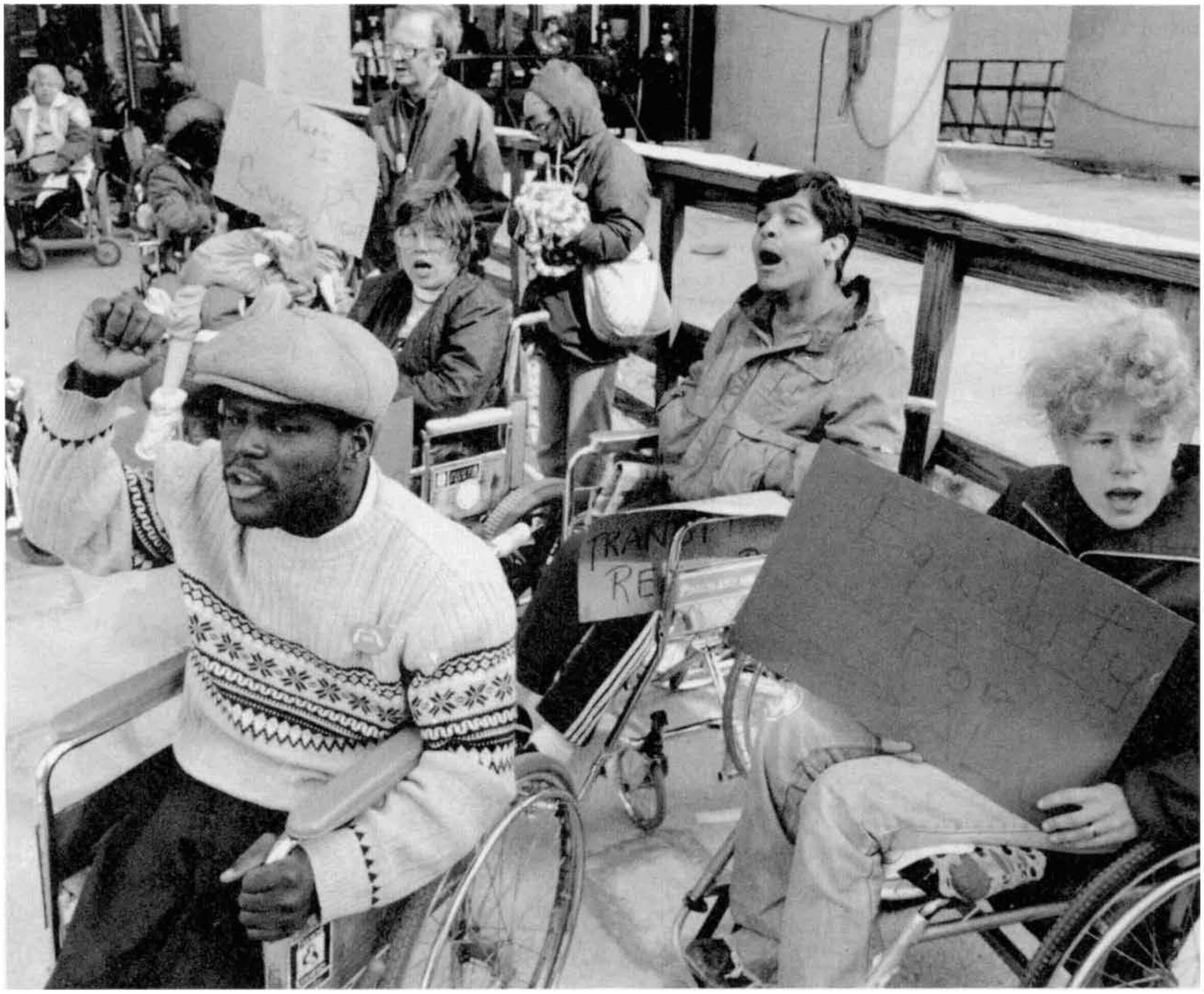

# Proud Voices:

## An Oral History of the Disability Rights Movement in Michigan (1960 -1980)

by Lauren J. Thomas

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the National Endowment for the Humanities, and the Kate and Richard Wolters Foundation.

*To RoAnne Chaney,*
*friend and mentor,*
*whose dedication to the present day*
*Disability Rights Movement*
*matches the passion of the early leaders*
*chronicled in these pages;*

*and*

*to Michael Daeschlein,*
*friend and mentor,*
*whose constant words and gestures*
*of comfort and challenge*
*reminded me that none of us works alone.*

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# Foreword

History is personal. No matter which civil rights movement is being chronicled, its early leaders tend to report the same life-changing experience, the moment of revelation: their individual issues suddenly take on a context, as the product of social oppression.

"The world turned upside down for me." This epiphany can occur at a lunch counter, on a bus, in a conversation with a maitre d' or a prospective employer, or anywhere we find ourselves as marginalized human beings in our daily encounters with the majority culture. It is the moment when we see ourselves differently, the moment we take possession of an idea that permanently changes our lives: I will not be a second class citizen anymore. Whether we are born with a disability, as Laurie Thomas was, or whether we acquire our disability later in life, as I did, we must all come to the moment of truth: that we have up until this moment accepted the identity assigned to us by society — up until this moment.

And the rest, as they say, is history. The Millennium Oral History Project captures that history "live," serving to illuminate the origins of the disability movement in Michigan for historians and students of public policy, by tapping directly into the personal experiences of those who led it. The Independent Living movement is widely thought to have had its beginning in Berkeley, when Ed Roberts and his mother Zona challenged the discriminatory admissions policies of the University of California. In fact, as Bay Area historians recognize and Laurie's work demonstrates, the movement was born in different places in the United States in the latter half of the last century.

Why is this project important to the disability community? For many reasons, I think. First of all, our movement is very young — even younger than the movements for racial and women's equality — and our work is very far from finished. We are beginning to suffer losses from our first generation of leadership, from a group of people who nurtured their dream under almost incredibly difficult circumstances. Their words can inspire us as we continue the struggle.

We also need to examine those early experiences as we work to chart our ideological course for the future. The first person accounts contained in this volume allow us to challenge our preconceptions. Is there a "right way" and a "wrong way" to start a Center for Independent Living, for example? We need to be careful in our judgments on the matter, for the three CILs which are chronicled in this project began as very different creatures . . . and all are thriving today. Is there a right or wrong language for our culture? The early usage in Michigan of the much-maligned term "handicapper" supported the development of our identity in powerful ways. Who is the enemy of our movement, and who is to be trusted? The role played by Michigan Rehabilitation Services management and employees in building the movement is extremely thought-provoking.

Much remains to be done in securing our rights and establishing our place in a fully inclusive society. We cannot be successful in our drive for inclusion until we have built our own community, moving from shared experiences to shared values to a sense of our own culture. That becomes the well from which we drink deeply and draw strength, so that we can be heard. Here in this volume, our history speaks. It is the language of heroism that went largely unrecognized in its time. History is personal. In our hearts, we must respond to what is being said to us, so that we can keep the dream alive.

Mike Zelley
*The Disability Network*
*Flint, Michigan*
*March 31, 2001*

# Acknowledgements

Thank you to all the persons interviewed for this project. These people shared their lives, perceptions and memories with me. Without these people, there would be no history to record. These individuals, indeed, are the proud and able voices to which the publication's title refers.

Deep gratitude goes to my editors Michael Daeschlein, Daniel Rubenstein, Elizabeth O'Hara, Chris Clampitt and Shirley Beckman. They were constant sources of helpful critique and comfort.

Thank you to those many unnamed people of inspiration in the present day disability community and in my spiritual communities of the Unitarian Universalist Church of Greater Lansing and the Leaven Center. They helped to remind me why the capturing of a history of any minority population is crucially important to their identity as well as to the larger American culture.

My gratitude to all the staff of Michigan Disability Rights Coalition - RoAnne Chaney, Norm Delisle, Kim Steele, Donna Aiken, Jane Schoneman, Nick Prass and Jim Bohr. They were my colleagues during this odyssey. Gracefully, they allowed me to interrupt their work when I had questions of many kinds.

Thank you to all those who made early financial contributions to this project. Special thanks are to be given to the Michigan Humanities Council and the

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I am appreciative of my transcriber, Kimberly Hauze, whose work transformed the audio tapes into professional looking transcripts. I am grateful for the expertise of Carol Ferris, whose desktop publishing skills and attention to detail were critical to the physical appearance of *Proud Voices.*

Lauren J. Thomas April 2, 2001

# INTRODUCTION

American culture during the 1950's and the 1960's went through a period of profound social upheaval. That turbulent time spawned the birth of several civil rights movements for African Americans and women among others. Often overlooked and unnoticed was the Disability Rights Movement which was born on the heels of the larger Civil Rights Movement. In California, Ed Roberts, widely considered to be the father of the Disability Rights Movement, was organizing his small band of rebels in Cowley Hall — a wing of a hospital turned into a dormitory on the campus of the University of California in Berkeley. People with disabilities weren't in the habit of going to college, much less living in dorms, because campuses were not accessible to them. At the same time, in Michigan, there were seeds of activism being watered. A band of early leaders began to emerge.

What happened in Michigan was nothing short of amazing. A small band of people helped write and pass groundbreaking legislation protecting the rights of people with disabilities. A small nonprofit organization, called Paralyzed Veterans of America, sued the Michigan Department of Transportation to demand equal access to regular line haul buses in Detroit.

*Pictured here are Ed Roberts, widely considered to be the father of Independent Living, and Nancy Jachim, an early advocate and interviewee for the Millennium Oral History Project.*

(Photo courtesy of the Michigan Commission on Disability Concerns.)

New organizations called Centers for Independent Living began springing up throughout the state. Still another group of people made state-of-the-art rules and regulations that governed accessibility standards all over the state. People with disabilities began to push to be recognized as citizens in good standing.

All culture must involve history. History is the constant weaving together of individual stories with how people collectively impact the world. It is a contention of this project that personal transformations often lead to social change. Most of the people with disabilities interviewed for this project had a powerful, pivotal experience that catapulted them into the quest for disability rights.

For any minority group to have a sense of identity, it must have a notion of where it has been. Much has been written about the history of other movements. Several definitive histories about the women's movement and the civil rights movement have recently appeared. Within the disability community in Michigan and all over the country, there is a new generation of leadership assuming the helm, a generation that has little or no connection to what has gone before. But it is not enough simply to record institutional history. It is essential that this history be a record told by the disability community itself, by the key participants in the movement. Probably sooner rather than later, a well meaning academic without a disability will write a history. It will lack the perspective of an insider — the ancestors will not be his/her own.

This monograph does not dare to purport to be a definitive historical review. Indeed, the history presented here is just a slice of a larger whole. All history depends on one's vantage point. Whether a primary consumer service provider, a legislator, or a parent, one's historical framework hinges on where one sat during those exciting yet turbulent times.

For purposes of sanity and focus, I chose to record the history of that part of the Disability Rights Movement that began in the 1960's and primarily blossomed in the 1970's. These early leaders were, in large part, people with disabilities themselves. They were pioneers, helping to set course and steer the train of the Disability Rights Movement. There are many more oral histories waiting to be done: an oral history of the parents' movement, an oral history of people with mental impairments, an oral history of people who were wrongly institutionalized, etc. In the course of writing, I struggled with several questions throughout:

> ***Who is the disability community?*** The focus of this history is on people with physical disabilities. The intent is not to exclude people with other characteristics, but I am trying to be true to history and maintain focus.
>
> ***Who is a leader? What constitutes a leader? Is the disability community to be defined only by those people with the direct experience of disability? Does this community include its allies?*** I answered in the affirmative, choosing to include all people who were involved in this civil rights struggle. To exclude allies would be to leave out key architects of the barrier free design code, such as Miriam King. This project adopted a broad view of who the disability community was.

There were more potential interviewees than this project had the resources to interview. Criteria were necessary to distinguish generals from foot soldiers. In this movement, there were leaders way out front who were doing innovative and groundbreaking things and organizing other people. There were foot soldiers, ordinary folks, struggling to live independent lives. This project generally sought to interview people in the first category.

It might be helpful to think of the Disability Rights Movement as a river and its tributaries. Among the many streams contributing to the movement were the parent advocacy movement, the space age (which produced light-weight plastics), and burgeoning medical technology that made survival from traumatic accidents and polio possible. Other streams included the vocational rehabilitation program, laws passed affecting special education, and the veterans returning home from World War II. All of these streams flowed into the river called the Disability Rights Movement.

## *METHODOLOGY*

Oral history is the method used to collect this history. Oral history involves tape recording of selected individuals to capture the history in their own words. Careful preparation of interview questions is a critical part of the interview. Once the interviews are collected and lightly edited, the tapes are transcribed. It is from these transcripts that an edited history was then written. The transcripts from this project are housed at the Bentley Historical Library in Ann Arbor, Michigan. Supporting material, such as individuals' papers, photographs and other related documents, were also collected.

Oral history was thought to be one of the most appropriate ways to collect the information related to disability rights history. There is increasing interest in creating a record of this history as evidenced by the work of Disabled People's Project, a national oral history project out of the Bancroft Library of the University of California (Berkeley). Oftentimes in the past, people with disabilities have been invisible. Acknowledged or not, the lives of people with disabilities have been sidelined. The life experiences of people with disabilities have been overlooked. This has carried over to the civil rights struggles of this population. Because of this silence, it was determined that the oral history method could add the most volume to these voices that haven't had their say. Indeed to truly be a "people's history," this record needed to be as close as possible to the lives of the people interviewed for this project.

# PAVING THE WAY

It is imperative before proceeding further that the reader try to understand what an impassable frontier Michigan's landscape was to persons with disabilities before 1974. There were no curb cuts. Ramps into buildings were not to be found. Accessible bathroom stalls were nonexistent. If you were a person with a disability, you literally could not count on any structure being accessible. If the person was a student, choices of classes were made by whether or not you could get into the building. Before 1974 public buildings were off limits to people who used wheelchairs or had some other mobility impairment. If one was a deaf student, one had to bring an interpreter to class.

Before people with disabilities could think about employment, higher education, housing and inclusion in their communities, they had to eliminate architectural barriers. So, out of nowhere, there emerged an unlikely band of comrades who declared war on all barriers to full participation in their communities.

One of those people was Nancy Jachim Johnson. She tells a story of something that happened to her shortly after her stay in a rehabilitation hospital:

> "I use this when I talk about the movement... I was driving very shortly after I got home with the hand controls and everything. I went to this one store that I had gone to all the time just to run in and get things (before the accident). I saw something I never saw before in that store. I saw a curb that I couldn't get over, you know, that was keeping me from being able to do what I needed to do ... So I was really livid."

Another leader in the early access struggle, Michael Delaney, describes his awakening to a world of hostile physical environments this way:

> "I was in Vietnam and (then) I was injured in an automobile accident in California within a few months . . . They sent me to Cleveland VA Medical Center for rehabilitation. As I said, I was there for six months and the first few months in the (inaudible) frame - looking down half the day and looking up the other half of the day . . . And wondering about a lot of things like where would I fit in, you know, in society? Where would I fit in in my family? I couldn't get into my home anymore. A lot of the things I took for granted were no longer available to me. And I began to think about things like can I get in the bathroom? Can I get in the house? If I want to go use my GI Bill, can I go to school? Can I go to college? And I began to think, you know, if my memory serves me correctly, a lot of those facilities were not accessible, nor were there any ramps or anything like that."

The third warrior in this early fight for a barrier free environment was a rehabilitation counselor named Miriam King. Miriam King's wake-up call came one day as she attempted to counsel with a man who had quadriplegia as a result of a pool diving accident. After talking with the young man, the awareness came, like a thunderbolt, that the man could have all the supports he could ever need, but if his environment were not friendly to his wheelchair, he wouldn't be able to go anywhere in life. This "Damascus Road" experience launched Miriam on the most important campaign of her life. The early Disability Rights Movement was enriched by Miriam's energy. She was the person making many late night phone calls

*Miriam King - champion in removing architectural and legal barriers.*

(Photo courtesy of Michigan Commission on Disability Concerns) "rounding up the wagons," making sure people knew about strategy sessions or testing her new idea about how to approach a legislator or some other agency official.

Miriam, Michael, and Nancy were just a few of the leaders in this crucial and early fight for physical accessibility. Other heroes include Les Sinclair, Harry Smith, Evelyn Lapham, Jelt Sietsma and Eric Gentile. Les Sinclair, who will be discussed in a later chapter, was a man with a disability. Jelt Sietsma, a state representative, introduced the Barrier Free Design Code into the Legislature. He was prompted by his Grand Rapids neighbor, Evelyn Lapham, who was a woman with a disability. Harry Smith was a rehabilitation counselor at the time, with valuable political connections and a knack for negotiation. Judy Taylor and Eric Gentile, both people with disabilities (see Student Movement section), were administrators at Michigan State University Simon Wachler, a lawyer from the Michigan Trial Lawyers Association, lent his expertise. These people met regularly and fashioned the rules and regulations of the first accessibility legislation. The construction industry did not like the law because they thought it would be costly.


(Photo courtesy of Myrtle Gregg-Lafay.)

*Pictured here are Harry Smith, a crucial person in early accessibility struggles, and Les Sinclair (in chair), key architect of Handicapper Civil Rights Act. (See Chapter 4.)*

Hence, those pioneers of accessibility fought back hard when exceptions were granted to builders by the Barrier Free Design Board. Harry Smith remembers one of these hard-fought battles:

> "We sued the Barrier Free Design Board and Chi Chi's restaurant chain, because Chi Chi's was trying to get exceptions for some of its buildings. They had been granted some exceptions to buildings, arguing economic necessity, because they had a sunken area in their design and to put all that seating on one floor would impose a great burden upon them. So we went and got an architect who was part of this group . . . he actually came up with designs that refuted the arguments that the Chi Chi's corporation made and actually increased the seating in that area (along) with an accessible ramp."

These were times that demanded intensity and vigilance. Once one fire was extinguished, another would break out.

## *STUDENT MOVEMENT*

Out of the unrest brewing on most major American college campuses came a cadre of activists with disabilities. Len Sawisch puts it this way:

> "Recognizing that I was outraged by the Vietnam War, but there was no way I was going to do that (fight in the war). I was very much upset with what was going on with blacks in this country, but I was white. I was outraged with the treatment of women, but I was a man. I thought this was terrible. I have this empathy for what's going on around me, but I don't belong to any of these groups. . . But suddenly it begins to dawn on me that I didn't miss the boat. That's one of the reasons I had this empathy for these other groups: because I've been treated in the same way."

Len went on to be the person people looked to as community organizer and spokesperson. With Jeff Pieters, he founded STIGMA (Students for Total Inclusion, Greater Mobility, and Accessibility). About that early coalition, he

> "We were a cross-disability group. In that first group we had a few chair-users, but we also had a couple of folks who were hard of hearing, one who was deaf, (and) myself: a dwarf. We just had a nice cross section of folks with disabilities — a very nice way to start off. A fun group of folks. We would have STIGMA meetings which were intense gatherings. But we also had parties. So we had a core of eight to ten people who were real active. And then we had twice that number who were sort of hangers-on . . . Our agenda was for better accessibility on campus, more accessible housing, more instructional videos that were signed or captioned, some better parking consideration, better portrayal of people with disabilities."

Sawisch was very instrumental in helping his fellow students to develop a sense of disability pride and a sense of their own power. Out of this pride and empowerment, these students went on to make substantial changes in the way that other students with disabilities were viewed and treated.

At Michigan State University, Judy Taylor and Eric Gentile were emerging as leaders of a nascent student movement. In 1973 Judy was the first director of the Office of Programs for Handicapper Students at MSU. Eric and Judy had an evangelistic zeal when it came to making the world accessible and changing people's attitudes. They both worked tirelessly with the powers that be at the University and in the community to change the physical accessibility of the campus and the greater Lansing community. Judy Gentile's caring and advocacy will always stand out as her lasting contribution to the movement.

*Judy Taylor initiated a novel Handicapper terminology and activist philosophy.*
(Photo courtesy of Myrtle Gregg-Lafay.)

Eric and Judy were crucial in another way. They were the creators of a "handicapper" terminology that helped revolutionize the way persons with disabilities thought of themselves. No longer was it acceptable to lump "the disabled" or "the handicapped" together. Now one was an individual "handicapper" and one was part of a "handicapper" movement. There was an extremely empowering force connected to this terminology. Les Sinclair reflects back on the handicapper language:

> "The terminology represented exactly what the disability community needed to be doing and that was to take control of the symbols that are describing that experience. It was folks with disabilities saying this is how we want to call ourselves."

People with disabilities began to think of themselves in different ways and had new language to define their life experience. This shift in thinking was from referring to people with disabilities collectively as "the disabled" or "the handicapped" to individuals with experiences and expertise who happen to have a disability. From history's vantage point, this language might appear outdated. But in reality, the handicapper language was indeed the first "person first" language developed.

Alongside the new language, Judy Taylor and Eric Gentile developed a symbol to further emphasize the dynamic nature of the handicapper experience. The symbol was the universal wheelchair sign with a racing twist to it. This symbol depicts the chair and person angled forward with movement lines coming from the chair, as opposed to the common static wheelchair symbol. This icon symbolized people with disabilities as people on the move. This was in powerful contrast to a culture that viewed people with disabilities as passive individuals ready to take only what society would hand to them.

Taylor and Gentile offered a model of leadership that students could react to. From nearly all accounts, their style was one of single-mindedness and no room for compromise. As one might well imagine, this working style proved too intense for young adolescents tasting their first freedom from home. Primarily college students, they believed that changing the world should involve having fun along the way. Gentile and Taylor certainly contributed spark and zest, but there were other ways of being radical as well. Early leaders who came after them would soon learn the art of compromise. For example, in the fight for accessible transportation in 1976, there were several different notions of how many buses needed to be made accessible. Harry Smith remembers:

> "We fought about what percent of retrofitted buses had to be accessible from grade. Well, Eric Gentile would say all of them. The Michigan Public Transportation Association was absolutely opposed to any requirement that the retrofit include accessible vehicles. We were just as adamant that at least some of them had to be. So it was a huge battle and big impasse over how this was going to get worked out."

There were other universities around the state blazing trails by providing students with disabilities the opportunity to pursue higher education. There was an early program at Wayne State University, which wasn't as activist as Michigan State University, but nonetheless committed to providing a quality education. Before the early 1960's, one has to remember that students with physical disabilities were a rare sight on college campuses. At Wayne State University the emphasis was not on changing the environment so much as it was on working around the environment. Again, the empowering of students would gain steam as the years wore on, and as women, people of color and other minorities would find their rightful voice.

## *NATIONAL ASSOCIATION OF PHYSICALLY HANDICAPPED*

If the student movement gave visibility to the beginning of disability civil rights, different chapters of the National Association of the Physically Handicapped were the quiet force behind the scenes. Formed in 1958 in Grand Rapids, the National Association of Physically Handicapped (NAPH) had chapters all across the country. In Michigan there were several chapters, including groups in Grand Rapids, Saginaw, and Washtenaw County. Most of these people believed that social change came about through civil involvement. They wrote letters, gently pressured local legislators and voiced opinions with their vote.

Out of the Kent County (Grand Rapids) NAPH chapter came a group called the Kent County Barrier Free Design Committee. Jeanne Ashworth remembers what this group did:

> "We went around to different businesses all over town, requesting that they put in level entrances, put curb cuts so that we didn't have to get up over a curb to get in their doors. Some places we met a lot of resistance. They didn't want to do that."

## *MICHIGAN CHAPTER OF PARALYZED VETERANS OF AMERICA*

Veterans coming home from the Vietnam War were encountering the same architectural barriers as students wanting to go to college. A key player in the struggle against architectural barriers was the Michigan Chapter of the Paralyzed Veterans of America (PVA). Mentioned earlier, Michael Delaney, of Detroit, was one of the prime movers in this effort to eliminate barriers. His story is an excellent example of the blending of individual story with social impact. He tells the powerful story of sitting in a Veteran's hospital in Cleveland (because there were no spinal cord facilities for veterans in Michigan in the 1960's), refusing to use a wheelchair, feeling sorry for himself and wondering if he should continue at all. Delaney describes what happened:

> "The first thing that happened was a couple guys from the Buckeye (Ohio) chapter of PVA said to me that they were going to have a protest at Cleveland City Hall and would I like to be a part of it. And I said, 'Protest what? And they said, Well, there are no curb cuts.' And I said, 'Oh man, I've been thinking a lot about that lately. And at that point they brought to me a wheelchair, an old Everest and Jennings wheelchair. I didn't even want to get in it. I was denying. I was still in denial that I was disabled. But the thought of being able to do something made me say, 'Okay, bring me the chair. I'm going to go to this protest. I want to be part of it ..."'I had not been in a wheelchair up until this point . . . But the notion that maybe we could change society was something that I needed to find out... I went to the meeting ... we had a rally. We blocked the halls and everything else . . . And I remember coming home (to the VA hospital) that evening and seeing the coverage on television. And sure enough, before I was finished (with rehabilitation), within that six-month period in Cleveland - things were happening - and I knew that we could affect change . . . And I went back to Michigan and immediately got in touch with the PVA chapter in Detroit. . . and got on the accessibility committee and began my work."

Michael joined with others in his community and in Lansing in the effort to remove architectural barriers.

PVA also made transportation a major priority, especially in Detroit, where there was a huge transportation system. This Department of Transportation wanted to have a separate system for anyone with a disability. Not only was the system separate, but a person with a disability had to make arrangements at least 48 hours in advance to get service to go somewhere. There were two issues: 1) that people with disabilities could get equal access to the regular bus system; and 2) that the special system work more efficiently.

Michael Delaney and Frank Lee were important people in this battle. At this point, Delaney had become president of the Michigan Chapter of PVA. The chapter eventually sued the Department of Transportation. Michael Delaney, with the help of the national PVA organization, set up a legal defense fund to take on giants like the Department of Transportation.

## *ROLE OF SPORTS*

*Roger McCarville, leader in sports and founder of the Michigan Wheelchair Sports Association.* (Photo courtesy of Myrtle Gregg-Lafay.)

Hand in hand with the college experience, disabled sports programs were beginning to pop up in places. These were people with disabilities who wanted to find athletic expression for their energies. These people and programs were raising the general public's consciousness about the capabilities of people with disabilities. Roger McCarville, from Oakland County, was an early leader in this effort. Following an injury in which a boat propeller cut off his leg and after a stay in a rehabilitation facility, Roger helped form a wheelchair basketball team, the Detroit Sparks. Michigan PVA and many of the major universities had other new sports programs for people with disabilities. Jack Donaldson, a Wayne State University student and a wheelchair user, was involved in the Michigan Wheelchair Association and ultimately the Para-Olympics in 1968. His sport was track and field. Other popular sports were swimming, archery and table tennis. Wheelchair sports gave people with disabilities a sense of what today is called "disability pride." Sports helped to build confidence in one's own abilities and provided unique opportunities for socialization and travel.

People of different backgrounds and experiences were instrumental in paving the way through hostile physical environments and ignorant attitudes. Persons interviewed for this project consistently reported feeling as if they were the only ones in these struggles and then suddenly finding that they had allies. Finding companions, these early leaders then put their heads together, learned how to work with each other, and literally changed the personal and political realities for people with disabilities in Michigan.

For those early pioneers, the Disability Rights Movement was like an all-consuming fire, taking up every waking hour and every ounce of energy. Involvement in the early movement was definitely not a "nine-to-five" job. The early leaders believed they were creating something novel, and there was a special intensity to their work. People such as Eric Gentile and Judy Taylor

*Eric Gentile (center), speaking at the White House Conference on the Handicapped.*

(Photo courtesy of Myrtle Gregg-Lafay.)

gave some of the most productive years of their lives to this cause. After several years, some of these early leaders had to step back and claim their lives outside the movement, taking time for relationships, raising children and other ordinary pursuits.

# FORMATION OF EARLY CENTERS FOR INDEPENDENT LIVING

It is hard to imagine how revolutionary the concept of Independent Living was in the late 60's or early 70's. Until then people with disabilities were expected to stay at home with their families or in institutions. Back then it was common for rehabilitation professionals to encourage people with congenital (and only physical) disabilities (e.g. cerebral palsy, spina bifida) to attend sheltered workshops with people with mental impairments. Low expectations of what people could achieve were the unexamined rule. The notion that people could secure their own housing, get their own supports to live on their own, and make their own individual contributions to their community required a major paradigm shift in attitudes and public policy.

In the early 70's, Centers for Independent Living were created in conjunction with colleges and universities. Ed Roberts, John Hessler, and their fellow students at the University of California (Berkeley) created the first Center for Independent Living (CIL) in 1972. They defined the CIL as an advocacy organization run by and for people with disabilities. The primary goal of that first CIL was to help people integrate into their communities. This Center began with the philosophy that it was not the individual, but the environment that needed change — housing, transportation, and always, the removal of barriers. Throughout the country, Centers were established as this gospel or "good news" of independent living spread to more and more people. Independent

Living Centers were being established in Houston, Texas; Champaign, Illinois; and Boston, Massachusetts.

In Michigan in 1976, there was a first wave of funding for new programming around people with severe physical disabilities. Michigan Rehabilitation Services (then called the Bureau of Rehabilitation) served as the "pass through organization" for federal funds earmarked for these programs. These federal funds were called Innovation and Expansion Grants. The state director of Michigan Rehabilitation Services (MRS), Don Galvin, took a trip to Berkeley, California to see for himself what this concept of Independent Living was all about. Galvin attended a conference about Independent Living in 1975 where he met several of the movement's premier leaders — Judy Heumann, Ed Roberts, and Lex Frieden. Struck by the power of this new movement, he came back home to discover consumer leaders who had already begun to dream that Centers be started in Michigan. Gavin's role was crucial because he made sure that Innovation and Expansion money was used for the start-up of the first Centers.

With the first wave of funding in 1976, three Centers got their start: Ann Arbor CIL, Handicapper Advocacy Alliance in Lansing and Great Lakes Rehabilitation Center. All three Centers had distinctive personalities. Ann Arbor CIL (AACIL) followed an agency service model. For the Ann Arbor CIL, finding accessible and affordable housing was a priority. Lansing CIL began with a systems change focus. It assumed people with disabilities had certain rights that were being denied, and it was up to the people with disabilities themselves to advocate for access and fairness. The Great Lakes Center for Rehabilitation was shaped by the Rehabilitation Institute of Detroit, a medical facility.

The medical model commonly touted by rehabilitation professionals assumed that a patient (in this case, a person with a disability) was a person that had to be diagnosed, given a prognosis, and prescribed a fix or cure. In contrast to the medical model, the independent living model saw the problem in society. People lived in a society that had architectural barriers and long-held negative stereotypes. The Rehabilitation Institute of Detroit put an emphasis on transitional living, seeing transitional living centers (apartments where people came to live while learning the skills of independent living) as the way to independence.

### *Ann Arbor Center for Independent Living*

Corkie McCorkle was a woman who had lived her whole life in Ypsilanti, Michigan. By her lifelong example, she had consistently broken attitudinal barriers against what people could and couldn't do. Living at least part of her life in an iron lung, she was an advocate for access, along with the cadre of Michigan advocates such as Eric and Judy (Taylor) Gentile, Miriam King and Michael Delaney. Corkie began to have another dream: to create an organization run by people with disabilities themselves that would provide services and advocacy to people with disabilities. Corkie had served on the Michigan Rehabilitation Advisory Committee (a predecessor of the present day Michigan Rehabilitation Council). By this association, Corkie had a chance to get to know officials like Don Galvin, at MRS, who would eventually assist her with the financial resources to start a Center. She used earlier connections and went knocking on the doors of power and money in Lansing.

Corkie McCorkle used a large motorized wheelchair with a ventilator attached to it. One wonders what able-bodied rehabilitation professionals thought when they saw Corkie arrive at their doorstep. Even their physical facilities were not equipped to handle the likes of Corkie.

Corkie and others began to raise the ten percent local funds it would take to capture the Innovation and Expansion funds that MRS distributed through grants. Other team members involved, along with Corkie, in the Center's birth were John Weir and his brother Rick, Tom Tomsik and Bob McConnell. John Weir, who had recently acquired a spinal cord injury, had a keen business sense and, from all accounts, a wicked sense of humor. Tom Tomsik was the newly appointed supervisor of the Ann Arbor office of MRS and very supportive of the new effort. Tom's claim to fame in the CIL's birthing was that he built the Center's first accessible bathroom. Bob McConnell was the community liaison to the MRS state office.


*Eulene "Corkie" McCorkle was the Ann Arbor CIL's founder and first director.*

Once the initial grant was awarded, Lena Ricks who was living in Tennessee at the time, remembers:

> "Corkie calls me one night and said, 'We're doing this really exciting grant proposal. We're going to be moving ahead with it and if you're interested, I'd like to invite you to come up here for an interview.'And I said, 'You bet your life I'm interested,' because at the time I was working for a newspaper, making minimum wage, and raising three kids

> alone ... So I had the interview one week and went back to Tennessee. And I think that fall (1976), or maybe later that summer, they call me and said they wanted to hire me . . . And when they told me — you're going to laugh, but when they told me I could make as much as $10,000 a year, I couldn't believe it."

The board of directors of the AACIL was made up largely of Michigan Rehabilitation counselors and a few professionals from the community. Because of the heavy MRS influence, the AACIL had more of an agency flavor, as opposed to a community, membership-owned center, calling people with disabilities "clients" and working on caseloads. The Center opened its doors in November of 1976. It struggled with its mission and structure in those early years. The CIL gained its status as a non-profit organization in the summer of 1977. The staff consisted of Corkie McCorkle, John Weir, Jack Butler and Lena Ricks, all of whom had disabilities. Corkie was the Center's first director. John was coordinator of personal care attendants. Jack was a half-time housing coordinator, and Lena was coordinator of peer counseling. Lena recalls:

> "We also made many calls to people in the community with disabilities and let them know we were open, and eventually we began to get calls. I remember my first client at the CIL. Margaret Ling had had MS (multiple sclerosis) when she was in high school, was in a nursing home, and wanted to live in an apartment, wanted to live in Ann Arbor. . . And we worked with Margaret Ling until she died in 1989. She got an apartment and she lived her life very well. Margaret had a (Masters of Social Work.) She was a very bright woman and we worked with her a long time."

*Lena Ricks (right) worked for the Ann Arbor CIL as coordinator of peer counseling.*

In the beginning there was very little distinction between providing services, such as locating accessible housing or giving information, and doing advocacy. Giving information or hunting for accessible housing ***was*** advocacy. In an era where little information about options and services existed anywhere, information and referral (a core service of present day CILs) was critical and primary. Leaders in the AACIL chose to have a relationship with MRS, which was characterized by working within MRS guidelines, educating and being friendly adversaries.

Originally the Ann Arbor Center for Independent Living was started out of Corkie's home in Ypsilanti. It moved to an office on Stadium Boulevard before it found its present home in the Georgetown Mall.

## *Handicapper Advocacy Alliance*

More loosely organized as a group of good friends, the Handicapper Advocacy Alliance was a "grass roots" mixture of consumers. In its beginnings, the Alliance had more the appearance of a membership group where everyone had ownership of the Center's direction and mission. They also formed a nonprofit organization, because they could then accept Innovation and Expansion money from Michigan Rehabilitation Services. The Center's relationship to their funding source was more confrontational, an "us-them" approach. At first they did not want to be considered an Independent Living Center. Len Sawisch recalls the Alliance's start-up:

> "We, meaning this group on campus. It became obvious. I recognized that this (movement was) not just happening here (the campus). It's

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[1] In present day CILs, there is an ongoing dialogue as to what their mission is: service delivery (services that can be bought and billed) or advocacy (working toward reform of entire systems.)

> happening in the community. We really need to have a broader impact. And Rehab (MRS) was pushing us that way too. The Handicapper Advocacy Alliance, the HAA, was this group of community advocates who then went after an Innovation and Expansion grant to develop a community center. We were embarrassed, if not outraged, when people would say that we were an Independent Living Center. We were embarrassed because the bulk of the Independent Living Centers were transitional living programs, and they would primarily focus on folks that had mobility characteristics - paraplegics, quadriplegics if you will, which is perfectly fine, but not enough."

The Handicapper Advocacy Alliance, in those days, had three program areas: peer counseling, accessibility information and education. The education program focused on debunking negative stereotypes of people with disabilities. The Alliance put out public speakers wherever they could.

Kathleen Miller, first secretary at the Handicapper Advocacy Alliance, remembers having lunches and hearing Len Sawisch's stories while eating. These were stories laced with humor about what it was like to be a person with a disability and how one navigated in this world of prejudice and mistaken assumptions, etc. Kathleen recalls the stories being a great introduction to the whole disability (handicapper) rights culture.

The Handicapper Advocacy Alliance's first office was a large warehouse-like structure on Michigan Avenue in Lansing, near Sparrow Hospital. Pam Treece-Sinclair, the Center's first peer support coordinator, spent much time hospitalized at Sparrow. Again, Kathleen Miller remembers how Len Sawisch would find a gurney, load Pam onto it, and wheel Pam down the block to the Alliance's office for meetings. This obviously took place in a time and milieu of greater freedom when there was none of the present day obsession with liability.

### *Rehabilitation Institute Center for Independent Living*

The Great Lakes Center for Rehabilitation (now called the Great Lakes Center for Independent Living) spent its first seven years as a program of the Rehabilitation Institute of Michigan (RIM). Beginning in 1977, the Center was actually housed at RIM. Its original goal was to help patients from RIM live independently. When the Bicentennial Towers apartment complex was built in 1976, the Center moved there. An agreement was made with Bicentennial Towers to assign eight apartments to RIM. The Center used this space to teach RIM patients and others to live on their own with their disability. Subjects taught at the program included food preparation, assertiveness training, psycho-social skills and basic self-advocacy skills.

The Independent Living program was given free office space on the main floor of the same apartment complex. Ray Hill was the program's director from 1978-1981. From the outset, the Center struggled with finding good leadership and a sense of their own identity apart from the Rehabilitation Institute. A subject warranting further study is what role racial tensions played in the Center's beginnings and how that affected its relationship to the Rehabilitation Institute.

### *Race and the Independent Living Movement*

The Disability Rights movement has its beginning in white, middle class, college educated culture. Bob McConnell says about the Centers' beginnings:

> "I think it's significant that the movement started essentially on the West Coast at a university with essentially white, middle class people. As it moved in other places, it was heavily grounded in university settings with white middle class people."

Despite most of its attempts to reach out to minority groups, it has remained a white, middle class movement. This phenomenon, in part, can be traced to some deeply held values within minority communities. Bob McConnell goes on to articulate this well when he says that independent living, or self reliance:

> ". . . may not necessarily be the value of other cultures ... In many cultures interdependence or family dependence is much more prevalent. So the notion of being independent is almost counter-cultural. There is a certain luxury to being an advocate. To be an effective advocate you must have time, energy and access. And people of color traditionally have not had the resources or the time or the access. And so consequently the independent living movement, at least in its beginning, has had more of a difficult time being more than a middle class movement. And it's still struggling."

The inclusion of people of diverse backgrounds would be an ongoing struggle for Centers from their beginning to the present day.

# KEY EVENTS

In every movement, there are defining moments where the movement experiences accelerated growth and cohesion. In the Michigan Disability Rights Movement, there were at least three such occasions. They were the 1976 March on Transportation, the passage of the Handicapper Civil Rights Act in the fall of 1976, and the state and national White House Conferences in 1976-77. All three occasions proved to be the glue of community building. After each of these events, the disability community had a greater sense of its own identity and power. These occasions brought greater visibility to the statewide Disability Rights Movement.

## *March for Transportation*

The March for Transportation occurred in early April of 1976. Though it was mainly a Lansing-based gathering, it was the first time that people with disabilities were visible in a public demonstration in front of the state capitol. Leaving MSU's campus, the group marched the length of Michigan Avenue to the capitol. The marchers demanded access to public transportation. The theme of the march was "Public Means All People." STIGMA, (Students for Total Integration, Greater Mobility, and Access) the MSU student group mentioned in Chapter 2, argued that transportation cannot be called public if it excludes a specific group of people. STIGMA organized the march. The march attracted approximately 250 individuals and represented a good cross section of people with disabilities from across Michigan. Len Sawisch reflects back on that magical time:

> "That was a high point for what was going on in the disability rights movement in Michigan. I can still picture it. People going down the street. We couldn't have picked a better day. The crowd was great. The timing was great. The weather was great. It was a cool time! What I liked most about it, and I've never said this before, but I've never had a more powerful example of creating a situation where its cool to be a handicapper. And that turns people's heads around. That was a time when it was absolutely cool."

In addition to being a platform to develop disability pride, the march also led to improvement in the local transportation system. A city of any size usually has a transportation system that includes both a main line service and a specialized service which offers door-to-door transportation. The Capitol Area Transit Authority (CATA) changed their practices, making their demand-response time faster. (Demand-response time refers to the time that elapses between a request for transportation and when the door-to-door transportation service is actually delivered.) CATA agreed to make some mainline buses accessible for people with disabilities. Also, as a result of that demonstration, a moratorium on the buying of buses was put into place. Later a legislative mandate passed requiring that all new mainline buses purchased had to be accessible.

*Len Sawisch (right) and Jeff Peters leading a rally prior to the March on Transportation.*

(Photo courtesy of Len Sawisch.)

## *Passage of the Handicapper Civil Rights Legislation*

During the 1960's and 1970's, many laws were enacted that affected the lives of people with disabilities. The laws touched on all areas of life — parking, transportation, economic discrimination and voting. The mental health code was originally written into law during this time. Before much more time passes, a legislative history highlighting this progress needs to be written.

On July 28, 1976, the Michigan Legislature passed a groundbreaking piece of legislation called the Handicapper Civil Rights Act. This revolutionary legislation protected people with disabilities from discrimination, particularly in the area of obtaining and maintaining employment.

The passage of this law was a wonderful example of the power of individual citizens. It took all kinds of people working together to pass this law. Governor Milliken, a moderate Republican, received many letters in support of this legislation, so he took notice of the disability community members who were being quite vocal. Judy Taylor and Eric Gentile helped to draft the original bill that State Senator John Otterbacher then introduced early in 1973.

Passage of this legislation also took the political savvy of one individual in particular— Les Sinclair. (In 1984 through marriage, he would change his name to Les Treece-Sinclair.) A person with a progressive neuro-muscular disease, Les assumed his new position as director of the Michigan Commission on Handicapper Concerns in the fall of 1973. As he went around the state getting acquainted with the people and issues concerning the disability community, Les became convinced that protective legislation was needed. He began to support this legislation even though the chair of the Commission worked in the business community, feared that business interests might be threatened, and failed to see why people with disabilities needed a separate civil rights law.

Eventually Les won the critical support of the Commission on Handicapper Concerns — an important governor-appointed council.

Les Sinclair waged an unanticipated battle with the Department of Civil Rights. The Department of Civil Rights objected to the inclusion of people with disabilities in any civil rights legislation, because not enough progress had been made with the already protected groups, i.e. Blacks, Hispanics and women. To include people with disabilities, the Civil Rights Department reasoned, would mean the watering down of already scarce resources. The Department failed to see the disability community as a minority group like the other groups. Like much of society at that time, the Department of Civil Rights saw disability as a medical phenomenon and not a matter of justice needing to be corrected. And, like other groups before and since, the Department worried about the financial costs of protecting the civil rights of people with disabilities. Les Sinclair remembers a particular encounter:

> "I requested a meeting with the director of the Department of Civil Rights. And I was told no. They didn't particularly want to meet with me on this. In fact, they opposed the legislation themselves. This is the Department of Civil Rights. The director was a woman who was very active in the women's rights community, but could not see the parallel, could not see the connection. Sometime later (possibly 1974) I'm in my office one day . . The Department of Labor (which housed the commission) was in an old, old building on Michigan Avenue and my office was on the first floor. And all of the sudden, unannounced at my door is the director of the Department of Civil Rights, the chief deputy director and two deputies. I mean, this was high-priced overhead for that Department standing in Les Sinclair's office doorway. I'm at best a mid-level civil service employee and they are there basically to tell me why this shouldn't happen, why this legislation shouldn't pass, that they're going to be opposing it. And each of them went through a litany of reasons why. I listened very politely, made notes, and when it was all over I just said, 'We're going to pass this legislation. I hope you'll join us. Thank you for

> coming today. Goodbye.' Their reactions are etched in my mind. It was just wonderful. They could not believe it. They expected me to argue with them, which I didn't. I was very polite, very courteous, just made it clear that we're going to be passing this legislation. This (legislation) is something that has to be. They left."

A sophisticated advocate, Les had the patience and the tenacity to work both sides of the aisle of both the state Senate and House of Representatives. He developed critical relationships with legislators who became allies, and organized the disability community to support this legislation. Les and others had to work and wait four long years before the Handicapper Civil Rights Act was passed. The word that Les Treece-Sinclair used as he reflected on this process with twenty-five years hindsight was "empowerment." Hard work, patience, and diplomacy won the day.

No other state in the country had legislation like this. So innovative was Michigan in crafting disability civil rights legislation that the American Civil Liberties Union included the Michigan legislation as a model in a little, handbook they published about protecting the civil rights of the handicapped.

### *White House Conference on the Handicapped*

The White House Conference on the Handicapped (1976 -1977) was one of the disability community's first efforts at community organizing. Put into motion by the President's Commission on the Employment of the Handicapped, every state held regional meetings to caucus together about the critical issues facing people with disabilities. Dick Smith, a man with a spinal cord injury and a law school student at the time, was selected by Governor Milliken to be Michigan's commissioner to the conference. In Michigan, state meetings of the White House Conference occurred in Marquette, Kalamazoo and Dearborn. After information about issues was gathered, people met in Lansing to select delegates who would then go to Washington, D.C. for the national White House Conference. Twenty-four delegates and twenty-four alternates were chosen from Michigan.

Almost to a person, the delegates selected already were or would become leaders in Michigan's new Disability Rights Movement. Many people garnered their own meager financial resources and went simply as observers of this first-time national event. Never before had there been such a huge gathering of people with disabilities (3,500) in one place for the purpose of creating a common Disability Rights agenda. At that time, Myrtle Gregg-LaFay was an observer and a newcomer to the movement. She recalls the trip to Washington and her reactions:

> "In those days with not much money, it was a matter of pooling resources, and so I remember we traveled to the conference, several people in one car. I think it was Les Sinclair, Kathy Miller, Len Sawisch, and myself... So I get to Washington and here are thousands of people from all over the country, and I must tell you there was part of me that is still a farm girl from rural Michigan and so to go to this conference — at first it was devastating. Maybe not devastating. It just hit me emotionally. It was like somebody socked me in the gut to look around me, and all I saw were persons with disabilities everywhere. It was the most phenomenal experience I ever had."

The White House Conference, like the smaller March on Transportation, gave these early leaders a sense that the movement was larger than their own local interests and a sense of solidarity with other people with disabilities from all over the nation. Myrtle Gregg-Lafay, a woman with sclerosis, came back to Michigan and went on to work as director of the Michigan Commission for

Handicapper Concerns. In the late 1970's, the commission was the only truly consumer-directed council that had power over statewide policies and practices.

*Myrtle Gregg-Lafay worked as Executive Director of the Michigan Commission on Handicapper Concerns from 1977-1987.* (Photo courtesy of the Michigan Commission on Disability Concerns.)

The issues brought to the White House Conference are strikingly familiar to present day advocates, when one has twenty-five years of hindsight: physical access, housing, transportation, community integration. But Myrtle Gregg-Lafay heard one issue above all others:

> "I was hearing all these issues and concerns from all over the country and . . . there was a resounding issue of employment, employment, employment discrimination issues over and over and over again. So I had a sense that this is not just an issue in Lansing, Michigan, but it's an issue everywhere and a huge issue that needs to be addressed in (different) ways."

The Michigan contingent of the White House Conference came home from that mountaintop experience with broadened horizons and a renewed sense of solidarity with people with disabilities. They had experienced the reality of being part of something that was larger than themselves. For the first time, they had witnessed and participated in a powerful gathering of a national Disability Rights Movement that spread far beyond the borders of Michigan. After the conference, these leaders came home emboldened to continue the work of creating advocacy organizations, dispelling myths and misconceptions about people with disabilities, and insuring physical access.

# National and State Landmarks in Disability Rights Movement

**1966**

First accessibility law passed in MI legislature.

**1967**

12 disabled students living in Cornell Hospital in Berkeley, CA.

**1970**

Physically disabled student programs starts in Berkeley, CA.

**1971**

Mandatory MI Special Education Law passed. P.A. 94-142

**1972**

Berkeley CIL is formed with Ed Roberts as first director.
Disabled students program started at MSU with Judy Taylor as first director.

**1973**

Federal Rehabilitation Act is passed.

**1974**

Judy Heumann and others staged sit-in at health, education, welfare bldg. in San Francisco to protest watering down of federal legislation.

**1976**

**Early April:** March for Transportation state conferences of White House Conference held in Marquette, Kalamazoo and Detroit.
**July 28:** MI Legislature passes the MI Civil Rights Act.
**November:** Ann Arbor CIL opens.
Handicapper Advocacy Alliance is established.
Great Lakes CIL is started under auspices of Rehabilitation Institute of MI.

**1977**

**May 23-27:** White House Conference on the Handicapped

# THEN AND NOW

Where is the movement today? Have we matured as a movement? Or have we compromised our principles? These are questions that arise when people in the Disability Rights Movement think in a retrospective way, when we want to take stock of how far we've come and what lessons history has to teach us. To answer these questions in their present form would be to treat history and growth simplistically. From the outset the question has to be reframed. What does maturity look like? What do the experiences of those early leaders have to teach us about the struggles our movement encounters today. What do bold leadership efforts of today tell us of our potential and our maturity? As advocacy organizations, how do our relationships with our funding sources shape or control our mission, the way we serve people with disabilities?

In order to wrestle with these questions, we need to look at how the movement has evolved. We need to examine the differences between now and then in terms of financial resources, relationships and power dynamics.

Twenty-five years ago, Centers for Independent Living were a loosely organized group of people who came together to fight for recognition and access. There were no set core services they had to provide — these would be developed later. Grants of ten thousand dollars were considered very sizable. Three individual CILs charted their own courses, determining their own priorities and taking on their own distinct personalities.

From those humble beginnings, the Independent Living Movement in Michigan has made substantial gains. Today there are ten existing CILs and five developing Centers. Centers' existing operating budgets range from $450,000 to 1.2 million dollars. In fiscal year 2000, the Centers assisted approximately 26,600 people.

As a movement and as individuals, we have attained a certain sense of status that translates into financial stability. Centers' operating budgets are five or sometimes ten times those of the original three Centers. Does financial stability lead to complacency? Someone has suggested that the passion today revolves around funding rather than real issues.

An example of changing relationships and contemporary leadership happened in 1998 when Michigan Association of Centers for Independent Living (MACIL) initiated a new approach of educating and forming relationships directly with legislators in order to convince them of the value of the CILs' work and presence. MACIL circumvented the old way of waiting for MRS to increase CIL funding and encouraged communities to have relationships with their elected officials for the purpose of generating funding specific to their communities. MACIL risked the anger of MRS when they refused to continue in the status quo, passive role of just taking what MRS would give. The paradigm was shifted dramatically when communities and individual CILs were empowered to go directly to their legislators.

We have moved from an "us/them" antagonistic way of doing advocacy to a realization that we need all partners in this work. An "us/them" paradigm of advocacy was useful in the 1970's to establish visibility and credibility as advocates. A sense of identity in those early days was critical to the movement's gaining momentum. If one could identify oneself over and against the "enemy," one gained a greater sense of one's own power. This approach is still valuable if we want to include the energy of youth in our movement. But some would argue that we have moved to a partnership method of creating systems change, where all the players are invited to the decision-making table. I am not sure if this is an either/or proposition. Another way of addressing the question: Which is more valuable - institutional power or grass roots activism? Or is this is false dichotomy?

Relationships between people in our movement have become professionalized. Peer support has become a service one renders, not a natural network of sustaining and empowering relationships. Clear lines have been drawn between one's work life in the movement and one's "outside" life. Twenty-five years ago, the line between those two spheres was constantly blurring. The community worked and played together.

In some CILs, clear lines have been drawn between CIL staff and the "consumers" they serve. CIL staff are held up as the experts, and the consumers are subtlety considered lower in the hierarchy. Consumers are less able, less informed and more needy. To be sure, CIL staff bring areas of expertise to their work. Yet this distinction between staff and consumers should be regarded with care and suspicion. Left unexamined, this division can erode the empowerment Centers were created to promote.

It is my contention that those original leaders did more toward advancing the movement's cause with far fewer resources. On the other hand, people didn't have the choices they enjoy today. The unemployment rate was even more appalling. People with disabilities lived in nursing homes in alarming numbers. The public safety net, Supplemental Security Income and Social Security Disability Income, was put into place in 1975. When the National White House

Conference on the Handicapped was called to order in May of 1977, there were no travel budgets to cover expenses. People used their own resources, literally their own cars to drive long distances to get there, because they hungered for solidarity and validation. It was the struggle for recognition and equal treatment that fueled people's passions.

Twenty-five years ago, life was as fast paced as it is today. Issues were presenting themselves at such a head-spinning rate that one didn't have time to reflect on what was happening. Perhaps this is why there are so few photographs that remain from that time. Who had time to remember to take pictures when the immediate experience of giving birth to a movement was so all-consuming?

Twenty-five years ago, the struggle that our movement faced was for recognition. People with disabilities were seen as nonentities, as objects of no account. We weren't at the table — we didn't have voices. Until 1980 we were not given a position on the Civil Rights Commission — a governor-appointed commission which protected the rights of all minority groups. The times called for an "in-your-face" style of systems change which insured visibility and which the able-bodied community could not ignore.

Have attitudes changed as much as we would like to believe? To be sure, discrimination and ignorance are still alive and well and flourishing. People who live and work exclusively in disability circles tend to forget the ongoing reality of ignorance in most social circles. Most people in the larger society still carry with them unexamined prejudice and low expectations of people with disabilities.

Through this project I have tried to give voice to a proud, unlikely band of people who began a movement twenty-five years ago. I could not possibly listen to all the voices. These leaders cleared the first hurdles removing architectural barriers, protecting civil rights and founding advocacy organizations. Some of these leaders were uncompromising truth tellers. Some of them possessed a unique political savvy. Some shattered myths of helplessness. Still others silently worked behind the scenes, preferring to avoid the heat and light of controversy. No matter who they were, I am and we are heir to the movement they all gave birth to. When we stop long enough to hear these proud voices, we find inspiration and hope for the journey ahead.

# APPENDIX A
## Biographical Information on People Interviewed for the Project

**Jeanne Ashworth**

A native of Grand Rapids, Jeanne Ashworth worked for twelve years as a bookkeeping supervisor at Old Kent Bank. Jeanne was on the ground floor of the initial accessibility efforts in Kent County in the late 1960's and 1970's through the local chapter of the National Association of the Physically Handicapped.

**Marge Chmiewleski**

Receiving both a B.A. and a Ph.D. from Wayne State University, Marge began her career teaching at a Catholic high school in the Detroit area. Later Marge worked for ten years as director of the Office of Handicapper Affairs at Michigan State University before her untimely death in 1999. In 1963 Marge was one of a handful of early students who were the first people with disabilities to attend college.

**Michael Delaney**

A Vietnam Veteran, Michael Delaney was chapter president and executive director of Michigan Paralyzed Veterans of America. Since then he has held several volunteer and staff positions with the national office of PVA. He presently works in Washington, D.C. as Associate Director of Corporate Marketing for PVA.

**John Etherton**

John is a Navy Veteran, serving in Cuba and Vietnam from 1960-1965. He began his career at Michigan Paralyzed Veterans of America (MPVA) as a Veteran Benefits Counselor. Since 1981 he has been Executive Director of MPVA.

**Myrtle Gregg-Lafay**

Myrtle Gregg-Lafay began her career as an early childhood teacher of children with disabilities through Head Start. She then went on to become Executive Director of the Michigan Commission on Handicapper Concerns. Myrtle was co-founder and served on the first board of directors of the Handicapper Advocacy Alliance, a CIL in Lansing. Presently Myrtle is an Equal Employment Officer for the State of Michigan.

**Nancy Jachim-Johnson**

In 1973 Nancy became involved and passionate about advocating for changes that accommodated people with disabilities. She was the founding director of the Grand Rapids Center for Independent Living in 1981 and the director of the Oakland/Macomb Center for Independent Living in 1986. She continues to work with people with disabilities by providing rehabilitation case management and therapeutic counseling.

**Miriam King**

Miriam was a rehabilitation counselor for Michigan Rehabilitation Services and Oakland Schools from 1967-1975. She was a member of the Michigan Commission on Handicapper Concerns for fifteen years until 1990. Miriam was, by all accounts, an early champion for the removal of architectural and legal barriers. She has received several national, prestigious awards honoring her commitment.

**Roger McCarville**

Roger was instrumental in starting the Oakland Handicapped Association, the Oakland Macomb Center for Independent Living, and Michigan Wheelchair Basketball. Presently, Roger is host to a locally produced television show on Detroit's Public Broadcasting Channel called "Disabilities Today."

**Bob McConnell**

Bob was former administrator and community liaison with Michigan Rehabilitation Services. He presently teaches rehabilitation counseling in an adjunct faculty position and works as a consultant.

**Eulene "Corkie" McCorkle**

Corkie founded the Ann Arbor Center for Independent Living in 1976. She also had several leadership roles with the National Association of the Physically Handicapped.

**Gerry Mutty**

Gerry started his career in the early seventies, with a focus on moving people with mental retardation and mental illness out of state institutions and into community settings. He is now the Executive Director of the Michigan Commission on Disability Concerns, formerly the Michigan Commission on Handicapper Concerns.

**Lena Ricks**

Lena has held several positions at the Ann Arbor Center for Independent Living. Using her Masters of Social Work, Lena has a private practice of psychotherapy. She is involved in coordinating a program called "Partners in Personal Assistance."

**Lynnae Rutledge**

Lynnae served as director of the Handicapper Advocacy Alliance for a short time during the late 1970's. She has worked in Oregon state government since 1986. Lynnae presently serves as Assistant Administrator for Planning and Policy for the Oregon Vocational Rehabilitation Division. She has committed her life to the employment and empowerment of people with disabilities.

**Len Sawisch**

Since co-founding the Handicapper Advocacy Alliance, Len has held several positions with Michigan Rehabilitation Services. Currently Len works as an Internal Consultant, focusing on accomplishing work with groups of people for the State of Michigan. He also collects, refinishes and researches antique fishing reels.

**Betsy Schrauder**

Betsy was an occupational therapist in the Army. She has a Masters in Rehabilitation Counseling. From 1960-1990 Betsy was a counselor and Director of the Physically Disabled Students Office at Wayne State University.

**Michael Simon**

Michael was a rehabilitation counselor for Michigan Rehabilitation Services from 1974-1978. He was the director of Kent County Chapter of the National Association of the Physically Handicapped from 1978 -1980. Since that time, he is self-employed and has his own private rehabilitation company. Michael is extremely proud to say that his mentor was Russell Schmidt - an early leader who died before this project could interview him.

**Les Treece-Sinclair**

Before moving to Washington state, Les held a few positions in Michigan state government, the most important position being that of Executive Director of Michigan Commission on Handicapper Concerns. He served in Washington in a corollary position. Before his recent retirement, he worked as Executive Director of the State Rehabilitation Council in California.

**Pam Treece-Sinclair**

While she lived in Lansing, Pam was a wheelchair basketball athlete, photographer, and founder of the Peer Counseling Program. She held several positions in the Owens Corning Fiberglass Corporation in Seattle, WA. Pam and her husband Les Treece-Sinclair now live in Sacramento, CA.

**Harry Smith**

Harry is a long-time activist and ally of Michigan's Disability Rights Movement. He was a senior administrator of Michigan Rehabilitation Services. Harry is an active member and past president of the National Rehabilitation Association.

**While the Disability Rights Movement was beginning in Michigan, Lauren Thomas was growing up and coming of age in Northbrook, Illinois, a Chicago suburb. Laurie received a Master of Divinity from McCorrnick Theological Seminary in 1981. She moved to Michigan in 1985. Since 1988 Laurie has been involved in the Michigan Disability Rights Movement as a professional advocate and writer.**

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*(Cover photo courtesy of the Michigan Commission on Disability Concerns)*