on the mentality of I don't really need very much I'm not that different from you
just do this and this and I'll be fine
and not really thinking about people that really are @a lot different from you and need a lot more@
and saying that and putting *that* on your agenda
I think
the independence more implies this myth of I can take care of myself just you know do this and
like just put a curb cut there and I'm fine
as opposed to um I need a lot of support in these ways
in that way I'm @just like everybody else@
and when I get support I can contribute just like other people do
and that's more of an interdependent way of looking at things
(Second Ervin transcript, p. 24)
Interdependence, which I showed in chapter I to rest on the naturalized belief of WE HAVE RIGHTS, can be seen as a half-way meeting point, a negotiated zone between dependence - a socially undesirable state in which a person's needs are entirely the province of other people - and independence - often aspired to by members of US culture, in which a person meets his or her own needs completely without help from others. Chapter I discusses how the members of the Chicago disability rights movement considered independence a poor choice of goals, contrary to the fundamental nature of life and society. The dominance of that value in the culture of the nondisabled, however, made it a starting point for many entering the movement. This may have been especially true for those who acquired their disability after taking part in the culture of the nondisabled during their formative years, as opposed to those with congenital disabilities. For many, embracing interdependence required a prolonged act of unlearning what had gone before.

i know it was stressed in my /family a great deal/
i don't think we ever understood..
that
it was a ^dangerous^
thing to
^prize^
so ^highly!^
um
made it hard for me i know
to come to grips
it was one of the things about my disability that was
and and really integrating it in my life that was so..
complicated nee- this needing help thing  (Nussbaum interview transcript, p. 23-24)

In the culture of the nondisabled, the association between the concept of independence and the concept of rights can be seen most clearly in the way that minors are treated. Minors (it is assumed) both are, and should be, dependent upon adults for the fulfillment of not just their desires, but their basic needs. They are also not accorded full civil rights under law. Some examples of civil rights that adults are granted by law,
but which are denied to minors, include: the right to vote, the right to marry, the right to enter into an enforceable contract, and the right to purchase and consume certain items associated with vice (e.g., alcohol and cigarettes). The ostensible reason why these rights are not granted is that minors are not responsible enough to handle their consequences. I would argue that one of the reasons why minors are considered to not be responsible enough for the consequences of these rights is the assumption mentioned previously, that they should be dependent upon adults economically. If U.S. society allowed minors to attain economic independence, they could also be considered responsible enough for the rights currently held by adults - especially if they used their economic power to demand those rights. It should therefore come as no surprise, then, that many people with disabilities who are dependent upon others economically will feel that they are treated “like children.” In the culture of the nondisabled, with the high value placed on independence, they are in a similar class of being. Despite the fact that their economic dependence may be due to the construction of society – to the system disabling them, rather than their impairment – society does not view them as worthy of the rights it grants to its full-fledged members, because they are economically dependent. They become twice-disabled.

The solution to this phenomenon, discovered by the early disability rights movement in Chicago, is to assert that what is demanded is not a civil right (a right to personal liberty established by law), but rather a human right (a fundamental right inherent to existence as a person, with which law should not interfere). Recall the chain of basic needs that Ervin spelled out in Chapter I that must be fulfilled for a person to participate in U.S. society in the modern era:

- you need a place to live
you need uh people to help you with whatever it is you need help with in that place where you live
ahum but unless you want to stay in your home all day then you need public transit
ahum and you need a decent a "basic" income of some kind

then when you get somewhere you need to be able to get in
the buildings or the places or the whatever that you are
when you’re "in" there you need to access whatever it is that’s available there

(Second Ervin transcript, p. 22)

Housing, personal assistance, mainline transportation, income, accessible
infrastructure, and accessible institutions: if participation in human society should be
considered a human right, and these constituent elements are universally required for a
person to be able to participate in society, it follows that these elements are also human
rights.

There is, however, a stumbling block: “you need uh people to help you with
whatever it is you need help with in that place where you live.” If “whatever it is you
need help with” is not universal – if it differs from person to person – is the basic need,
and therefore the human right, really the same? Ervin argues yes. He states, “i need a
lot of support in these ways in that way i’m @just like everybody else@ and when i get
support i can contribute just like other people do and that’s more of an interdependent
way of looking at things” (second Ervin transcript, p. 24). When viewed through this
lens of interdependence, Ervin’s need for a personal attendant when managing his
personal hygiene (as discussed in “Blessed Are the Butt-Wipers”) is not fundamentally
different from a nondisabled person’s need for a plumber should a pipe rupture in their
bathroom.

Recall what Gill said in the Ervin article “Disabled kids having fun in a circle of
friends”: "If people with disabilities choose to get together, that's a community. But if
they're told that's where they need to be by authority figures, then the message they
can get is, 'I'm not like other people.' And from there it's a short step to thinking 'I'm not
fully human”’ (13). The “short step” that Gill refers to does not always get taken; for example, when discussing how his father handled Kemp getting teased at the age of three for his physical impairment, Kemp muses, “For the first of many times, he told me that I was different – not better, worse, or special – than other children and that other children who couldn’t accept me for using prostheses had problems, not me. Thank you, Dad, for giving me the gift of pride in being equal as well as different” (195). However, Gill pegs it correctly as a short step indeed. It is difficult, when presented with a binary pair, to hold them as different but equal in value; it is tempting to at least attempt to evaluate one as superior to the other. As a consequence of the belief that they deserved the same human rights as the nondisabled, members of the early Chicago disability rights movement experienced a tension between the desire to claim a different-but-equal status (which Ervin found more frequently in more radical groups such as ADAPT), and the desire to claim that the differences between themselves and the nondisabled were really quite superficial (the "I'm okay, you're okay" attitude of the less radical groups). How could the movement get past this tension?

E. **POWER IS GOOD… But Who Gets to Wield It?**

L: … how did this difference in approach play out in the early years of the Chicago movement
M: um
   well fortunately...
   as opposed to other cities @@ that uh you know when we met people via adapt
   fortunately we never had a lot of big tension between access living and adapt in that regard
   ahum
   other groups maybe
   but other groups didn’t really matter we could manage
   without the support of other groups
   we coulda managed without access living but it woulda been a whole lot harder
   probably woulda been a lot less successful
   but um
   so in Chicago not too badly but when we did run into trouble that’s where we did run into it
   (second Ervin transcript, p. 25)

M: we all had respect for each other because
and then we all
we’re trying for the same thing so i think that was the main
reason why we got along it was pretty stupid to
to fight about uh little things you know
   (Ervin interview transcript, p. 31)
Those members of the early Chicago disability rights movement who could move beyond this tension did so by focusing instead on a common goal. No matter what they believed the degree of actual difference between the disabled and nondisabled to be, disability rights groups could agree that POWER IS GOOD and worth working towards.

Ervin's commitment to this goal comes through in his writings time and again. One good example is the column "A short, unrevised history of the holiday", summarized in Chapter I of this thesis, which discusses Ervin's take on Columbus Day (recall, "It just seems un-American to lobby against having a day off"). Ervin qualifies the observation that Columbus was "an Indian-slaughtering slavemonger" by saying that this observation came from "Revisionist historians" (B2), but he has his own complaints about Columbus, which are essentially revisionist:

Even as a kid I never understood the big deal about Columbus, but I knew better than to argue with the gift horse. They told us Columbus discovered America, but he landed somewhere down by Cuba. And there were already people living here, so what was there to discover? Like the other day I was reading where there is a dispute over which 19th-century male physician discovered the female clitoris. Now I'm sure women knew it was there long before either of these guys stumbled across it, but it was never really officially there until so decreed by a white male. So it was with the American Indians. Until the white men discovered, named and killed them, they were never really alive. (B2)

In this passage, we see Ervin's use of humor to humanize, and bring the oppressor "back to earth" as he would say, in action. Power can be used to very destructive results - from the claiming of an entire gender's sexual territory as a personal "discovery" (which enables the "discoverer" to feel they have the right to control the "discovery"), to genocide, to the selection of certain lives as worthy of the historical record while other lives get forgotten. But power itself does not destroy, and Ervin knows "better than to argue with the gift horse."
In this respect, Ervin demonstrates again that his principles are in alignment with those of Alinsky. In *Rules for Radicals* discussion of means and ends (power and results), Alinsky writes:

> Life and how you live it is the story of means and ends. The end is what you want, and the means is how you get it. . . . The man of action views the issue of means and ends in pragmatic and strategic terms. He has no other problem; he thinks only of his actual resources and the possibilities of various choices of action. He asks of ends only whether they are achievable and worth the cost; of means, only whether they will work. To say that corrupt means corrupt the ends is to believe in the immaculate conception of ends and principles. The real arena is corrupt and bloody. Life is a corrupting process from the time a child learns to play his mother off against his father in the politics of when to go to bed; he who fears corruption fears life. The practical revolutionary will understand Goethe's "conscience is the virtue of observers and not of agents of action"; in action, one does not always enjoy the luxury of a decision that is consistent both with one's individual conscience and the good of mankind. The choice must always be for the latter. Action is for mass salvation and not for the individual's personal salvation. He who sacrifices the mass good for his personal conscience has a peculiar conception of "personal salvation"; he doesn't care enough for people to be "corrupted" for them. (21)

In Alinsky and Ervin's view, if you want time off from work, you take it, even if it's given to you in Columbus' name. And if you want to demonstrate disdain for Columbus' legacy, you don't defeat yourself by giving your free time back to your own personal oppressors; instead, you demand more, and lay claim to what your culture considers heroic. Tongue in cheek, Ervin proposes, "We could scrap Columbus Day and still keep everybody happy if we make an official holiday out of Ernest Borgnine's birthday" (B2).

Professed beliefs may not always translate into actions taken, but beliefs do have consequences. In the case of POWER IS GOOD, this naturalized belief opened the door for the more privileged members of the disability rights movement to begin setting the agenda for the movement as a whole.

M: . . . they concentrated more at the time
on infrastructure
and things that affected uh=
/should i say more privileged people\ /i guess/
uh..
being uh
i think those were where the agenda tended to come from because the people
and i don't mean this as a put down it's just how it was
the people who uh f- founded the movement who ran the centers ^were^ the most privileged
as a rule disabled folks

I think the main difference between then and now
is that now we concentrate a lot more on
on the policies and institutional biases and things like that
that have more an effect on people that aren't so privileged
but I think at the time it had a lot to do with
"infrastructure"
uh antidiscrimination and that type of thing

(Errin interview transcript, p. 4)

The leaders set as their highest priority the social changes that they would see
immediate and personal benefit from. "If action should be for mass salvation instead of
personal salvation," the activist asks, “but POWER IS GOOD, where lies the harm in
working for a type of mass salvation that is also personal salvation? Am I not part of the
mass?" Moreover, not all members of the Chicago movement agree with Ervin about
the significance of the "difference between then and now":

it was
always integrated and yet it was ^always^
i mean the top people with
the power and the say so and all of that uh
were always white
access living is still struggling with that
in and
or ^not^ struggling with it
but it's still a huge problem
even after ^years^ of /trying to fix it/
they can't
it's like they're at a loss

(Nussbaum interview transcript, p. 18)

Whether they thought it "right" or not for an elite to exist within their numbers, members
of the Chicago movement chose not to argue with the gift horse (or at least, not to argue
too loudly). The priorities were set and the struggles took place. Perhaps we should
ask, what message did those leaders choose to tell, to themselves, to each other, to the
less privileged, to the world?

F. ANGER IS A TOOL… But Might It Be a Dangerous One?

i guess others feel like it's a uh it's a /stereotype/
that they don’t wanna buy into the stereotype of the bitter /cripple/
ahum i think that some people feel that we need to...
uh /not be threatening/
and then people will /learn to like us/
if we're not threatening
ahum i think some people are afraid
o=f some of the more privileged
disabled folks are afraid of it looking unprofessional or undignified
or somehow um you know making us look like riffraff
and thus um
threatening whatever inroads they’ve made into polite society
one of the biggest roles in putting us in the hole that we’re in
is our fear of being angry about things that everybody else would have a
the right to be angry about like I said if para – if public transit were modeled like paratransit in the eighties
people would have been really pissed off and nobody would have said "Oh you’ve got no right to be angry you should be glad that a bus comes at all Q"
if they had applied it to mainline and uh so I think that you have a right to be angry and
if you don’t express it.. you can only repress it and that doesn’t do much good to you it helps the people that are trying to push you away it helps them a lot but it doesn’t do any good for you (second Ervin transcript, p. 21)

In the preceding quote, Ervin floats the idea that some of the privileged within the Chicago movement tended to spread the message that people with disabilities who openly display anger look like unprofessional, undignified riffraff, and that such people “threaten whatever inroads [the privileged] have made into polite society.” Radicals must struggle with this message in other movements besides the disability rights movement, and it’s one they’ve developed an answer to, as Ervin revealed in a quote from the activist Shel Trapp in the profile piece “Here comes trouble”:

Very often people think they can change things if they’re just nice, if they’re just respectable. They think they can show the enemy facts and figures and they will see the light. A slumlord knows he’s a slumlord 99 percent of the time. When he changes it’s not because of good will but because someone forced him to. I’m a firm believer in Leo Durocher’s saying, ‘Nice guys finish last.’

Ervin understood this full well and had no problem with it, but many of the elite within the movement did not see the situation the same way that he did:

when people from within would get pissed off uh it would come from people that I think wanted to be more polite and felt that we weren’t representing ourselves correctly if we ^weren’t^ being polite that we were somehow perceived as a threat and that was a ^bad^ thing i always thought it was good in this case to be a threat um if you’re threatening something evil it’s good to be a threat @@ and uh and I thought that that was pretty evil so um
This conflict, between the naturalized belief ANGER IS A TOOL that undergirds the value of human community, and the desire of some members of the elite to avoid being perceived as a threat, was in some ways more difficult for the movement to surmount than the question of how different the disabled are from the nondisabled. The best method for doing so would be to focus efforts again on a common goal, this time justice, rather than power.

G. **PEOPLE WANT JUSTICE… But Can They Ever Get It?**

$$\text{there is}$$
$$\text{^no^ attempt as far as i can tell } \text{\l'dunno\}$$
$$\text{to really engage with other movements}$$
$$\text{and draw them in}$$
$$\text{um=}$$
$$\text{and to support their}$$
$$\text{movements and there's..}$$
$$\text{i mean i go to the demos there's people}$$
$$\text{with ^flags^ there's people who ^really believe^}$$
$$\text{^strongly^ in}$$
$$\text{^america right or wrong^ um=}$$
$$\text{and america's the greatest country on earth}$$
$$\text{who don't struggle whatsoever or have a consciousness about}$$
$$\text{^racial^ oppression or}$$
$$\text{^sexism^ um or}$$
$$\text{^heterosexism^ or..}$$
$$\text{anything like that you know}$$
$$\text{there's ^no^...}$$
$$\text{there are n- never}$$
$$\text{and there are many opportunities i think for}$$
$$\text{in the evening after the demos}$$
$$\text{you know little}$$
$$\text{little group meetings perhaps}$$
$$\text{or have a speaker come in and talk about}$$
$$\text{racial oppression}$$
$$\text{or}$$
$$\text{you know work with some people in adapt who are minority folks}$$
$$\text{to uh and different minorities 'cause there are all different kinds of racism apparently}$$
$$\text{and um..}$$
$$\text{to me that would be}$$
$$\text{the logical next step}$$

---

7 I say “theoretically” because I did not encounter sufficient concrete examples in my review of Ervin’s writings of divisions in the disability community about its use of anger to fully “prove” this point. I will speculate that I did not encounter much published material about this because there was a desire to present a “unified front” to mainstream society, to not be viewed as factionalized and weak, and therefore information about splits within the movement were suppressed. However this is only conjecture on my part.
In this transcript passage, Nussbaum describes one possible solution to the conundrum of ANGER IS A TOOL: recognizing that anger is legitimate, but keeping it channeled at sources of oppression (no matter what axis that oppression occurs along), and away from the oppressed, in an attempt to pursue that elusive societal quality, justice. Nussbaum’s frustration stems from her perception that ADAPT has chosen not to pursue this solution.

Unfortunately, this "middle ground" compromise of questing for justice when attempting to resolve the issue of what role anger should have in the movement introduces another complicating issue: the ever-evolving nature of oppression. Successfully combating oppression in an egregious form often results in an unmasking of one or more of its more subtle forms. Nowhere is this more apparent than in the “resolution” of Ervin’s article about Willie, the disabled former convict who takes elaborate, dissembling precautions when leaving the nursing home in Ervin’s article “Bustin’ Out”. Let’s revisit just what Willie escapes to:

The lobby of the public-housing high rise where Willie has arranged to live is dark and gloomy. But the walls are clean, and the elevators work. They yawn open. In the corner of the one on the left are soggy cigarette butts in a pool of urine… Willie’s new place is a one-bedroom cube, about 500 square feet. No bed in the bedroom. Just a lot of boxes. His bed is the lounge chair in the living room. Next to it is a threadbare sectional couch. On the chair is an old manual typewriter with a sagging ribbon as worn as the couch. A boom-box radio is on the windowsill. Directly below is a park where children play Little League ball. Greens versus whites. Beyond is a spectacular view of the skyline. Willie’s especially proud of that. (22)

Willie embraces this cube-with-a-view as God’s work on his behalf. This speaks volumes about the lack of control that people who are living in nursing homes have over their day-to-day circumstances, but the text makes clear that the measure of self-determination that Willie feels so grateful for is still not self-determination in any absolute sense of the term. His environment remains distasteful by the standards of many of the article’s readers in several ways; while Ervin does not state what Willie
would want for himself if he had even greater control of his living conditions, it is
doubtful he would choose to place “soggy cigarette butts in a pool of urine” in his
elevator. Note that what Willie is especially proud of about his new apartment, his new
life, is “a spectacular view of the skyline;” he feels proud of what he can see, but no
mention gets made of what he can do. In the theatre of life and society, Willie has
earned the ability to be a spectator, but he does not appear to have any place on the
stage. True justice for him would involve the ability to make choices and take action,
and this type of justice continues to elude him at article’s end. His oppression
continues, less overtly, more perniciously.

Can this quest ever end? Will Willie ever be done? Alinsky, as quoted in
Chapter I of this thesis, says no. Willie, and by extension all of us, faces a choice, each
day, every day: engage in the struggle, or disengage in search of illusory security. The
struggle itself will always be there. Any activist worth his or her salt comes to terms
with this, and chooses to engage, by joining forces with others. Trapp, as profiled by
Ervin, was certainly worth his salt. He made this observation:

> With Martin Luther King, it wasn’t his philosophy that changed the white power structure. It
> was the fact that when he spoke up, 10,000 of his friends were there. If he stood on the
> street corner alone saying all those marvelous things he said, they would have said, “Look at
> the idiot on the street corner.” (“Here comes trouble”, p. 3)

Some people, however, when greeted with the prospect of a never-ending challenge,
will not feel exhilarated as an Alinsky, a Trapp, or an Ervin would. Some will feel only
frustrated. Some will choose to disengage. What could the members of the movement
tell themselves that might help to fight that frustration, and keep them engaged in the
struggle?

H. **THE SYSTEM IS RIGGED… So Maybe Independence Is the Way to Go?**

i remember seeing an inaccessible bus
somewhere that i wanted to go i was
i was at marshall fields and i lived over on belden street and there was a number eleven bus
that would go right from one door to the other door
and i remember uh
sitting there 'and thinking'\n\<Q motherfucking bus Q>\n\but i knew we had an ^action^ coming and i was like <Q just wait Q>
and i felt *better* knowing that we had an action coming where if i didn't have that
all i would have felt was the frustration (Ervin interview transcript, p. 22)

Of the different values for the Chicago disability rights movement that I discussed
with Ervin in his interview, he expressed the most ambivalence regarding self-
determination. When examining the movement's value system directly and consciously,
Ervin connected this ambivalence to the fact that for him, the concept of self-
determination is very tightly linked to the mainstream ideal of independence, and he
prefers to align with interdependence:

L: . . . self-determination
M: okay
L: /can you talk about how that was a value in the movement at that time/. . .
M: well i think it was it was . . .
strong
ah which was a good ^and^ a bad thing
i mean at the time
uh it's ^short-sighted^ \in a way\
because it impl- it's short-sighted in the same way that
the word independence is short sighted when actually interdependence is probably a better
word
or something ^like^ interdependence um..
but uh i think that that was something that was very very um
/consumer control could be another word for it/
but i mean that's why we want to get on the bus because we wanted to be have more control
over our own lives
so yeah that was a strong
yeah i would say that that was a strong uh value and theme at the time but again
it was it also had its
drawbacks which i think we've done a better job of addressing since then
L: so you feel like
the movement now is not as much about /self determination as it was/
M: (O) i think it's i think it's got-
i think it's recognized the drawbacks of that of that word (Ervin interview transcript p. 21)

The interdependent mode of thinking actually promotes another value over self-
determination: community-determination. It is this value which has come to prominence
in the movement. Ervin's embrace of it makes his ambivalent response to an
individualizing concept like self-determination logical. Also, an argument can be made
that the concept of self-determination would make Ervin feel uneasy and ambivalent for
another reason. Ervin’s texts that deal most explicitly with self-determination, as analyzed in Chapter I of this thesis, naturalize the belief that THE SYSTEM HAS BEEN RIGGED - my blunt way of phrasing the concept of thought-based hegemony, in which oppressors control the oppressed by limiting what the oppressed can consider as possible courses of action. This naturalized belief is precisely the sort of conclusion a burnt-out, frustrated member of the movement might draw before choosing to disengage, and it runs counter to Ervin’s own personal value system, in which conflict should be faced and fought, in perpetuity if necessary:

I think that the people who criticize usually come from ‘you shouldn't say anything at all about this person’ and I’ve never agreed with that. I think that um that you need to do that. I think it’s fair and I think people should give it back to ya if they don’t like you they should. They should give it back to you rather than tell you that you have to shut up. (second Ervin transcript, p. 11)

These are the words of a fighter, and Ervin has consistently given this message for decades. Recall that as early as 1990, Ervin said regarding the censorship of public art at the Cermak Plaza shopping mall, "even if their purpose was to mock, ridicule, it is their right. If the people don't like it, they should exercise their right to mock back. They should maybe commission a sculptor to do a statue of the mall owner in his underwear" ("Offensiveness is in the eye of the beholder", p. B2). Ervin would clearly prefer to trouble the waters, rather than smooth them, if oppression lies submerged beneath them. He does not consider surrender to frustration.

A culture’s values, even ones that form a system and evolve as a sequential response to complications, need not operate with perfect, internally cohesive logic.

---

Ervin seemed reluctant to explain clearly what his critique of self-determination was, and I chose not to press him on the topic because I sensed it was a present evaluation, not something that had a strong place in a historical exploration of cultural values. If my own critique is unclear, that may be due to my personal support of the value of self-determination. I do not consider this value problematic.
Here we see an inconsistency in the system. THE SYSTEM IS RIGGED, when carried through its full arc, conflicts with the value of tolerance for lack of resolution. Ervin clearly prefers the latter value, over the naturalized belief. Ervin believes in hope, rooted in the ability to take action:

M: . . . . . .for a lot of people that's the first step and sort of the the high they feel when they when they find the community and get active it's just sort of like a big dose of hope that they hadn't had before or in a different form in a more realistic uh form in a different form than the jerry lewis is gonna cure me type of hope one that feels more powerful one that feels more like hope in terms of if i take action i'm gonna get this result rather than the hope of hopefully these other people will save me (second Ervin transcript, p. 26)

The ability to directly take action in order to obtain a desired result, instead of having to rely on others to take action, might be considered at least a component of self-determination if not its entirety, even though Ervin does not use that term to describe the sort of hope he finds so positive (I elicited the preceding quote with a question regarding the ability to transform disability from a deficit to a source of pride). It would seem that Ervin feels less ambivalent about self-determination when approaching the concept obliquely. Doing so may allow him to more easily separate it from the concept of independence, which he feels antipathy towards.

This link between self-determination and independence in the minds of members of the movement can be seen as a reaction to the perspective of frustration expressed in the belief that THE SYSTEM IS RIGGED. Paradoxically, it closes the circle of beliefs and complications for the Chicago movement's value system, by re-connecting that circle to the value system of the wider U.S. culture and its admiration of independence. Recall that interdependence is a negotiated zone between dependence and independence. That means it will contain elements of both. Self-determination's
presence in the Chicago movement's early value system serves as a marker of the difference between interdependence and dependence, a condition in which the dependent person can only pray "hopefully these other people will save me."

I. **Conclusion**

My goal for this chapter was to complicate the naturalized beliefs that undergirded the value system of the Chicago disability rights movement of the 1980s and 1990s, and to demonstrate how the components of that system responded to those complications in order to make the system stronger and better able to self-sustain. Hopefully I have also demonstrated how this system of interrelationship between belief and complication resulted in a varied texture of values, in which certain elements, when directly contrasted with each other, can be found to clash, but when separated and held in balance by other elements, work in favor of the strength of the system in its entirety. The early disability rights movement in Chicago could not have survived the struggle against the entrenched position of the CTA if its members had not found its value system compelling, and that meant it needed to be able to provide answers to challenges thrown its way. The idea of hegemony, of limiting the range of options someone can consider in order to channel his or her choices and actions, might be seen to come into play here; apparently, those considered oppressors are not the only people who rig systems.
when people would get mad at adapt it would be like oh we’re doing some –
you guys are doing something that’s going to make people um
^think^ that we’re:
radical or that we’re
um !angry!
those kinds of things we’re like <Q well, so we !are! you know Q> (@@)
i mean if you had to sit on a street corner all day and wonder if your ^bus^ is going to
show up or not
and if it was going to take you all around the city you’d be angry too so
why shouldn’t we be angry (Ervin interview transcript, p. 16)

I introduced this thesis by discussing a gap that, in my previous coursework at
UIC, I had found in the historical record. This gap can be seen in the dearth of
scholarship and publication dealing with the twentieth-century disability rights movement
in the Midwest. Throughout the length of this thesis, my goal for writing has been to
explore one particular aspect of that movement – the values present at that time for the
movement in its hub, Chicago – in the hopes of helping to fill that gap. The task of truly
filling that gap is beyond the scope of a Master’s thesis, but I believed I could examine
one piece of the puzzle, and I have done so to the best of my ability. When I first began
researching these values by reading Ervin’s published works, I never expected that I
would discover that they could be sequenced in a way that would not only follow the
logic of analytical theory, but would also be borne out by the experiences of the activists
who believed in them, as told to me decades later in interview. However, that is exactly
what has happened in the course of working through this process.

At the start of this thesis, I posed the central research question, *How did the
cultural values of the disability rights movement in Chicago manifest between 1980 and
2000?* I have used the writings of Ervin, as well as the retrospective viewpoint
expressed in his interview and that of Susan Nussbaum, to demonstrate that five of
those cultural values manifested through interrelationships of naturalized belief (teased
out through critical discourse analysis) and consequential complication, and that two
others were present in the tapestry even if their threads did not interweave with the others. The results of this demonstration can be summarized in the following chart.

<table>
<thead>
<tr>
<th>VALUE</th>
<th>NATURALIZED BELIEF</th>
<th>COMPLICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>personal connection</td>
<td>PERSONAL CONNECTION BRINGS JOY</td>
<td>experience of responsibility</td>
</tr>
<tr>
<td>interdependence</td>
<td>WE HAVE RIGHTS</td>
<td>triggers questions about the nature of the difference between the disabled and nondisabled</td>
</tr>
<tr>
<td>acceptance of human difference</td>
<td>POWER IS GOOD</td>
<td>authorizes the existence of an elite within the movement</td>
</tr>
<tr>
<td>human community</td>
<td>ANGER IS A TOOL</td>
<td>frightens and puts off members of the elite</td>
</tr>
<tr>
<td>tolerance for lack of resolution</td>
<td>PEOPLE WANT JUSTICE</td>
<td>frustrates due to goal’s unattainable nature</td>
</tr>
<tr>
<td>self-determination</td>
<td>THE SYSTEM HAS BEEN RIGGED</td>
<td>leads towards re-valuing independence</td>
</tr>
<tr>
<td>disability humor</td>
<td>HUMOR IS HUMAN</td>
<td>is not appreciated universally (triggers questions about human nature)</td>
</tr>
</tbody>
</table>

I believe that the most significant implication of the analysis performed in this thesis is that, as manifested in Ervin’s writings and the interviews that I conducted, the value system of the early Chicago disability rights movement had neither perfect internal consistency, nor chaotic incoherence. Rather, it was a product of, and response to, the interaction between belief or assumption, and experience of social phenomena. It would seem that the members of the movement believed what they needed to believe,
to face a struggle that many did not dare to face after perceiving the scope of the opposition. On a deep and most likely rarely articulated level, the members needed to have answers to face the challenges and criticism besetting them on all sides. In keeping with that image – of being beset on all sides – those answers also had to be multidimensional, at the price of consistency. Their inconsistency – the conflicts inherent between them – can actually be seen as a mark of the value system’s sophistication and flexibility, allowing it to better survive the fires of the complicated social reality it grew to oppose.

I propose that the formula I employed to create my research question opens the door for other, related questions. Such future research could use critical discourse analysis to examine:

- Other disability culture values that might have manifested in the Chicago movement during my specified timeframe;
- Other values from mainstream US culture, in addition to the value of independence, that still had an effect on the perspectives of members of the movement;
- Values from other cultures that the movement interacted with that might have permeated the movement to any extent;
- Activist movements centered on other aspects of identity and issues of social justice besides disability, doing work in Chicago during the specified timeframe – such as the feminist movement, racial justice work, or (as Nussbaum might phrase it) the anticapitalists;
• Disability rights activism that happened during this timeframe in other cities, such as Denver or Los Angeles; and
• Disability rights activism that happened in Chicago during a different timeframe, such as from 2000 CE to the present day.

The variables that I used to narrow down what I would be examining – value set, activist movement, city, and timeframe – could be manipulated, separately or in concert, to expose a new set of naturalized beliefs, a new set of complications struggled with, and ultimately a new facet to the gem of history. One could also keep the exact same research question and simply look at the writings of a different activist besides Ervin. The value system presented for the movement might be starkly different if drawn from the words of someone with a less (or even more) progressive political philosophy.

I believe it appropriate to end this thesis on a personal note. If history is written by the winners, and this thesis contributes to the history of the disability rights movement in the Midwest, then I supposed I should count myself among the winners. The victories of groups like ADAPT have had ramifications throughout U.S. society:

You see
evidence of
what we did
and what disabled people around the country did
everywhere you go i
i mean when um
every time i get on and off a bus
i think
i we did that!
every time i use a ^ramp^  
and i see a bunch of mothers with strollers or
^any^ kind of people that are
needing the ramp
you know dragging their luggage around or stuff
i say well i you know we did that!
you know y-
thank the disability [rights movement
you know]  

(Nussbaum interview transcript, p. 4-5)
After completing this thesis, I now find Ervin, Nussbaum and their contemporaries to be sources of great inspiration – not because of what they did “despite” their disabilities, but because of what they did because of their disabilities. They worked to redistribute power, enhance self-determination, and reshape the understanding of interdependence in Chicago. That kind of work inspires me, whatever the disability status of the worker. I will treasure the personal connection I was able to form with Ervin through the work I did for this thesis in the years to come. His words, both written and spoken, gave me a rare glimpse at the internal processes of the early years of the Chicago disability rights movement. Certain members of that movement, and the CIL Access Living, are known nationally in disability policy and service circles; but through careful analysis of Ervin’s publications and interviews, I was able to understand more fully what was going on “behind the scenes”, and how power was distributed and maintained in the movement during this era.
## APPENDIX A
### DUBOIS TRANSCRIPTION CODING SYMBOLS

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intonation unit</td>
<td>{carriage return}</td>
</tr>
<tr>
<td>Word</td>
<td>{space}</td>
</tr>
<tr>
<td>Truncated word</td>
<td>-</td>
</tr>
<tr>
<td>SPEAKERS: Speaker identity/turn start</td>
<td>:</td>
</tr>
<tr>
<td>Speech overlap</td>
<td>[ ]</td>
</tr>
<tr>
<td>ACCENT AND LENGTHENING: Primary accent</td>
<td>^</td>
</tr>
<tr>
<td>Booster</td>
<td>!</td>
</tr>
<tr>
<td>Lengthening</td>
<td>=</td>
</tr>
<tr>
<td>TONE: Fall</td>
<td>\</td>
</tr>
<tr>
<td>Rise</td>
<td>/</td>
</tr>
<tr>
<td>PAUSE: Long</td>
<td>. . .</td>
</tr>
<tr>
<td>Short</td>
<td>..</td>
</tr>
<tr>
<td>Latching</td>
<td>0</td>
</tr>
<tr>
<td>VOCAL NOISES: Inhalation</td>
<td>(H)</td>
</tr>
<tr>
<td>Exhalation</td>
<td>(Hx)</td>
</tr>
<tr>
<td>Laughter</td>
<td>@</td>
</tr>
<tr>
<td>QUALITY: Quotation</td>
<td>&lt;Q Q&gt;</td>
</tr>
<tr>
<td>TRANSCRIBER’S PERSPECTIVE: Uncertain hearing</td>
<td>&lt;X X&gt;</td>
</tr>
<tr>
<td>Indecipherable syllable</td>
<td>X</td>
</tr>
<tr>
<td>NON-TRANSCRIPTION LINE</td>
<td>$</td>
</tr>
</tbody>
</table>

(selected from Schiffrin, 422-3)
Exemption Granted

February 16, 2012

Lyn Wilder
Disability and Human Development
2S754 Winchester Circle W, Unit 2
Warrenville, IL 60555
Phone: (630) 393-1890

RE: Research Protocol # 2012-0117
"The Publications of Mike Ervin, 1981-1999"

Sponsor: None

Dear Lyn Wilder:

Your Claim of Exemption was reviewed on February 14, 2012 and it was determined that your research protocol meets the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)]. You may now begin your research.

Performance Site(s): UIC
Subject Population: Adult (18+ years) subjects only
Number of Subjects: 2

The specific exemption category under 45 CFR 46.101(b) is:
(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.

Phone: 312-996-1711 http://www.uic.edu/depts/overs/ Fax: 312-413-2929
2. **Record Keeping** You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.

3. **Final Report** When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).

4. **Information for Human Subjects** UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. When appropriate, the following information must be provided to all research subjects participating in exempt studies:
   a. The researchers affiliation; UIC, JBVMAC or other institutions,
   b. The purpose of the research,
   c. The extent of the subject’s involvement and an explanation of the procedures to be followed,
   d. Whether the information being collected will be used for any purposes other than the proposed research,
   e. A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
   f. Description of any reasonable foreseeable risks,
   g. Description of anticipated benefit,
   h. A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,
   i. A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).
   j. A statement that the UIC IRB/OPRS or JBVMAC Patient Advocate Office is available if there are questions about subject’s rights, which includes the appropriate phone numbers.

Please be sure to:

→ Use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, B.S., C.I.P.
Assistant Director, IRB # 2
Office for the Protection of Research Subjects
CITED LITERATURE


NAME: Lyn Wilder-Dean

EDUCATION: B.A., English and Theatre Arts, University of Iowa, Iowa City, Iowa, 2002

M.S., Disability and Human Development, University of Illinois at Chicago, Chicago, Illinois, 2014

PROFESSIONAL EXPERIENCE: Rebuilding Together

Depression/Bipolar Support Alliance, GLBT Chicago Chapter facilitator for peer support group meetings, 2011