

**SELF-ADVOCATES ON THE MOVE**  
**A JOURNALIST'S VIEW**  
**(Chapter 2 in *New Voices: Self-Advocates by People with Disabilities*. Edited by Gunnar Dybwad and Hank Bersani. Brookline: BrooklineBooks, 1996)**

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Trying to define the self-advocacy movements is like trying to hold back a river with one's hand. It just keeps moving.

Such a movement by persons with developmental disabilities was unthinkable three decades ago. Then, in the late 1960s, in defiance of all professional standards, small pockets of persons with disabilities began organizing and trying to speak for themselves. Their first attempts were ragged, but they kept trying. Today these persons represent themselves with a sophistication and confidence that amaze us all. No one even tries to project what these groups will be doing in ten years!

Even so, some professionals are driven (or funded) to create charts showing the sequential steps one takes to become a self-advocate. Others engage in projects to define self-advocacy and to measure its progress. The movement, however, just keeps flowing over every educated attempt to corner it and classify it.

So how does one even begin to understand this rapidly changing, always-flowing thing called self-advocacy? By watching it – simply *watching* it.

What follows is a series of brief journalistic reports all strung on a chronological line. No attempt is made to be comprehensive or to analyze or to interpret. The purpose is merely to *show* what self-advocates have done in the past and how such rich nonconformist activities increase with each year.

**An Unwitting Shutdown of the Human Spirit**

This writer remembers working in institutions in the latter 1950s and the 1960s, long before self-advocacy became a fact. Large numbers of people with the same kinds of disabilities were housed together in these out-of-the-way places. The tasks of a good worker were clear and without equivocation.

- A good worker became the unquestioned mouthpiece for his or her “patients” (“We speak for those who cannot speak for themselves”).
- A good worker made oft-repeated use of a single adjective, *appropriate* (“Joe, it’s not appropriate for you to speak now”) or “Sally, your behavior is inappropriate”).
- A good worker hewed to the common denominator (“Bill, if I let you have this special privilege, then everyone on the ward will want it, too”).
- A good worker utilized a herd mentality (“C’mon, gang. Let’s head ‘em up and move ‘em out. We have five minutes to get to the dining hall”).
- A good worker knew how to force the right choice (“James, if you straighten up you can stay in the day room. If you don’t, we’ll put you in the seclusion room. It’s up to you”).
- A good worker offered a badly paved, one-way street called *benevolence* (“We must always give to you, but we refuse to let you give to us”).

Picture to yourself forms for males and dorms for females – separated by expanses of grass. Picture a new innovation in the 1960s, the Saturday Night Dance, with visitors from surrounding towns coming to watch. Picture also a goodly number of institutional staff members being ordered to attend the dance as well. Specially trained staff members “worked” the dancing patients like cutting horses, employing the “one-two-three rule”: A worker walked past a couple dancing too close. “Not so close,” the smiling worker would say *sotto voce*, “this is a warning number one.” Any close dancers continuing until they got a smile and “number three” knew they would be restricted from dances for six months.

Don’t picture it, but try to think about males who were castrated when they began to masturbate. Think about females being sterilized shortly after menstruation.

Think about people whose teeth were pulled for biting.

Think about “patients” lining up for medications prescribed not so much for their health, but to keep them docile and under control.

As painful and unbelievable as it may now seem, try to sense the clash between the formal inservice training of new workers and the everyday pee-group training on the wards. There was a day not too long ago when some veteran workers proudly called themselves *bughousers*. They expounded their own curriculum to young workers who took in their authoritative-sounding statements like baby birds in a nest.

“I remember the days when we only needed two drugs,” one bighouser said. “If someone got too high, we knocked them out with chloral hydrate. If they got depressed, we cleaned them out with Epsom salt,” “It was those conscientious objectors during World War II who really messed things up,” another said. “They were too soft. They never could control a ward like we could”).

### **The Longing to be Useful**

One a Sunday evening in October 1963, Jimmy Briggs, a nine-year-old with severe disabilities, wandered away from an institution and became lost in the woods nearby. All off-duty personnel received calls to get to the institution as fast as they could. Everyone met in a large meeting room and received search assignments. As the staff members moved out, Ray Kind and Elmer Abernathy, two teenagers who lived at the institution, stopped this writer and asked if they could look for Jimmy, too. The superintendent was consulted. He pondered the situation for a moment, then said, "They can go if they stay close to you."

Ray and Elmer found Jimmy.

During the institution's Thanksgiving pageant, the superintendent called the boys to the stage. He presented them with certificates of appreciation for finding Jimmy.

Everyone cheered.

Much, however, remained unsaid: Ray and Elmer knew almost every hill, gully and tree in that wooded area. They moved out quickly that night. The real trick was to stay close to them! Better than 60 able-bodied teenagers like Ray and Elmer lived at the institution. They knew these woods, too. After all, the institution's recreation department used this area for hikes and campouts.

### **The Dignity of Risk**

STOCKHOLM, SWEDEN, November 8, 1969. Ten persons with mental retardation and six university students – all good friends – came together for a special adventure. They met in a small room on the second story of a downtown building. They sat down and reviewed all of their plans for the day. Then down to the street they went. They moved through winding streets until they came to the Swedish Royal Theatre.

An employee greeted them. Together they moved to the dressing room of Anita Bjork, the star of the currently-running play *Karlson on the Roof*. They presented the actress a bouquet of flowers. She visited with them in a relaxed and gracious manner for at least 15 minutes. Then for the next two hours, with the employee leading, the group of friends moved frontstage, and backstage, into every nook and cranny of the theatre.

They saw the set workshops. They looked at costumes. They examined the harness used by Karlson when he flew off the roof. One member was strapped into the rigging and the others pulled him along the cable. They even climbed up to the catwalks five stories above the stage and watched the workers below. It was a dangerous perch, but everyone wanted to go up.

Leaving the theatre, the sixteen went to a coffee shop and discussed all that they had experienced. Everyone decided they wanted to see the play at a later date. So, right then and there, they began making a checklist of preparations. As they left, the group decided not to

return to the club. They agreed to break up at this new and strange location and each find his or her own way home.

Later, Bengt Nirje, the director of the Swedish association for persons with retardation and the creator of the club system, explained what had just taken place. The system consists of 24 loosely organized clubs of 20 members each. Half the members of each club are persons with retardation; the other half are university students. Most of these small bands met at the same second-story room at different times.

The Nirje-designed guidelines for the clubs are interesting. There is no leader. Persons can only be members-in-full-standing after proving they can travel to and from the club on their own. For some this takes help and practice. Each excursion contains three separate movements: a meeting for talking and planning, going on the adventure, and a meeting for talking about what the members have experienced.

Nirje did admit to teaching a principle he called “hidden social training” to the university students before they became group members. This concept made a great difference. For example, one group went on a weekend outing, each with the equivalent of \$15 in their possession. During the outing, the student-members were “called away,” leaving those with retardation to spend the day alone. On the next day when the group was reunited, the members talked at length about what they experienced.

Nirje’s program flew in the face of most professionals of that time. Most believed persons with retardation must be protected at all costs. Nirje disagreed. “These people feel that human beings must never be protected from risk,” he said. “To be allowed to be human means to be allowed to fail” (Perske, 1970, p.17).

### **“We Are People First”**

SALEM, OREGON, January 8, 1974. Eight residents or former residents of Fairview Hospital and Training Center met at Doris Brown’s White House Home, a group home on Liberty Street. On that day, they officially initiated the first self-advocacy organization in the world. According to their historian, “It wasn’t a very fashionable birth for an organization that would in just five years grow up to become 1000 members strong in Oregon alone, and would have sister groups in three states, with 42 states requesting assistance for starting similar organizations” (Edwards, 1982, p.13).

The seed for such an organization began to sprout after two workers and three residents of the Fairview institution attended a Canadian meeting on Victoria Island in 1973. The meeting had been billed as “The First Convention for the Mentally Handicapped in North America.” The Oregon contingent was touched by how the “conference participants spoke out firmly about their frustrations at being called retarded and being treated as though they were children their entire lives” (p.10). The Oregonians began to build on this experience.

The Canadian convention served as the stimulus. Those five participants came home to

Oregon anxious to explore the possibilities of Oregon's persons with retardation being able to speak out for themselves. So, Dennis and Ann Heath, Nancy Hufford, and Patty Barney began telling people about their experience in Canada and their dream for Oregon. Unlike the Canadian meeting that was organized and directed by professionals, they dreamed of building a self-advocacy group that at long last would release them from the intentions of professionals, organizations and agencies and allow them to advocate for themselves. They, too, dreamed of a convention that would allow them to get together, but they wanted one that was organized and directed by themselves, with helpers assisting only when they reached out and sought assistance (Edward, 1982, p.10).

By five months after the organization's first birthday, members were deeply involved in the rudiments of official meetings – the democracy, listening, speaking one at a time, making decisions, and voting. Much energy and arguing went into deciding the organization's name.

All at once out of the back of the room someone suggested that the name ought to reflect what they were all about. Their name should say who they were and what they wanted. "We are people first," someone said, in a loud voice. **"PEOPLE FIRST!"** As the vote was taken and the decision made, a real step was taken in giving a sense of identity to the group. From that day on people proudly identified themselves as PEOPLE FIRST (Edwards, 1982, p.14).

### **Glorious Confusion**

OTTER CREST, OREGON, 1974. The first self-advocacy convention took place on October 12-13, 1974, on the scenic Oregon Coast. It was the major flash of the year that was sparked by the organization's founding in January. Two hundred participants were expected, but 560 showed up!

The registration area was jammed up with people, everyone was talking as old friends found each other and confusion reigned. There was a sea of bodies everywhere, but no one seemed to mind. There was too much to see and too many old friends to get together with for anyone to mind. Everything was off schedule. Meals had to be double-shifted and rooms had to be shared, but no one got lost or forgotten; that in itself was a miracle (Edwards, 1982, p.17).

Then came the opening session:

The earth moved just a bit when Valerie Schaaf, first president of People First, stepped up to the podium and spoke clearly into the microphone: **"This, The First People First Convention, is officially called to order!"** The room fell silent as all eyes turned their attention on Valerie ... Five hundred and sixty very special persons united and drew strength from one another during that first meeting. There was no doubt in anyone's mind that the beginning of a very wonderful revolutionary moment had begun! People First had carried off what had seemed impossible in many persons' minds just ten months earlier (Edwards, 1982, p. 18)

### **One Man's "Brainstorm"**

OMAHA, NEBRASKA, 1985. Ray Loomis was a tall, rangy man with deep-set, piercing eyes and a brow he could furrow when struggling with a problem. Professionals tended to underestimate this man's power during his fifteen years at Beatrice State Home. When he was released in 1968, the superintendent predicted that he wouldn't succeed more than three days on the outside. He stayed out, but the going was rough (Shoultz, 1982, p.19).

After seven years in the community, Loomis approached officials of the Greater Omaha Association for Retarded Citizens (GOARC) and the Eastern Nebraska Office of Retardation (ENCOR) with "a brainstorm."

He felt that people who were leaving the institution needed a group to belong to – a group whose focus was on helping its members to face problems. Although neither he nor any of the ENCOR or GOARC staff who helped him had ever heard of "self-advocacy," Ray knew instinctively that the group must be self-directing. He saw that the members of the group who were not mentally handicapped should be supporters and helpers but not leaders. He knew and acted on this even though it was two years before the group even defined itself as a group for mentally handicapped people (Shoultz, 1982, p.19).

From that time on, natural leadership talents radiated from this man. Other former inmates from Beatrice State Home gathered around him and their leadership talents began to bloom as well. He even fell in love with a woman from the institution. He admitted to always liking Nancy Schwein, but the rules of the institution kept them apart. According to Loomis, the punishment for being with a woman was 12 hours of hard labor – waxing the same floor over and over.

He married Nancy. Later, a son, Billie Joe, was born.

Loomis proposed that the Omaha group be called "Project Two." His thinking: Community-based services served as the first project, and the self-advocacy movement was the second.

Loomis was a philosopher at heart. He led the group in thinking about basics: "What is Project Two? What is self-advocacy? What is the role of Shirley Dean, Tome Miller and Bonnie Shoultz [the group's helpers]?" He also saw that everyone needed to practice their leadership skills. So he worked on plans to rotate chairpersons (Shoultz, p. 23).

Interestingly, Project Two organized with the same fervor and reaped the same massive statewide results as their Oregon counterparts.

Then Ray Loomis died.

It was a time of heartbreak. On September 24, 1979, Loomis failed to recover from open-heart surgery. On September 24, Omaha's Holy Name Catholic Church was filled with over 250 persons from across the state who said goodbye to this well-loved self-advocate. Ten days after the funeral, Nebraska staged its second People First convention. Interestingly,

Ray's wife, Nancy, and other members of Project Two, filled Loomis' leadership shoes. Over 220 attendees left the convention, vowing to keep his dream alive.

### **A Senator Gets His Mind Changed**

OMAHA, NEBRASKA, 1979. It happened two months after Ray Loomis' death. Ten-year-old Jonathan Allen, a resident at Beatrice State Home, was visited by his mother. She found him badly bruised. She questioned the staff members. No one seemed to know what happened. She drove Jonathan to Omaha and placed him in a hospital.

As soon as the story came out in the media, some Project Two members visited the mother. Upset by the occurrence, Project Two went into session and struggled over what they might do. Then they moved.

They wrote a press statement, rehearsed for a press conference, and invited the media. With TV cameras running and reporters taking notes, the statement was read. It began:

**We believe people should be treated like human beings – with kindness, fairness, and love. We are upset that a child may have been abused at Beatrice. Jonathan Allen could not defend himself. We believe that it is the responsibility of the State of Nebraska to provide more care and to watch over its residents more carefully.**

**We also believe that all the people should be moved out of Beatrice into their own communities. We believe that all people, no matter how handicapped they are, can live in their own communities. We think that the money that is being spent right now to keep people in Beatrice should be spent to bring them back here** (Shoultz, 1982, p. 227).

Next, the members asked to meet with their state senator, Vard Johnson. Johnson felt the institution should not be closed. To prove his point, he asked them to accompany him on an unannounced tour. They accepted.

The members who were chosen to tour took special training on how to conduct themselves and what to look for. Of course, being former residents of Beatrice, they already knew a lot about the place and the way it really worked.

Ten people – six Project Two members, two professional helpers, Senator Johnson and an aide – headed for Beatrice. After a thorough tour, the self-advocates explained what they observed and what they heard from residents with whom they once lived. Johnson was moved.

Things, however, did not stop there. After their discussion, the self-advocates asked Senator Johnson to take one more tour with them – through the community-based services in the Omaha area. He accepted.

After the community tour, Johnson told the media that he had changed his mind. The headline in the *Omaha World-Herald* proclaimed, “Visits to Retarded Changed Senator’s Attitude” (Shoultz, 1982, p. 17).

### **Kansas University Overpowers Self-Advocates for Federal Grant**

SALEM, OREGON, 1980. The accomplishments of Oregon self-advocates captured the interest of many people across the world. They expanded their scope and became known as People First International. The federal government was so moved by the organization’s success, its Developmental Disabilities Bureau sent out requests for “technical assistance” grant proposals for starting People First organizations in other parts of the country. The Oregon group applied for the grant. They never dreamed any agency could be more in the running, considering their remarkable track record.

Nevertheless, Kansas University got the grant. Its University Affiliated Program received \$75,000.

People First International reacted. They argued that after five years of experience in this “consumer movement” – inspiring and helping to start 270 self-advocacy groups in 41 states – they deserved the grant award.

The Bureau disagreed. It stoutly defended the selection of the University of Kansas over People First International, saying the Kansas application was “technically sounder” (Edwards, 1982).

Kansas University had used professional grant writers – even though their experience in the movement amounted to one big zero. The grant request from People First International was written largely by persons with disabilities.

### **Bernard Carabello Becomes Quick On the Uptake (1981)**

NEW YORK, NEW YORK, 1981. Eleven years earlier, on January 11, 1972, Geraldo Rivera had met Bernard Carabello for the first time. Rivera, an ABC-TV reporter, was scheduled to interview the 21-year-old man with cerebral palsy and learn about his life in Willowbrook State School. The interview was held in the home of William Bronston, a medical doctor who worked at Willowbrook. “Because the palsy severely limited Bernard’s control over his muscles,” Rivera said, “he writhed in his chair and his arms were in constant involuntary motion. I was afraid he wouldn’t be able to answer any questions, but he did.” With struggling speech, Carabello talked about his 18 years as a resident of Willowbrook, about not being able to read, about being too old for the school program—and then he began to cry. That night, Rivera featured Carabello in his report on the evening news. He closed by

saying, “My God. What a waste. Leaving a boy like that to vegetate on one of those stinking wards all day long. Just rotting away, when with more training he could become a productive member of society” (Rivera, pp.63-66).

Later, Carabello moved into the community and Willowbrook was closed. Something else happened, too, that, to this writer, is just as touching: Rivera and Carabello developed a close, rich friendship that continues to this day.

The greatest happening, however, became apparent when Bonnie Shoultz interviewed veteran self-advocate Carabello in 1981:

**I’m much better at helping others. I talk to people. I got SSI for someone who really needed it. I got a home for someone else. That makes me feel really good.**

**I try not to treat people “special.” They don’t need that. I have people come to me and talk down to me, as if I’m a child or hard-of-hearing: “How are you?” “You’re a good boy!” I had a woman give me a dollar and tell me to go buy myself some ice cream. I said, “You need it more than I do.” She said, “Thank you.” Sometimes I’ll jokingly say, “Hey, you’ve got to do this for me – I’m handicapped!” It makes a point. One time a salesman knocked on the door, and he saw me and said, “Is anybody home?” I said, “Who the hell do you think I am?”** (Williams and Shoultz, 1982, p. 78)

Carabello still works hard at making his lips form the words he wants to say, but not quite as much as the day when Rivera first interviewed him. Also, one can’t help but notice how Carabello’s sentences are quick and effective, like a shortstop’s throw to first base – like the sentences used by his friend, Geraldo. Copying the syntax of his friend and practicing in self-advocacy situations has paid off for Bernard Carabello.

### **Speaking For Ourselves**

THE GREATER PHILADELPHIA AREA, JUNE 1982. A class-action lawsuit focused national media attention of the Pennhurst Developmental Center – for being utterly rotten about helping people develop. Consequently, the residents of this institution moved into community settings in the five counties nearby. Although these “brothers” and “sisters” were scattered, they came together as one of the most powerful self-advocacy groups in the nation. When the time came to give themselves a name, they decided to call themselves “Speaking for Ourselves.” Later, member Roland Johnson was asked how they arrived at such a picturesque name. Mr. Johnson screwed his face up into dead seriousness. Then with the voice of a judge, he said, **“Oh, can’t you see it? What we call ourselves is what we do.”** Becoming even more somber, he said, **“We simply refused to give ourselves one of those alphabetic names – like NARC or AAMD or TASH – and force people to sit on their hands for days trying to figure out what those letters meant.”**

Interestingly, most self-advocacy organizations chose descriptive names as well. People First continues to be preferred the most. Others, however, have come up with The Pioneer Club, Progress Ahead, Citizens United, The Trailblazers, and, of course, Project Two.

### **Investigative Reporters**

SACRAMENTO, CALIFORNIA, 1983. When the state of California wanted inside information its service system for persons with developmental disabilities, it chose six receivers of services to do the job. The investigators – Barbara Blease, James Drake, Tom Hopkins, Sandy Jensen, Connie Martinez, and John McMillan – were active members of People First of California.

Through oral training – not reading – the group gained a thorough understanding of the Lanterman Developmental Disabilities Service Act, California’s own bill of rights and service deliver law. Each received training in the use of tape recorders. Ten, with one advisor and a recorder/writer, they moved through the state. They traveled 1500 miles, talked to 150 people with disabilities and made 70 hours of recorded tapes.

The issues a scathing report of over 200 pages, showing how people were being *retarded* b the system and wee struggling to *survive* it (People First of California, 1984).

Some interesting points were raised:

- **“The Lanterman Act pushes for development, but the system pushes back”** (p.9).
- Some talked about being treated as commodities, not human beings – only things worth month to the agencies service them (p.8).
- Some described how case managers told them they weren’t ready to leave a residence when they knew they were being held back because of the money they brought into the system (p. 56).
- Many voiced their hatred for going bowling and to movies in large groups (p. 14).
- Some felt successful services are rare because success is not rewarded (p. 58).
- The investigators felt that every service provider needed training in the Lanterman Act – like they received it (p. 33).
- Some talked about workshops that made them more retarded (p. 32).
- One workshop employee registered his utter disgust for making wind chimes (p. 66).
- Questions were raised about being a Boy Scout at 35 (pp. 13-14).

### **Seizing the Moment and Grabbing the Power**

PRINCETON, NEW JERSEY, MARCH 21, 1986. It was the first of a two-day “Interstate Seminar on Self-Advocacy for Persons with Disabilities.” Agencies from Connecticut, New Jersey, New York and Pennsylvania funded a conference for 156 persons—professionals mingled with an equal number of persons having disabilities.

Professionals and persons with disabilities were paired together. Each pair shared a hotel room. They took their meals together and sat together during the sessions.

Even so, professionals felt some strange need to discriminate. They saw that all persons with disabilities received the title *self-advocates*. Everyone else became known as *advocates*.

Things went smoothly until after the first small-group sessions. In the general assembly that followed, small-group recorders on the front stage began giving their reports when Steve Dorsey of Pennsylvania stood up in the audience. **“I just wondered how come there aren’t more self-advocates on the platform,”** he said.

Everyone became aware that all but one of the ten people in front were professionals.

Bernard Carabello of New York rose and voiced his disfavor with the way the term *self-advocate* was being used.

**“Everybody should be self-advocates.”** T.J. Monroe of Connecticut said.

**“If I’m a self-advocate, when do I become an advocate?”** Linda LaCourse of New Jersey added.

These honest statements from persons with disabilities moved the professionals to slowly let go of the reins, and the so-called self-advocates – in their own ways – began to pick them up (InterServ, 1986).

Other moments at the Princeton conference:

- Warm and friendly joking went on between New York Commissioner Art Webb and his roommate, Bernard Carabello (**“I just got a call from Governor Cuomo. He appointed me Commission of Mental Retardation and Development Disabilities. I’m sorry, Art Webb, your job is over”**) (p. 3).
- T.J. Monroe woke up his roommate, Connecticut Commissioner Brian Lensink, at 4 A.M. He wanted to know why professionals had been so lousy about teaching special education (p. 3).
- In the general assembly room, every participant had a microphone and an on-off switch on a desk in front of them. At one point in the session, everyone wanted to respond to an issue at the same time. Too many pushed their mike buttons at the same time – knocking out the system (p. 5).
- Connecticut self-advocate Dick Nazzari, for the first time in his life, made a formal statement to a large assembly. He struggled painfully for each word. He paused. He spoke again. The audience quietly waited for him to get it all out. Then the whole assembly cheered and applauded him loudly (p. 5).
- New Jersey Commissioner Eddie Moore confessed that for the first time in his life, he not only heard how some self-advocates hated the word *retarded*. He also sensed how it could diminish them in the eyes of others (p. 7).

- Polly Tulley, a parent, told the general assembly how much she had learned. She felt other parents should attend meetings like this. Someone in the audience disagreed. **“All parents aren’t like you,”** the person said. **“We want our parents to come and observe – not participate** (p.9).
- Karen Kreitler’s father entered the back of the large assembly room unannounced to hear his daughter’s keynote speech. Later, after being touch by what his daughter said, he asked a professional if anyone had taught her the meaning of the word *honorarium* yet (p. 10).
- Self-advocate Loretta Claiborne responded to another self-advocate in the assembly who had demanded a dishwasher in her new apartment. **“I have two dishwashers – my hands!”** Ms. Claiborne said (p. 15).
- Most memorable: Professionals – at break times – admitted to each other how much they used the word *mental retardation* in their everyday dealings, not rally sensing how much that word could wound people. Some felt this single consciousness-raising issue made their attendance at the conference worthwhile (p. 17).

### Well, It Seemed Right

SOMEWHERE IN CONNECTICUT, MARCH 28, 1986. Timothy Johnson (not his real names) left the Princeton conference and returned to his town and his job at a supermarket. He did it with new fire for taking risks.

On this day, while putting cereal boxes on shelves at the supermarket, a small child nearby began to cry loudly. The child’s mother told the little one to shut up. The child kept crying, Finally, the mother reached down and slapped the child.

Mr. Johnson slapped the mother.

Mr. Johnson was fired.

### Every Great Movement Has Its Songs

STAMFORD, CONNECTICUT, DECEMBER 4, 1987. The Communist Party has its *Internationale*. The U.S. Civil Rights Movement gained power and determination from *We Shall Overcome*. *Bread and Roses* raised the spirits of those in the Feminist Movement. Now the self-advocacy movement has its anthem as well.

Karl Williams, a songwriter who also works with persons with disabilities, came to the four-state (New York, New Jersey, Pennsylvania and Connecticut) self-advocate conference at Stamford, Connecticut. He brought his guitar and he asked to say a few words at the opening session.

“I attended an earlier self-advocacy meeting,” he said, “ and I heard a leader say, ‘You people are in a revolution, but revolutions have songs that keep them going. Where are your

songs? Your revolution doesn't have any songs." (InterServ, 1987) Williams said he thought about that statement for a long time.

Then he wrote a song for self-advocates. It appears at the beginning of this section, opposite page 1 of this book.

He played the song for his audience. Everyone liked it. The melody was rich and the words were catchy. They liked it so much every plenary session opened with it for the next two days. By the end of the conference everyone sang the song along with him.

Today self-advocacy groups all over the world begin their meetings by singing this truly revolutionary song. The lyrics:

Chorus:        We are speaking for ourselves  
                   Speaking for ourselves  
                   No one else can do as well  
                   Speaking for ourselves

Chorus

Once I was afraid to speak  
 I was lonely, I was weak  
 With a voice so very small  
 I had no voice at all

Chorus

Then I found a friend like me  
 And another made us three  
 And we laughed and then we cried  
 And this is what we tried

Chorus

We've been called by many names  
 We've been made to feel ashamed  
 We've been locked behind the door  
 But we'll come outside once more

Chorus  
 Repeat Cchorus

### **ADA: An Explosion of Fresh Directions**

WASHINGTON, DC, JULY 26, 1990. Over 2000 persons – most of them with disabilities – traveled from all parts of the nation. They converged on the south lawn of The White House to witness President George Bush’s signing of the landmark civil rights bill for persons with disabilities, the Americans with Disabilities Act.

“Let the shameful wall of exclusion finally come tumbling down,” the president said as he signed the bill. Bush appealed to “my friends in the business community” to accept persons with disabilities. “You have in your hands, the key to the success of this act.”

The act prohibits discrimination against persons with disabilities in employment or in limiting access to public accommodations, such as restaurants, stores, museums, and theaters. Employment provisions of the law will be phased in between 1992 and 1994, while the equal access measures take effect in 18 months.

While President Bush said the law would be implemented cautiously (“We have all been determined to ensure that it gives flexibility, particularly in terms of the timetable of implementation, and we’ve been committed to containing the costs that may be incurred”), many advocates and self-advocates expressed impatience with the slow pace of change.

Although the act has far-reaching implications, some basics are clear. It guarantees persons with disabilities access to:

- *Public Accommodations:* Must be accessible after 18 months. Businesses with 25 or fewer workers and gross annual receipts of \$1 million or less have six additional months to comply; those with 10 or fewer workers and gross annual receipts of \$500,000 have an additional year. New facilities must be accessible.
- *Transportation:* New buses, commuter-rail and Amtrak cars must be wheelchair accessible. One car per train must be made accessible within five years. Key stations and new stations must be made accessible within three years.
- *Employment:* After two years, businesses with 25 workers or more are required to disregard handicaps in hiring and make accommodations at their own expense for workers with disabilities, unless the cost is too great. After four years, the law applies to those with 15 workers or more.
- *Telephones:* Utilities are required to provide special services for customers with hearing and speech impairments within three years (Spears, 1990).

Most self-advocates see the act as a gateway to full citizenship in the United States. They intend to use the act in order to press for the same civil rights other citizens receive.

### **A Tribute to Today’s Self-Advocates**

Back in 1962, this writer conducted a group session with six teenage boys who lived in an institution for mental retardation. The session began with a film, "The Good Samaritan." When the film ended, the boys were encouraged to talk about the characters in the story.

Interestingly, all of them fixed on the man who was beaten up and left by the side of the road. Then they talked at length about all the mean and rotten things that had happened to each of them. No doubt about it, they had much to say.

Not one of them, however, talked about the magnanimous Samaritan!

They seemed unable to grasp and learn from such a lofty act of kindness – the binding of the man's wounds, getting him to an inn, telling the innkeeper to let him stay and rest until well – at the Samaritan's expense.

Why didn't they grasp the generally accepted focus of the story? Maybe they had received so little goodness from others that they had little to give. On the other hand, maybe staff, maybe staff members failed to grasp the high ideal that *these people could be helped to be givers in the world, too.*

When one watches a good self-advocacy organization in operation today, one gets a different picture. Of course, they work at fighting like tigers for their own dignity, respect and full citizenship! They, nevertheless, can also be seen working on the notion that it is more blessed to give than to receive!

This latter blessing showed itself vividly when some members of the new National Self-Advocacy Network read a report on Robert Wayne Sawyer. Sawyer was scheduled to be executed a few minutes after midnight on March 5, 1993 – even though recent evidence of mental retardation and brain damage had never been heard by a court. New evidence that might lead a jury to vote him innocent had not been heard as well (Perske, 1993).

Network members passed the word, and self-advocates from all over the U.S. *gave* of themselves quickly, writing letters asking for clemency from the governor of Louisiana.

Unfortunately, the cause was lost. Robert was executed.

Even so, my grateful response to this outpouring of sharing and concern went out to that national network. It was written in capitals because of a strong desire to get the message across. That letter appears on the next page.

## Epilogue

Self-advocacy organizations are very much on the move.

Their beginnings were ragged.

They dared to make *their own* mistakes and they began to learn from them.

Now, however, they move forward with greater sophistication and confidence.

No one could have predicted this movement three decades ago.

No one can even predict where they will be in ten years.

They keep moving and nothing can stop them now.

They often amaze others in the field by what they are doing.

So how can we understand and help these people who call themselves self-advocates?

Only by watching them – simply *watching* them ... and cheering them on.

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March 5, 1993

Debbie Robinson

The National Self-Advocacy Network

C/O Speaking for Ourselves, One Plymouth Meeting (#530)

Plymouth Meeting, PA 19462

Dear Debbie:

I am writing this after leaving the Louisiana State penitentiary at Angola, Louisiana.

You and your National Self-Advocacy Network did a kind thing. You got the word out for Robert Wayne Sawyer. Governor Edwards received over 500 letters from self-advocates. They came from all parts of the United States. Please thank all the people you contacted. Tell them they did the right thing.

Now it rips me up to give you the bad news: Robert was executed at nine minutes after midnight this morning. He died even though the truth was on his side. It was politics that killed him. Politicians saw him as a symbol. They failed to see him as a human being.

Last Tuesday, we battled for him before the Board of pardons. Jim Brolin, Executive Director of the ARC of Louisiana, spoke for him. I talked about how easy it is to convict people like Robert. Dr. Ruth Luckasson and other experts described his disabilities. It went on for six hours. We were convincing. We were sure we had won. Then the Board of Pardons voted, 3-to-2, that Robert die. The Governor refused to overrule the Board of Pardons' vote.

Debbie, tell all of your “brothers and sisters”: All Robert ever wanted was to be liked by others. He wanted to have good friends. He wanted to belong to good people – like you.

If little five-foot-two-inch Robert had been in a self-advocacy group, If he had been supported by people like you, he wouldn't have been so vulnerable. So many others wouldn't have wounded him the way they did. He wouldn't have gotten into this fix, been arrested, convicted, and killed. I'm sure of it.

With gratefulness for all of you,

Robert Perske

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