



Consumer Unity

Consumer Unity

New Platforms for Progress in the 1980s

The Proceedings of a Working Conference of New and Established
Consumer Leaders
Berkeley, California

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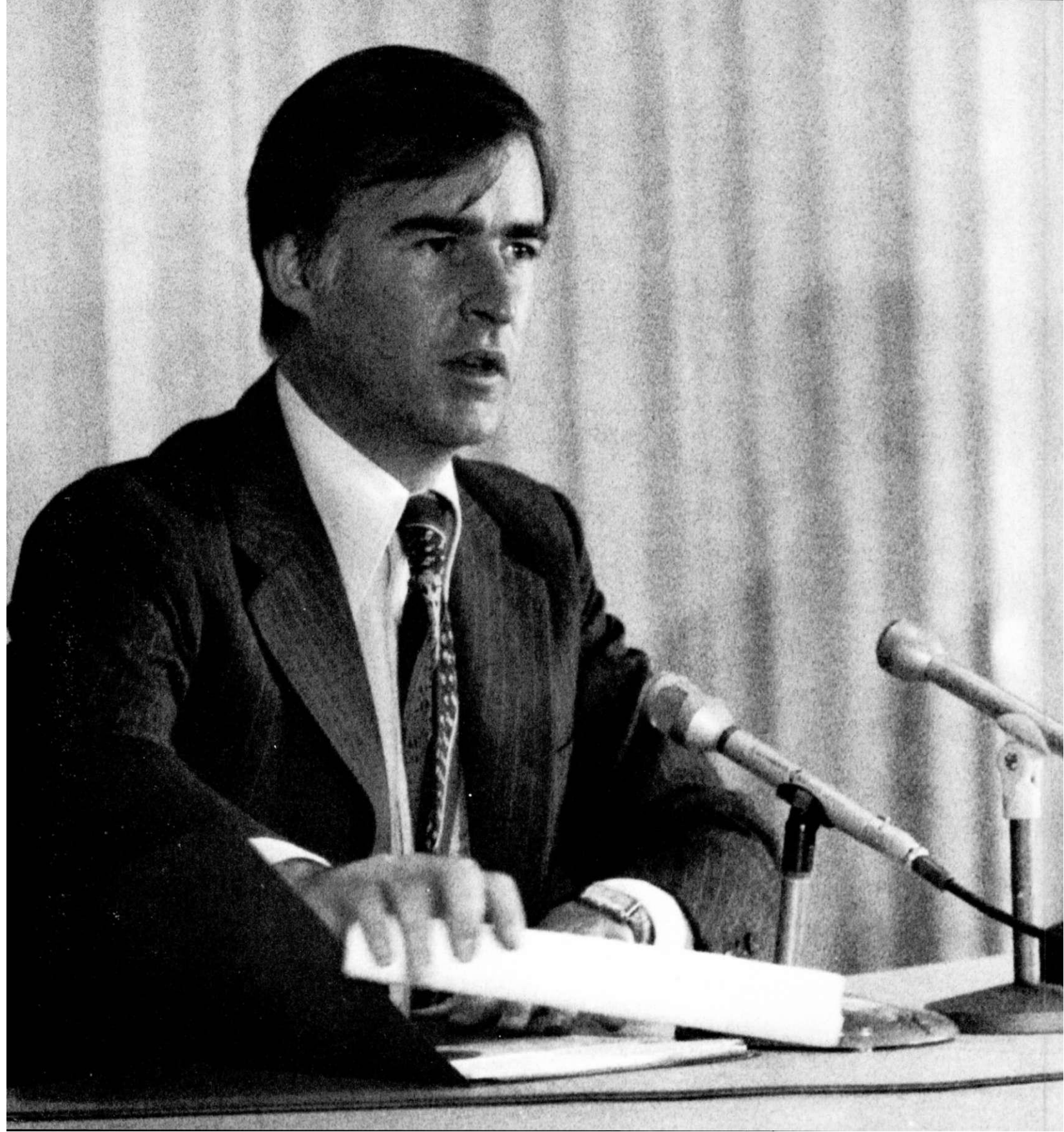
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The Untapped Potential

Quotation from presentation by
Governor Edmund G. Brown, Jr.

"What I've tried to do in my administration is to break through the conventional wisdom, the limiting stereotypes, and try to look at people as they are and as they potentially can become. This is a rich society. Co-existing with the wealth and the individualism there is a great deal of suffering, a great deal of isolation and a great deal of undeveloped potential. What I will try to communicate to the people of this state is that when a disabled or an elderly or a young person or anyone is stereotyped at a level beneath what they can potentially become, that situation not only deprives the individual of a right—rather a cold legal term—but it also limits the potential of an entire society. If the totality of the people are to reach a level much higher than we are now, then we have to draw upon the talent of all the people in society. As yet, there is still a tremendous gap between the work that must be done and the available talent quite capable of doing that work. Matching up the people to the work is the fundamental agenda for the rest of the century. When I say matching up the people with the work, what I mean is that there are so many people, whether they be children who are

neglected, whether they be elderly people who are locked in their homes or some rundown hotel or nursing home, or they be disabled people—physically, neurologically, autistically or some other category—there is so much potential locked inside of human beings that cries out for liberation that the work is just overwhelming, but it is still quite possible. And I see you people in the vanguard of raising the consciousness and awareness of people in this country. The image of the—you might say in an irreverent way—the Clairol image of what America should be is very far from the reality that each person experiences. To the extent that we can get beyond certain conventionally defined externalities and try to see people as they see and touch and feel, to know their underlying spirit—to that extent we'll have a society that is worthy of the name and we will be able to communicate to the rest of the world an idea and a reality worthy of emulation. And I see the power of this country lying not in neutron bombs and underground movable missiles and other conventional forms of diplomacy, military and non-military (although on occasion those things are necessary); I see the

underlying power as the ability, because of our wealth and because of our educational and informational technology, to create a society that is so striking in its humanity, and in the force of the unarmed power of the beauty and truth of that idea, that the rest of the world will be compelled to emulate it. If we can do that, I have no fear for the future."



To Deny the Rights of Any Person Is to Deny Our Own Humanity

An Affirmation of Human Rights

With the belief that every person, regardless of disability, has certain fundamental human rights, the California State Department of Rehabilitation and Health and Welfare Agency hereby make the following commitments:

To promote independent living.

To insure equal employment opportunities.

To develop a barrier-free environment.

To guarantee access to public facilities and transportation.

To provide the necessary supportive services for independent living and employment opportunity.

To end the segregated education of children with disabilities and to insure a free and appropriate education.

To secure the right of persons with disabilities to bear, raise and adopt children.

To guarantee the right to participate in all aspects of the political process.

To promote affordable, integrated and accessible housing.

1981

International Year of Disabled Persons

Mario G. Obledo
Secretary
Health and Welfare Agency
Edward V. Roberts
Director
Department of Rehabilitation

El Negarle los Derechos Humanos a Cualquier Persona es lo Mismo que el Negarnos a Nosotros Nuestra Propia Humanidad

Una AfirMACion de los Derechos Humanos

Con la firme seguridad de que toda persona, a pesar de su incapacidad, tiene ciertos derechos humanos fundamentales, el Departamento de Rehabilitación del Estado de California y la Agenda de Salud y Bienestar se adhieren a las siguientes metas:

Promover el derecho de vivir independientemente.

Asegurar oportunidades de empleo a toda persona.

Promover un ambiente libre de trabas o barreras.

Garantizar el acceso a los servicios públicos en general, así como a los servicios de transportación.

Proveer los servicios necesarios para asegurar que los individuos incapacitados logren vivir independientemente y tengan la oportunidad de asegurar empleo.

Dar fin a la instrucción segregada de los niños incapacitados y asegurar una educación libre y apropiada.

Asegurar el derecho de toda persona incapacitada a tener hijos, adoptarlos y educarlos.

Garantizar el derecho a la participación libre en todos los aspectos de la política.

Abogar para que se logren viviendas accesibles y de precio moderado en todas las comunidades.

1981

Año Internacional de Personas Incapacitadas

Mario G. Obledo
Secretario
Agencia de Salud y Bienestar

Edward V. Roberts
Director
Departamento de Rehabilitación

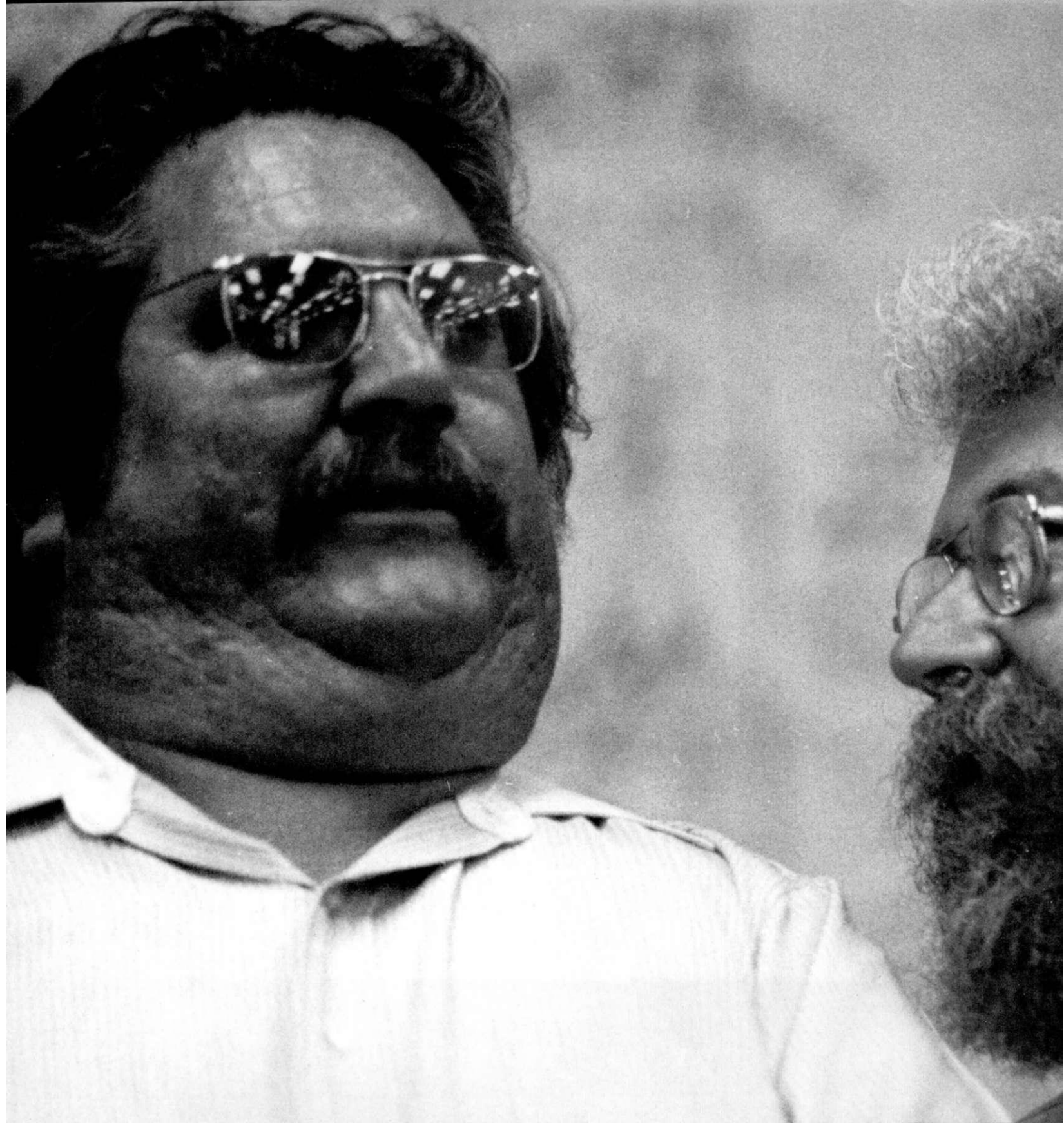


To Ettamarie Siordia
1949-1980











Preface

On April 27 and 28, 1980, over 200 consumer leaders gathered together at the Claremont Hotel in Berkeley to review past victories and defeats and to share organizing principles and procedures that work. The Consumer Unity Conference was sponsored by the Department of Rehabilitation and the California Arts Council, with technical assistance from the California Institute on Human Services.

The events of the Conference were visually recorded by David Sibbet, a graphic artist, on large sheets of paper taped to the walls of the meeting room. Photographic reductions of these drawings are included in this book.

Day One of the Conference reviewed past political achievements of people with special needs. The proceedings began with an introduction by Tony Apolloni, Director of the California Institute on Human Services, and a call for unity and cooperation by Ed Roberts, Director of the California Department of Rehabilitation. Michael Thrasher, Special Litigation Counsel, United States Department of Justice, summarized important legal and political

events of past decades. William Bronston, Medical Consultant with the California Department of Developmental Services, led a participant discussion of consumer victories across the past 30 years. In the afternoon, participants divided into work groups and brainstormed vital elements of past victories. Work group participants detailed what strategies *had* worked and why they had succeeded. A panel of representatives from the Gray Panthers, the Black Movement, and the AFL-CIO reviewed lessons to be learned from allied civil rights and union movements. Day One ended with an evening entertainment program which featured Joe Parente's process theater group, songs by Danny Deardorff and Danny O'Keefe, comedy skits by Andre Economopolous and Captain Stickey, and a dance by Carol Stensrud.

Day Two began with presentations by Mike Vader, Manager of the state's Affirmative Action Program for the Disabled; Judy Heumann, Deputy Director for the Center for Independent Living; Allan Bergman, Director of San Francisco Aid Retarded

Citizens; and Jeff Goedecke, Project Coordinator of People First of California. These speakers discussed menaces and opportunities which loom in the '80s. Next, Assemblyman Tom Bates reviewed strategies to cope with the taxpayer revolt and Kare Anderson, Coleman-Goff, outlined methods of influencing legislators. Finally, Richard Santos, Center for Independent Living, and Fran Smith, San Francisco Aid Retarded Citizens, concluded the conference by summarizing its content and format.

Postconference feedback from participants indicated that they experienced a sense of unity. In addition, participants felt that they learned useful things about influencing decision makers to achieve goals.

Abridged versions of some speeches, work session records, drawings, and photographs from the conference are included in this book. Copies may be obtained from the California Department of Rehabilitation, 830 K Street Mall, Sacramento, CA 95814.



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Welcome

Tony Apolloni
California Institute on
Human Services

"We have come together to consider how we might stand together and mold a common-front approach to the problems and opportunities we're

going to face in the eighties. We want to develop a grass-roots political base of consumer leadership."

Welcome to the Consumer Unity Conference, a leadership planning session for persons with disabilities.

Ed Roberts, Director of the California Department of Rehabilitation, is hosting this event and I am serving as the Conference Moderator. We hope that this conference will be very significant. The Department of Rehabilitation has invited us to consider how we may work together in a more unified fashion. Bureaucracies typically divide us into disability categories. The question before us is "How can we stand together and mold a common-front approach to the problems and opportunities that are going to face us in the eighties?" How can we work together to make a better future?

This conference is an attempt to help us get to know one another and to develop a grass-roots political base. We plan to set the stage so that you will share organizing skills with one another and with leaders of allied civil rights movements. We plan to identify principles and procedures for influencing the political systems that affect us.

Over the past thirty years, massive private and public funds have supported the growth and grouping of the many previously local and small non-profit organizations into the larger associations we know today—health care, social and rehabilitation and educational systems, United Ways, and research and development operations. Human services for persons with disabilities now constitute a major industry in the United States and a significant part of the nation's economy. The human services industry is now facing serious problems. Government support is leveling off, demand for services is increasing, technological and demographic changes are occurring, costs are skyrocketing, and private sector support is declining.

One outcome of the past failure of the family and the community to mobilize needed resources for its members with disabilities is the evolution of large alternate care and treatment facilities popularly known as "institutions." Target groups who are admitted to such facilities (such as the aged, offenders and delinquents, the physically and mentally handicapped) are segregated in large, often remote and

isolated facilities which have the effect of physically and socially separating persons with disabilities from society. Most institutions of this kind deprive their residents of the dignity and quality of life accorded other citizens. Such facilities also prove more costly because increased size does not necessarily result in greater efficiency and lower unit costs. The reverse seems to occur.

Progressive new laws and court decisions now assure disabled persons due process and equal opportunity rights. These legal victories are encouraging people with severe disabilities to participate in regular community activity—living in regular housing, attending colleges or universities, carrying out personal shopping and using regular recreational and cultural offerings. The majority of present service resources, however, are still oriented to segregated, congregate approaches. Individualized support for independent living requires different orientations in agencies' programming and funding.

With each decade, the issues facing the human services field become more multi-faceted, beyond the scope of any single organization. They require multi- and inter-organizational responses and multi-path solutions. Coordinated efforts are needed between consumer organizations, institutions of higher learning and research, and friends from allied civil rights and union movements.

The potential for a major breakthrough in the organization of human services now appears to be within reach. Never before has so much information been available on social change, partly as a result of recent research on organizational development, social dynamics, conflict theory, group dynamics, advertising, persuasion and communication. Significant change is unlikely to come from within professions and agencies now in the field, nor through traditional higher education approaches. The primary change agent will likely be some form of consortium, dedicated and organized to bring about far-reaching and in-depth solutions, with access to extensive technical and professional resources, leadership, and guidance. The consortium requires a partnership between consumer leaders and the world of research and higher education. Future program planners, administrators, and consumer leaders will need more sophistication in decision and systems theory and its application to the field of social change.

One alternative to solving the problems of the future is for consumer organizations and universities to share resources and/or develop cooperative ventures. Such associations and relationships can make both the consumer movement and the universities more balanced, more vital, and less isolated. The California Institute on Human

Services hopes to assist the consumer movement through facilitating inter-agency and interdisciplinary problem solving. We wish to help by acting as an intermediary for clarifying and generating solutions to social policy and service delivery problems. Intermediary vehicles are needed to resolve problems such as:

1. *Regional Disparity.* Not all disabled citizens have access to one standard of care. This is likely to continue and increase in the absence of some means of developing a programmatic equalization strategy.

2. *Prevention.* Prevention is on the agenda of most human service organizations for present and future action. There is much fragmented activity but little real impact. Future effectiveness requires some kind of coordinated effort and perhaps a clearinghouse for unified, social-political-administrative action.

3. *Centralization of Information.* The "explosion" of information flooding the human services field leads to waste, confusion, and ineffective utilization. Potential users need access to a centralized entity capable of responding to their needs.

4. *Personnel Preparation.* There is a real need for sharing information on curriculum development, standards, and credit or recognition systems, including peer counseling and instruction among persons with disabilities.

One way of creating new ideas is to step back from day-to-day reality and look at situations from different, non-traditional perspectives. New ideas and solutions are created by asking questions about the future in a different way. The rehabilitation pioneers posed the question of approaching treatment in a different way, which led to the multi-disciplinary approach and to unprecedented benefits for people with disabilities. Subsequently, others did so again, resulting in the concept of normalization, and its applied form, integration. Modern systems theory is also raising questions about the future in a different way, with new ideas about solutions—among them the concepts of comprehensiveness and continuity of service. As a result, new service delivery models are being designed to cope with continuing demands for improved service quality and the issues of complexity, resource utilization, and meaningful consumer involvement.

We at the California Institute on Human Services are proud to provide technical support for this Conference and we look forward to the opportunity to participate in the alliances of the eighties that will transform human services. Together we can make a better world. This conference is intended to be a beginning step in the Institute's relationship with the consumer movement and in our mutual venture to make the world a better place for all persons, including disabled and nondisabled citizens.







Conference Overview

**Ed Roberts, Director
California Department of
Rehabilitation**

It is a pleasure to join together today. I hope that each of us recognizes that we must play a strong role in this consumer conference. Each of us has something to contribute: by describing where we've been, what has happened to us, and some of the pitfalls that we've fallen into. Together we have come an awfully long way in the past few years. Our future is together, and our power is together. Our society and government are facing shrinking resources. It is becoming increasingly important for us to work in cooperation and to recognize how essential it is to develop all citizens to their fullest potential. If each of us is involved we can make the most profound changes that our society has ever seen.

Severely and profoundly retarded persons have come out of institutions to join us, mentally ill persons are here, and multiply disabled persons are here. I recognize many folks in this audience, including me, who have been in institutions.

We are making tremendous progress but we've got a great distance to go. This conference brings primary consumers together with parent leaders

"We will not tolerate another generation of young people with disabilities going through segregated education, segregated society, being dependent on their parents and public aid. We can make a difference in their future."

so that we can appreciate our common goal: equal opportunity to education, housing, transportation, and work for everyone. We cannot accept the limits and stereotypes that society places on us. We must recognize that the biggest barrier of all is the way people perceive us.

Consumer unity does not mean that our traditional consumer organizations should lose their individual identity. Rather, each of our organizations must maintain its own identity: the deaf, blind, mentally retarded, physically handicapped, etc., must continue to fight for the causes that are most pertinent to their own disability. The Consumer Unity theme is merely designed to help us recognize that we must stand together on certain commonly held objectives if we are to create a valued future for a lot of folks that are coming along, including the temporarily able-bodied.

It is increasingly clear that unless we are unified, unless we know what we want, unless we are pushing, unless we register and vote, and unless we recognize that disability and poverty are synonymous, we are all doomed. We

"If people with disabilities have a future, then everyone in our society will have a future."

must open our society and help people gain confidence to seek jobs, recreation, and whatever else is necessary to actualize their lives.

I believe that the next generation of young people with disabilities will not grow up to be dependent, helpless, stereotyped adults. We must dedicate ourselves to that end. We must not allow another generation of young people with disabilities to experience segregated education, segregated society, and dependency on their parents and public aid. We can make a difference in their future and we can make a difference in our own futures.

Parents of persons with disabilities should come together with people with disabilities. Together we are much stronger. How many people are here from blind and visually disabled groups? *All right!* How many people are here with hearing impairment groups? *All right!* How many people are here from People First? People who have been institutionalized in the past? *All right!* Big numbers. We have some firsts here today, and that's what we were hoping.

I know that each person in this audience is here for a reason. You are established leaders and emerging leaders, people who take charge. I remember the first time that I had to raise money for the Center for Independent Living. I couldn't have been more afraid of folks who had money. Fear made it very difficult for me to talk. But I swallowed my fear and came out with fifty thousand dollars. That's the kind of thing that builds confidence. It doesn't happen all the time. Please don't be afraid. We are all going to get into situations that are fearful. Nevertheless, we must push on.

We must educate the public to the potential effects of the taxpayer revolt because it has too much to do with our future, the future of young people with disabilities, the future of older folks in our society, and the future of all people who have been pushed aside. We can make a difference together.

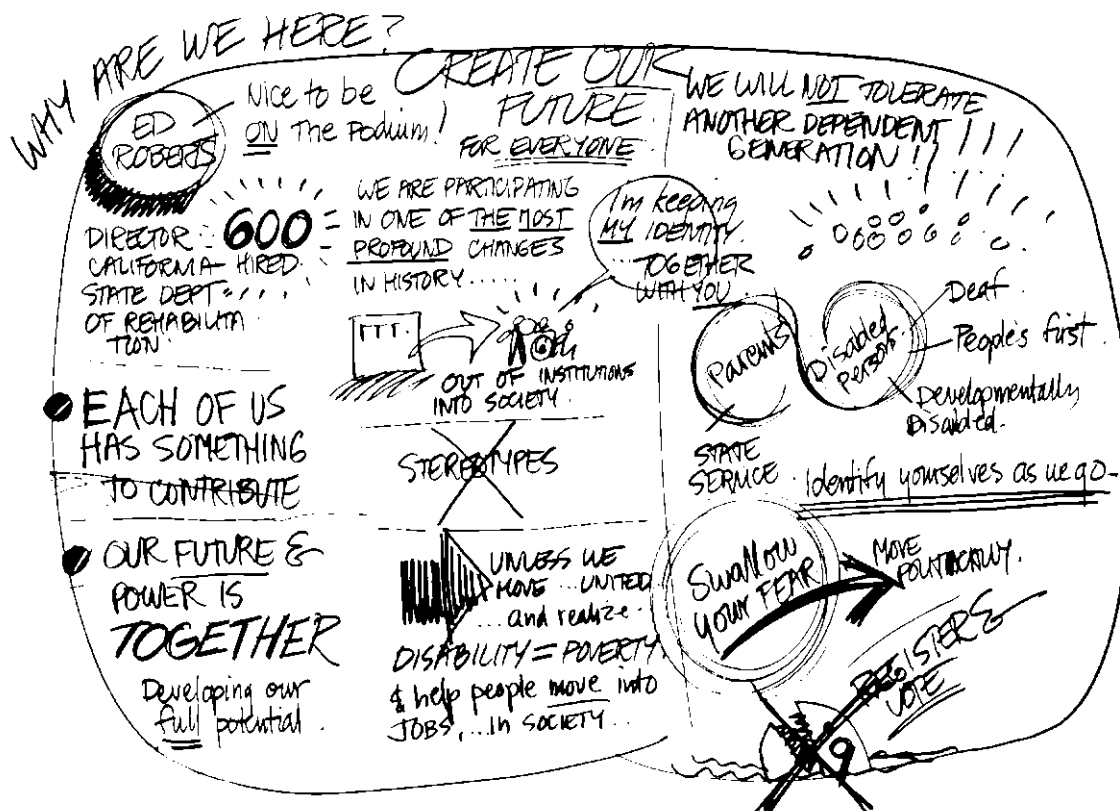
A few of you have already made a difference. A large number of us could create a future, a future that we can all participate in. I think we are going to be very proud of the future we build. It's going to be one that's based on our real humanity, our feelings of caring for each other, and probably that's the most important thing. If people with disabilities have a future, then everyone in our society will have a future. Thank you very much.





Why Are We Here?

DAVID SIBBET
Graphic Facilitator



Nice to be
ON The Podium!

WE ARE PARTICIPATING
IN ONE OF THE MOST
PROFOUND CHANGES
IN HISTORY.....

I'm keeping
MY IDENTITY
... TOGETHER
WITH...



~~STEREOTYPES~~

OF US
SOMETHING
TRIBUTE

UTURE &
R IS
GETHER

along our



A Review of Policy Achievements

Michael Thrasher

United States Department of Justice

I have been involved in civil rights litigation for approximately 12 years. The original cases I was involved in dealt with racial discrimination of various kinds. It was in 1972 that the Federal District Courts in the South began ordering, as they had in the racial cases, the United States to appear to assist civil rights litigants with disabilities in the development of their cases, because the litigants were unable to do so on their own. The law is blind, deaf, and mute as to different characterizations of people. The Constitution applies to people, and to persons. There is no exclusion in the Constitution for deaf people. There is no exclusion in the Constitution for retarded people. There is no exclusion in the Constitution for blind people. Constitutional protections exist for everyone in this country.

It's important for you to understand your place in the historical development of this country because everything springs therefrom. And it is very important for you to view what is happening from a Constitutional context. Legislators can change statutes. If the legislature can implement a statute, it can repeal it. But the rights of

"The Constitution applies to people, and to persons. There is no exclusion in the Constitution . . . Constitutional protections exist for everyone in this country."

persons with disabilities that have been established over the past decade are grounded in the Constitution, not upon state statutes. State statutes merely have been codifications of what the Constitution protects. This country is unique in the Anglo-Saxon world in that we have a written constitution. The history of England was quite the contrary. Their constitution was developed through practice and custom. Our Constitution was reduced to writing in 1789, as part of a revolution against central government control. The Constitution was originally written to protect citizens against the federal government, not to protect them from the activities of state governments. What was to be guarded against was a central government, to wit England, exercising too much control over people thousands of miles away. The Constitution was written to limit the powers of the federal, not the state, government. When the Bill of Rights was adopted two years later, in 1791, it also was directed toward defining what the federal Congress could not do. The federal government could not suppress freedom of speech, could not invade someone's home without a search warrant, and could not impose cruel or

"It wasn't until the blacks took control of the movement that things really happened. The civil rights of handicapped people will not fully move forward until you take control of the field yourself, which I urge you to do."

unusual punishment. It said nothing about state governments.

I think this is quite relevant because our experience in this field, of course, is that it is state governments that control the basic relations between citizens and governmental activities. It's important to view our situation in its historical context. It was not until the Civil War, where the main issue was what rights do state governments have vis-a-vis the people residing within their own boundaries, to wit black people, that the Constitution finally addressed what the powers of state governments might be, and how they might be limited. Prior to that time the powers of state governments were almost limitless. The 14th Amendment was passed to codify the results of the Civil War. Finally a relationship was defined between the central government and the persons living within state boundaries so that state governments could not interpose a block between the central government and its own citizens. The 14th Amendment provides, in basic part, that no state shall deny any person of life, liberty, or property without due process of law. For the first time the Constitution really spoke to the issue of

how to protect citizens against activities of their own state governments.

The 14th Amendment interposed itself between the state citizen and the state government. It nationalized the relationship of citizens to the central government. No longer are state governments free to act vis-a-vis their own citizens in any way they will, without review by the federal government.

The federal government comes in three colors: color one is executive, color two is legislative, and color three is judiciary. And all three branches have been actively involved in seeking to assert the protections of the 14th Amendment. The basic model to draw on in the field of disability rights is the development of civil rights law in the field of race.

While the 14th Amendment was adopted in 1868, it was not until approximately 100 years later that anything really happened. It was 1954 before the Supreme Court decided *Brown vs. Board of Education*. The rationale for the *Brown vs. Board of Education* decision was exactly the same rationale that is the compelling interest in the field of disability. The operative word in the 14th Amendment is "persons." Discrimination is not permissible under the 14th Amendment. It is not constitutional to set aside mentally retarded people, blind people, black people, yellow people, young people, or old people. To paraphrase Gertrude Stein, "A person is a person is a person."

Brown vs. Board of Education was the Supreme Court decision that outlawed segregation in public education. Now the 14th Amendment, as I indicated, addresses itself to state governments.

In order for the 14th Amendment to be operative, someone must show state action. It does not apply against private activities. Private discrimination is not unconstitutional. It may be illegal under state law, but what is prohibited by the 14th Amendment is state discrimination. For purposes of the 14th Amendment, state discrimination means the state government; its branches; its employees; and local, county, or city officials.

So much for a retrospective view prior to 1972. My involvement in this field springs from the *Wyatt vs. Stickney* litigation in Alabama. The *Wyatt vs. Stickney* case established for the first time a Constitutional right to treatment for institutionalized mentally retarded people. It started off as an employee rights case. The plaintiff in that case was an employee of the state government of Alabama who worked in an institution. He was laid off and filed a suit to get his job back. Somewhere in the complaint was an allegation that not only was he injured by his dismissal but, because he and many other people were laid off, the rights of the people confined in the institution were also seriously jeopardized. So it was almost as if by accident that the case became a right to treatment suit.

What, in terms of the 14th Amendment to the Constitution, is a right to treatment suit? There is no guarantee of treatment clause in the Constitution. The 14th Amendment provides that no state shall deny any person of life, liberty, or property without due process of law. It does not state "And, you have a right to treatment."

Wyatt involved two mental hospitals and one institution for persons labeled "mentally retarded." People were sub-

jected to involuntary commitment to these institutions. Persons were brought by other persons to the institutions, the other persons being their parents, guardians, or next of kin. Once they were committed, the superintendents of the institutions could decide to return a person's liberty or not to return their liberty. So what we had in 14th Amendment terms was a deprivation of personal liberty. The 14th Amendment says "No state shall deny any person of life, liberty or property without due process of law." The question then became, was there due process of law? A statement which says you can't do it without due process of law really says you can do it, as long as you do it pursuant to due process of law. Is confinement of retarded people and mentally ill people in institutions with locked doors denial of liberty pursuant to due process of law? That was the precise issue before the court.

The practice of law, in my judgment, is the practice of facts. In order for the issue to be "fact focused" and decided, one has to understand the facts of confinement in those and similar institutions.

Now I won't be telling many of you anything new and different. I'm convinced that you could, at least at that time and probably now, pick up a dart, throw it at a map of the United States, pick the nearest institution, and find the same thing. At any rate, in Partlow, the mental retardation institution in Alabama, it was the practice each evening for the institution to tie retarded people to their beds, in spread-eagle fashion. It was the practice to shove all the beds together in rooms, much like military barracks, so that one employee could look through a window and count the noses of all the people in the barracks.

Some residents, from time to time, were let into the custody of their parents for weekends. Parents would take them home and call the institution saying that their child (many of whom were now adults) was lying on the bed spread-eagle, yelling and screaming. What should they do? They were instructed to tie them to the bed and they'd stop screaming.

We found an adult lady in the institution who had been confined to a straight jacket for eight years. The sole justification in her medical records was that she had been biting her fingernails. After eight years, her large muscles had deteriorated and her arms were useless. We found her in the courtyard at Partlow in summertime Alabama flicking the flies off her face with her feet. The FBI agent who took photographs of her testified that as she breathed in, flies were drawn into her face and her mouth, and as she breathed out, some of them came out.

We found that people were required to work at menial jobs—laundry, gardening—for lifetimes without pay. This practice is a violation of the 13th Amendment, which makes involuntary servitude unconstitutional.

We found many, many instances of excessive drug use. It was clear that the retardation facility was using phenothiazines to control people.

We had a federal judge sitting in a federal courtroom in Alabama with facts coming in that included no staff on duty at nighttime in certain buildings that housed large numbers of acting-out patients; everyone bathing at the same time by walking through showers in car-wash formation; residents of the institution doing the bathing of each

other (which resulted in a hose being inserted in the rectum of one patient, killing him; hot water being sprayed over a wheelchair patient, scalding his testicles off; and a hose being inserted down the throat of another resident, also resulting in death). Now this was 1972, not 1672. Indeed, this treatment would have made the Stuart Kings of England look like pikers.

As I was saying, we have a federal judge sitting in a courthouse, a federal courthouse in the middle of Alabama, receiving these facts. He doesn't receive a Constitutional right to treatment—he receives facts. What the hell are the facts surrounding the confinement of these citizens of the United States? Do these facts constitute lawful deprivation of liberty? Is this denial of liberty pursuant to due process of law? The asserted purpose of the confinement of such persons was to ensure appropriate care and treatment so as to improve their condition so that when their conditions were improved, their constitutionally-protected right to liberty could be returned to them, and they could leave the institution. Well, is this treatment then? Is this why the constitutional rights of these citizens of the United States were deprived by the state of Alabama? I think the facts make the answer to that question very clear. In fact, the facts make the question very clear. And the practice of law is facts, facts, facts.

The 14th Amendment says no person shall be denied life, liberty, or property without due process of law. What does due process mean? Many people suggested that it must mean the Bill of Rights. Let's just take the first eight amendments: freedom of speech, the right not to have soldiers quartered in your house against your will, the right

to be free from unreasonable searches, the right to due process when your property is being denied, the right to trial by jury in civil procedures, the right to trial by jury in criminal procedures, and the right to be free from cruel and unusual punishment. Let's assume that is what due process means. Well, that is not what the Supreme Court said. The Supreme Court said, "We don't know what it means, so we are going to go on a case-by-case-by-case basis." And for the hundred years from 1868 until very close to the present time, that has been the constitutional history of the Supreme Court of the United States: does this factual situation indicate that due process was provided? That is exactly what happened in *Wyatt vs. Stickney*. Given the fact that the constitutionally-protected right to liberty was at stake, is what happened to these people due process of law? Since they could not get out until their conditions improved, and their conditions would not improve unless they received efficacious treatment, then clearly it was not due process of law; it was life imprisonment. Their conditions would never improve.

We have found the same conditions everywhere in the country. In preparing for the *Pennhurst* case, which was the recent Philadelphia decision, I came across a chart that intrigued me. I asked a unit worker what it was. It turned out to be the charting of unexplained fractures, bone fractures, on a month-to-month basis, of the population of Pennhurst. The injuries recorded on the chart were not broken fingernails; they were broken hips, broken backs, broken legs, broken arms. They had so many unexplained fractures that they literally charted them. And as you can well imagine, we put that chart in evidence and asked the institution to

explain it. Not only was the experience in the cases not indicative of treatment, it was indicative of cruel and unusual punishment.

Approximately the same time that *Wyatt* was being tried and decided, the *Pennsylvania Association for Retarded Children vs. Commonwealth of Pennsylvania* decision was handed down. This addressed the condition, which existed everywhere at that time, of handicapped children being totally excluded from public education. The court said, "Gee, we went through this with blacks. You segregated blacks but at least you put them in school. The Supreme Court in 1954 held that even if you provide blacks with education, you can't segregate them in separate schools. Hell, here you're not even providing handicapped children with any education. How can that be constitutional, given the historical development of the civil rights movement and the Constitution of this country?" Well, it cannot, of course. The District Court of Philadelphia held that the exclusion of handicapped children from services that the state provided to all other children was unconstitutional. So why is it unconstitutional? Because of the 14th Amendment. The 14th Amendment prohibits states from denying citizens equal protection of the law. This means that states can't classify one group of citizens in one bowl, and another group of citizens in another bowl, and treat them differently.

There is no constitutional right to treatment, and there is no constitutional right to education. The 14th Amendment does not speak in positive terms. It speaks in restrictive terms. It limits what a state can do. If a state chooses to provide education, it cannot treat different classes of citizens differently.

What it means in the institutional context, and the right to treatment cases, is that there is no constitutional mandate that states provide mental retardation services at all. It may be a violation of a state's statutes, but it would not be a violation of the Constitution. But if a state opts to provide mental retardation services, if a state opts to confine handicapped people, then it must do so pursuant to due process of law.

The cases that I have described are the foundation upon which the statutes that you are all familiar with have been built: Public Law 94-142, the Education for All Handicapped Children Act; the Developmental Disabilities Act; and Section 504 of the Rehabilitation Act of 1973.

The statutes needed to implement constitutional protections are now largely in place. I am sure there are other statutes that need to be passed, but statutes and constitutional protections are not necessarily worth a damn. People must monitor what state agencies do, what local schools do. One of the dangers of all the procedural protections which now obtain, the 94-142 regulations and Section 504 regulations, is that we have now set up so much due process—you must have proper IQ testing, Individual Education Plans, annual reviews, periodic reviews—that states will respond in paper fashion because they want to get federal funds, but nothing will change. Perhaps what we have done is to legitimize the results which appear now. *Without strong consumer pressure, issues may not be brought into focus and statutes may not be enforced.* We need local, in-place monitoring by people who are intimately familiar with facts, who are able to point out problems with statutory implementation,

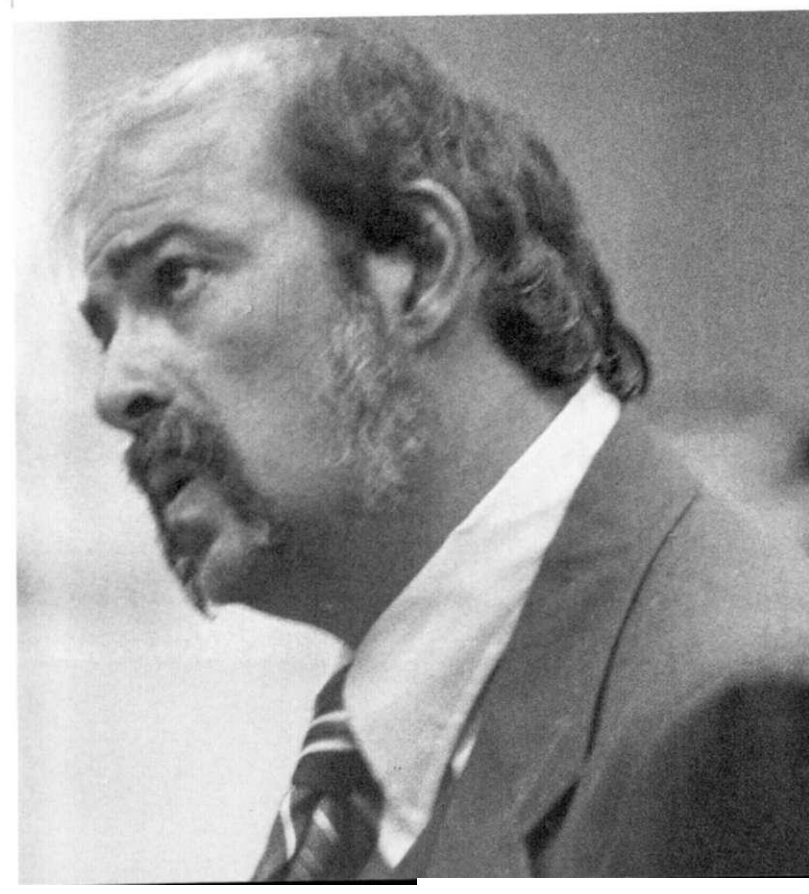
and who are willing to bring complaints to the proper agencies.

Let me close with two statements.

The big turn in the assurance of civil rights to racial minorities came when blacks took control of the civil rights movement. Up until that time, it was the white lawyers and other white people who defined the conditions, the standards, and the laws that would apply. It was not until the blacks took control of the movement that things really happened. I suggest to you that the same is true in the field of disability rights. The civil rights of handicapped people will not fully move forward until you take control of the field yourself, which I urge you to do.

My final point is that if you want to do something effective in the field of institutional rights, get the federal government to stop funding state institutions through Title XIX at a ratio of three to one. Once this happens I think you'll see great voluntary movement on the part of state governments to develop quality community alternatives.







Exercising Political Power

**Mario Obledo, Secretary
California Health and Welfare
Agency**

Thank you very much for the privilege of speaking to you. I wanted to spend some hours here learning, if you will, from those in attendance. I understand that the participants here are representative of a wide range of special developmental needs: the blind, deaf, physically handicapped, aged, mentally retarded, and many others. I was listening closely to Mr. Thrasher's comments. Regrettably, I think I've lost more faith in the judicial system than in any other government system. You go to the courts for years on end, get very little settled, and after you do get a final decision, it is very difficult to enforce it. I call to your attention the *Brown vs. Board of Education* case of many, many years ago. It is still being litigated. I have personally experienced the agony of litigating a particular case for years on end, and never really getting any definitive decision from the courts. And even though it may be worthwhile to go through the courts with a particular matter, it appears to me that the best and the fastest route is the political route, i.e., seeking resolutions to your problems by mounting pressure on appointed and elected public officials. This approach often gets results at a much faster rate.

"We need to be constantly reminded about our work and our duty and our responsibility to people."

I tell the Chicano people that political pressure is generally more effective than the courts. It would take a matter of seconds to desegregate a school system if we were to elect the school board. Once elected, it would take a motion and an affirmative vote and you would have a desegregated school in seconds versus taking ten years through the courts. We have made some progress in state government, but not enough. I must confess that I oftentimes lose track of the problems of a particular area, and oftentimes it is difficult to hear the truth, and to try to understand it. But I am the Secretary, and we have so many problems in different areas. I sometimes must temporarily focus my attention on one area to the exclusion of all others to achieve change. I wish that I could tell you that I can pursue all of them at once. I'll give you an example. Mike Vader has been on my case for two years, encouraging me to employ a disabled person at the agency level because, even in 1980, insofar as I know, there is not a single disabled person working in the office of one of the Secretaries. We have been derelict in the implementation of Section 504 but we are trying to improve our performance. We need to be con-

"The ideal in my mind would be to subsidize families. Some persons need medical attention and we would use private hospitals for that kind of care."

stantly reminded about our work and our duty and our responsibility to people.

You are going to be hearing from Dr. William Bronston, Ed Roberts, Mike Vader, and other people in California government who will relate what we are doing, and something about our future hopes. I humbly request that you constantly keep monitoring our performance, bring pressure on us, on myself and the other people in state government. Get some reaction from us, one way or the other, so that you can hold us accountable to our particular actions or inactions.

You are the best protectors and the best advocates for your areas of concern. Other groups, Hispanics, for example, are concerned with their issues. You have to put forward your energies, your talents and your commitments to speak out on behalf of the constituency you represent. I think you are doing very well in this state, but certainly your efforts and achievements can be improved.

I wish that I could truthfully tell you that I fully understand the plight of the disabled. I cannot. I have to be told, I have to be sensitized. I try to sensitize people of good faith to the plight of Hispanics, not because they have any malice toward Hispanic people, but because they never really think. They didn't grow up in a barrio, they haven't visited the Hispanic communities of our large cities, they are not aware of the particular problems faced by Hispanic communities. I know that there are people who do not have a disability and yet are very sensitive about the rights of the disabled. I point to Dr. William Bronston. He is a fighter, he is an advocate, he is a person who is totally committed to this endeavor. So you could very well say, well, Obledo, you may not be disabled, but why aren't you that totally committed when there are other people that are? I don't know; maybe it is because it's only in the recent past that these things have made an impact on me. I am going to be devoting more time to this area. I am available whenever you need to talk to me, or whenever you want me to address a problem. I wish you success in your struggle.

Questions and Answers

Question: Secretary Obledo, we have a problem with the planned phase-out of the developmentally disabled wards in state hospitals. I was at a meeting with a social worker from Lanterman State Hospital and I was told they would not close. Then I got copies of regulations and found they will close. Community care facilities are not adequate. I am really concerned about what plans exist to provide adequate housing and adequate supportive services for per-

sons moved from hospitals to community living arrangements.

Obledo: Ed Roberts, Bill Bronston, or others may be touching on what we will be working on insofar as community care services and independent living centers are concerned. We need not only centers but mechanisms. The ideal in my mind would be to subsidize families. Some persons need medical attention and we should use private hospitals for that kind of care.

Question: I'm from Pasadena. I am sent Medi-Cal stickers but sometimes we don't get the services that our doctor wants us to have. One problem is transportation back and forth to Medi-Cal services. Medi-Cal has denied me, among others, the transportation to get back and forth to the doctor. So why do they send us these stickers if we can't use them?

Obledo: Because that's government for you. That matter was brought up at our hearing last week and we are seeking a solution.

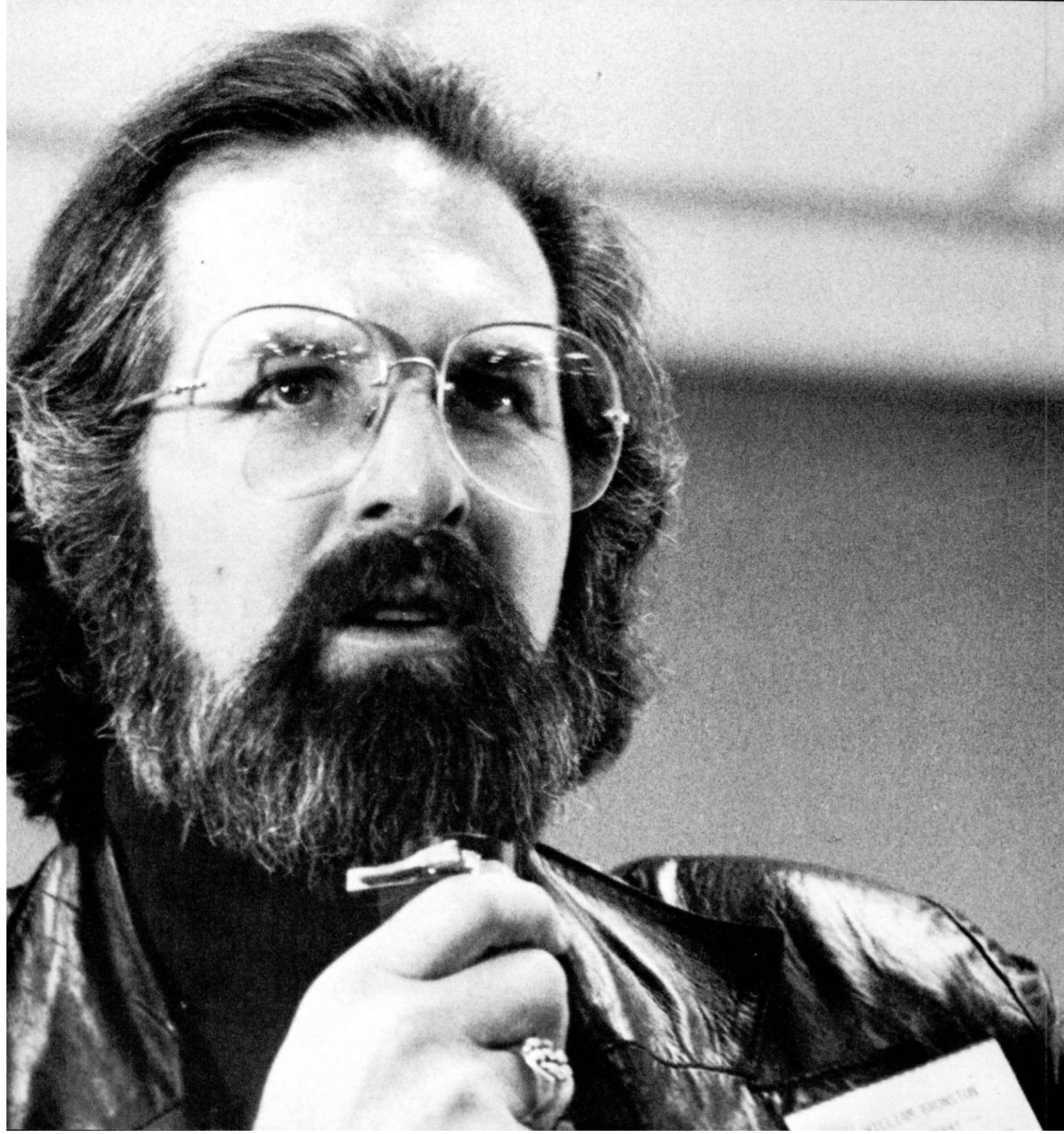
You mention government. I will give you a good example of how government works. Down on the first floor of our building there is a sign with a roster that's got my name and others' names on it. I wanted a change in a title of one of the persons underneath me, so I had to put in a work order. I don't know where the work order went, but after two months the sign still wasn't changed. I used to check it every morning to find out whether it had been changed. After two months I saw a janitor and I said, "Can't we get this sign changed?" He said, "Well, I can't do it unless I get specific orders." I said, "Well, let's take the glass off and I'll do it." And he said, "No, let me—I'll

go ahead but somebody might get after me." I said, "I'll take up for you." So he took the glass off, and changed it in two minutes. And I still don't know where the work order is. It's somewhere in government.

I don't know what you say in closing to a beautiful group like this but I know when I speak to Mexican-American groups I close off with Viva la Raza, which means "Long live the race." Perhaps here I say, "Viva 504!"







Our Civil Rights History

William Bronston
Department of Developmental
Services

Without a history, people cannot powerfully choose their future nor fully understand their present. History serves interests: to render people inactive and feeling helpless or to clarify and catalyze action. Today we have heard men speak about the achievements of our struggle, the "official history," so to speak, of our movement. Lawyers, judges, intellectuals, and bureaucrats have been characterized as heroes. The action has been theirs; the power to change has been focused in their hands. These descriptions have implied that the system works. Injustices have been corrected, or at least addressed, by the institutions of society. We can sleep peacefully because someone cares somewhere who can deal with the system, and always does, in the interest of the majority of people. At the bottom line, however, this perspective on our history renders the majority unnecessary and irrelevant to the process of social change and dependent upon the few elite actors who possess the real power.

"We the people have not yet developed a history that is our history. And without that, I really believe that we're going along handicapped in our movement."

In reality, nothing could be farther from the truth. Without a commitment to struggle, risk, sacrifice, care, and service on the part of common people, nothing would change except for increased exploitation and abuse by people who live by "me first." Winning a day in court, passing a law, getting a few dollars to do this or that job does not secure justice. Justice comes from everyone struggling together and understanding what it takes to make life valued and shared by all.

Each of you has played a part. This Conference isn't just somebody's good idea. Rather, this Conference is being held due to the recognition of a need by the movement. We recognize a need to try again and again to find ways to come together, to increase our success and to make our lives more humane together. It comes from insight into true people-based experiences and from political awareness gained through protest against the humiliation and dehumanization of our society toward those having special needs.

Please, everyone ... let us together each recall, recapture, declare, summarize those things that we did or were part of that mattered. Let us try and build a picture from the *real* events of each of our lives that shows the force that we collectively represent.

To date there is no book, no library, no museum, no mural that documents all the incredible effort and energy that we have devoted to opening and elevating society. Let this be a beginning toward creating this needed documentation of our collective history. Let's share our personal experiences of liberty, of integration, of protest, of achievement that underpin the "official history" we have already heard. Let us begin to recognize, accumulate, and share a people's history. It is the many who are the real heroes. Let it be known and disseminated that it was only when thousands and millions of Americans cared enough to organize their immeasurable will and power that progress occurred.



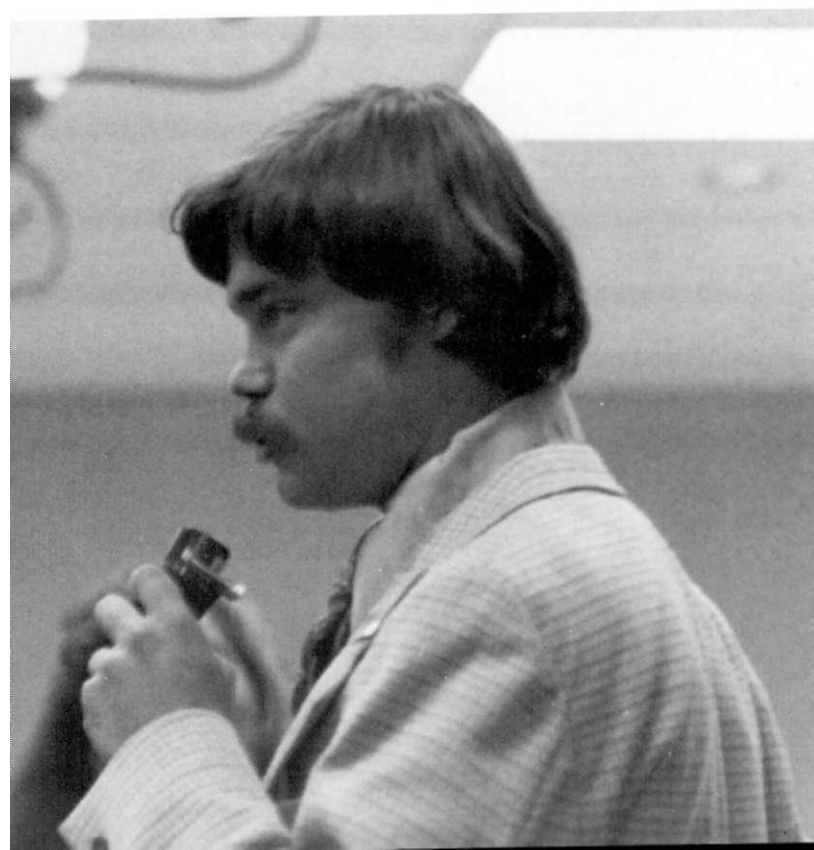


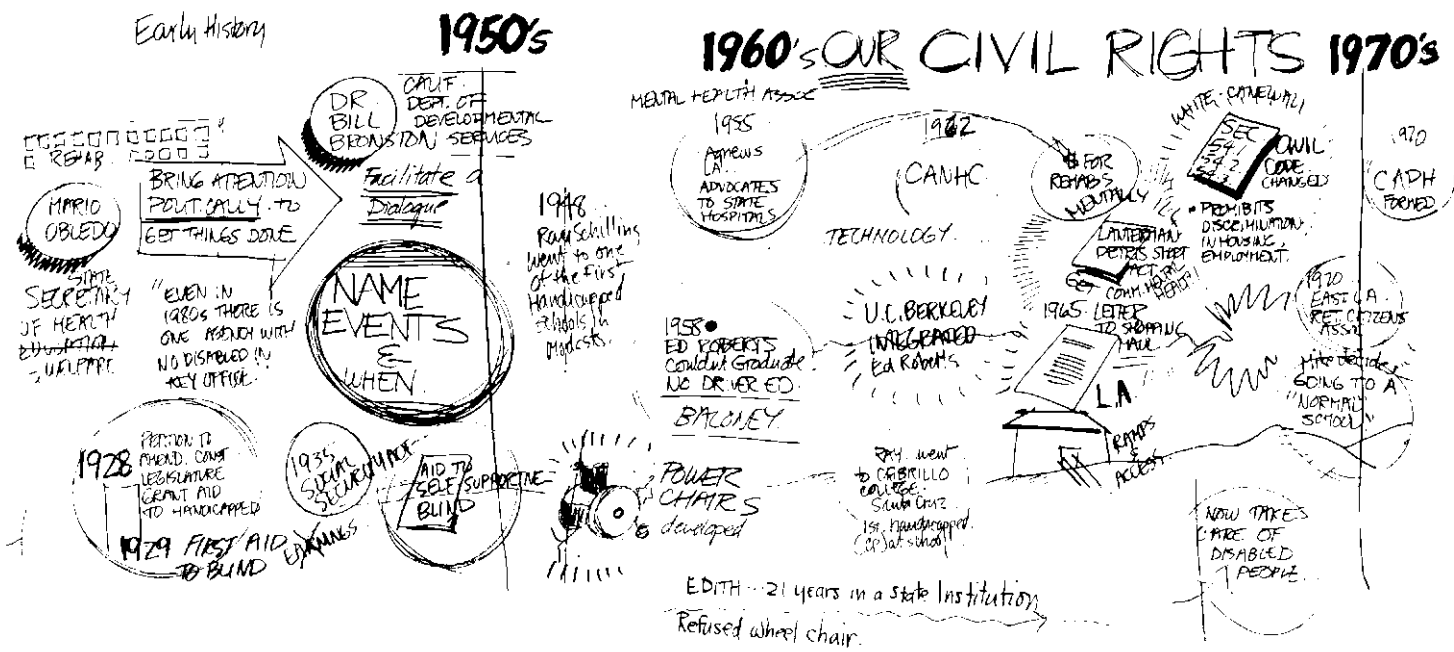












Work Group Leaders

Andre Economopolous
People First of California

Joanne Jauregui
Center for Independent Living

Ettamarie Siordia
State Personnel Board

Jim Gonsalves
Center for Independent Living

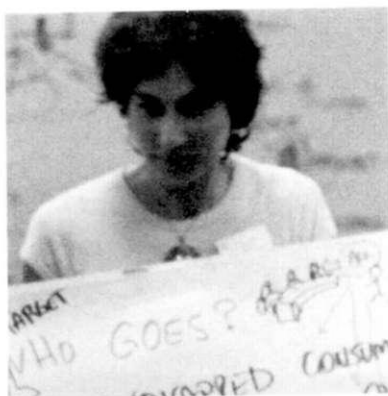
Mitchell Pomerantz
National Federation of the
Blind in California

Carlos Zentella
Arriba Juntos Center

Cy Hubbard
California Governor's
Committee for the Employment
of the Handicapped

Judith Reich
United Cerebral Palsy

Anthony Tusler
Office for Students with
Disabilities, Sonoma State
University



Participant Comments

Andre Economopoulos

"When I was three years old, I was placed in Sonoma State Hospital, a place, like many others, that should not exist. At the age of seven I finally reached my first care home, stayed until 14 and was put in another care home. I went to regular high school, but in special education. Immediately after graduating, I went into TRACE, an apartment setting, where I learned to live on my own. I now live in the community, actually making it on my own, with a job.

"I'm the engine, an engine that was put together with a malfunction. I had to go through a state-operated Grand Central Station, the wrong station, but I got out anyway. This engine got fixed, and learned to do the things it needed to do to run on the track. Now this engine is able to go out and pull other cars, i.e. other people with similar disabilities. The others can follow this engine and learn what they need to learn in order to get out in the community. I want to be a role model for young people to encourage them to learn to be on their own."

Donna Schinowsky

"I am really excited about this conference, because I think that we must work together. I think we also must work individually as advocates in the job market, and in other places. I do not work in a disabled unit. I am the only disabled person. I feel that by doing my job and doing it well, I'm proving that handicapped people are not really handicapped. I may not walk as well as some people, but I can do my job just as well as anyone. So I believe in the importance of working together but I also believe that we can do a lot by ourselves by saying 'I am able. I am disabled, but I am able.' "

Ettamarie Siordia

"I work for the State Personnel Board, in the Affirmative Action for the Disabled unit. This is the unit that was established to help implement affirmative action in state government for disabled persons. We are interested in seeing that persons with all types of disabilities are accepted in the employment market. We know that they can be involved in the working world and we're setting up programs that will help achieve that employment.

"People at this conference are able to see people with all kinds of disabilities, are able to talk to them, to find out about their problems. Historically, disabled people have been kept in institutions and have not been accepted in the world of employment, except for maybe sheltered workshops, where they were paid 250 an hour if they were lucky. Now we all know that nobody can live on 25c an hour. We need to have wages that are commensurate with our abilities, a wage that will allow us to live in society.

"Before we were just patients in a hospital. It makes me so mad when I hear a disabled person called a patient. It shows that stereotyping still exists. We're people. My patience is running out!

"This conference is helping to pull people together and start them saying 'Hey, we're not going to wait any longer.' And together we're going to get our needs met."

Mitch Pomerantz

"I'm a member of the Executive Committee of the National Federation of the Blind in California, which is the largest and oldest consumer organization of disabled people in California. The Federation's been around for about 40 years. We've realized the importance of developing our own abilities so that we may represent ourselves. It is our philosophy that as blind people we are the best representatives of our cause. I believe wholly in the cause of consumer unity. I do not believe in coalition. Instead, I believe in what we call common front: the idea of groups who are internally strong banding together on specific issues of common concern.

"I don't believe that the traditional coalition approach works. Common front does work, however. It is critical that persons with disabilities begin to band together on specific issues, common concerns, to achieve fixed term goals.

"I believe that the issues of concern in the '80s will be economic and attitudinal kinds of concerns. There is a movement here in California and nationally for more fiscal responsibility in government; a turning away from social service programs which lack accountability. We must deal with the public and with the pervasive philosophy that

all the disabled need or want is more money. What we really are looking for is equality. We must make the message clear that we are concerned about the same things as the rest of society. We want good schools, not only for disabled children, but, as parents, we want good schools for our nondisabled children. We are concerned about taxes; we are concerned about crime. We are trying to mainstream ourselves into the work force. We must make these points very clear because until we do, and until we are seen as people who are citizens of the community and of the country who happen to be disabled, we will not fully achieve social acceptance."

F.A. Caliguiri

"The major problem of the deaf has been communication between deaf and hearing people. Deaf people use sign language and hearing people don't. There hasn't been continuity between the deaf and the general public. Now with interpreters, we are beginning to overcome the communication barrier. The deaf are beginning to develop, to emerge and to become more and more mainstreamed into everyday society.

"The deaf are not united and organized enough. Their education is fragmentary. There are different perspectives of how and what the deaf should be taught. Some think that it's better to learn using the oral method and others stress using sign language.

"In the past, deaf people were excluded, barred, from meeting with other handicapped groups and with other people that mattered. We are now beginning to join with other groups to deliberate the issues which are important to us all. This conference is an excellent example of this new trend of involvement between the deaf and other disability groups.

"I hope that I will live to see a time when people forget that deaf persons and other handicapped people have handicaps and instead accept them as people who can function on an equal level."



Lessons We Have Learned as Organizers of the Disability Rights Movement: A Summary of Work Group Products

Michael Vader
Affirmative Action Program for Disabled Workers in State Service

Constance Bulkley
Governor's Office

Participants divided into nine work groups, each facilitated by an emerging leader in the disability civil rights movement. Work groups were requested to review their advocacy experiences and list actions which worked to achieve

desired goals. Michael Vader and Constance Bulkley subsequently integrated the lists of the various work groups to eliminate redundancy. The lists on the following pages summarize the best thinking of participants.

General Lessons

Perseverance—persistence—vigilance—honesty
Maintain integrity
Lots & lots of letters
Get agreement on method
Increase self-advocacy
Share information on rights
Identify and make friends of people in power
Stick together
Provide resources to help "them" implement changes
Do consciousness raising
Meetings every week
Make *personal* contacts
Be visible to others who need to know your issues
Be realistic about goals
Control anger, use logic
Form a group to be recognized by the community
Make loud noise—it doesn't work to stay in place
Exert your own initiative if you want to be independent
Guts

Use legal force
Identify common need
Overcome stereotype
Know more than the "opposition"
Know where to apply pressure
Know enough to talk circles around
Small groups—outmaneuver the "opposition"
Identify problem—do research
Have key constituents on boards
Obtain legal status
Provide needed education
Fight to make it work
Provide reinforcement & follow through
Seek help
Identify handicap as "positive"
Get many people involved and make them visible
Choose the right leader
Learn the system
Take the responsibility to make it work
Learn rules of how to "crack a hard nut"
Identify benefits of plan to those in power
Other groups joining together

Take overview and educate others to the total picture and broaden perspectives
Share concept of adaptability of issues to others
Form own leaders
Have element of surprise
Get consensus to assure effective action
"Model" for community
Don't overlook help from others because of labels
Develop credibility & trust through involvement in other areas of community
Get all decision-makers together
Talk their language to them
Timing must be right
Peer counseling approach
Develop activities & friends
Outline problem to decision-makers
Provide the means by which "they" can consider themselves good people
Formalize strategy to approach those in power (money)
Find out decisions made
Articulate needs

- Identify commonality
- Form organized network with support group
- Mobilize students
- Show, then offer help
- Long range planning
- Media can be used effectively
- Ask for more than you want
- Go over some heads—present issue to highest authority
- Never accept what the "establishment" says
- Demonstrate need by numbers
- Be consistent—persistent—know and use the law
- Identify personally with the problem

Issue-Related Lessons

- Consumers speak out about importance of independence
- Close election race (small margin = more power)
- We found out our rights under the system and were able to counter their arguments
- Round up most affected persons
- Enlist support of all friendly or affected clubs (on campus)
- Circulate petition to validate support
- Learn new language—culture of the housing industry—become "housing professionals"
- Employees realize that patients' rights are based on law
- Judicial review
- Personal protest
- Organizing consumer action
- Working independently in advance & on behalf of others

- Select an issue which impacts on one group and then broaden it to include added groups & other settings

Struggle-Related Lessons

- Political pressures: physical presence—speak up—write letters—"phone tree"—translate to power
- People First helped—stand up for yourself against caretakers—show parents
- Educate those in power
- People with disabilities form coalitions
- Hold demonstrations in capitol
- Do homework—get expert testimony—limited opposition, letter writing, lobbying
- Make union leadership aware of problem
- Work both sides—bureaucrats and politicians
- Peer exposure of issues
- Publicity—disabled are getting powerful
- Attend public hearings—confront housing bureaucrats, legislators in public
- Get a lawyer
- Keep after parents to hang together
- Mandated staff training
- Country-wide lobbying
- "Rent a crowd" capability on short notice (volunteers that can be called to show support)
- Know neighbors personally
- Get people associated with other disabilities
- Chapter—state—national conventions & resolutions
- Demonstrations and other political actions
- Lawsuit—legal action

- Self-advocacy—disabled people in groups

- Do not back off

- Go political—build constituency—contact disabled consumers—many groups—blind, deaf, elderly, low income—form a coalition

- Demonstrate needs—show blatant shortcomings

- Scare the hell out of 'em when other means are exhausted

Legislative-Related Lessons

- Learn legislative process
- Decide on whom to contact in lobbying
- Identify arguments that would reach legislators
- Tack on legislative riders
- Maintain visibility within the state legislature















Lessons We Can Learn from the Black Rights Movement

Cecil Williams
Glide Memorial Church

"You don't ask people to give you your rights. You must struggle to take your rights."

"Maximum danger brings maximum hope."

Each of us has to realize that we have the power to change the world in which we live so that it is the most humane society possible. Nobody's going to get anything—I don't care who you are, or where you come from, or what you are involved in—by being nice, kind, weak, placid, docile, and passive. You don't ask people to give you your rights. You must struggle to take your rights. There is a passage in my book which I feel very strongly about: "Maximum danger brings maximum hope." You have to create tension! There has to be conflict! If there is no conflict, then you do not make gains. You don't accomplish anything. Your goal has to be tension.

One of the primary reasons that I have been successful in my organizing efforts has been that I am convinced, and I have always been convinced, that the only way to get what I had to get, and to make sure that others get what they had to get, is to succeed in conflict. Those who have power don't give up power. The only way one can begin to embrace power, their power, is to begin to create the conflict by which those who have power begin to understand that they cannot hold onto it any longer, that there are people out here

who demand opportunity. The people who are oppressing you must be made to understand that they are going to have to deal with people that they have never seen before, and they are going to have to respond like they have never responded before. If you are going to get power, you have to work for it. You have to suffer for it. You have to make sure that you stand up and let it be known that, while you may be afraid, you intend to make those who have power equally uncomfortable.

We cannot do what we need to do unless we are able to embrace some definition of ourselves. Don't let anybody else define you. You define yourselves. For a long time, I let other people define me, but for the last ten or fifteen years I have done the defining. I say who I am, by what I say and by what I do. Self-definition is critical. It is also important to engage in what I call self-assertion. Be willing, when you begin to work on your self-definition, to put yourself out there. Don't hold back. How can anybody know what you feel and think? How can anybody know what your rights are unless you articulate them? Put yourself out there. Fight!

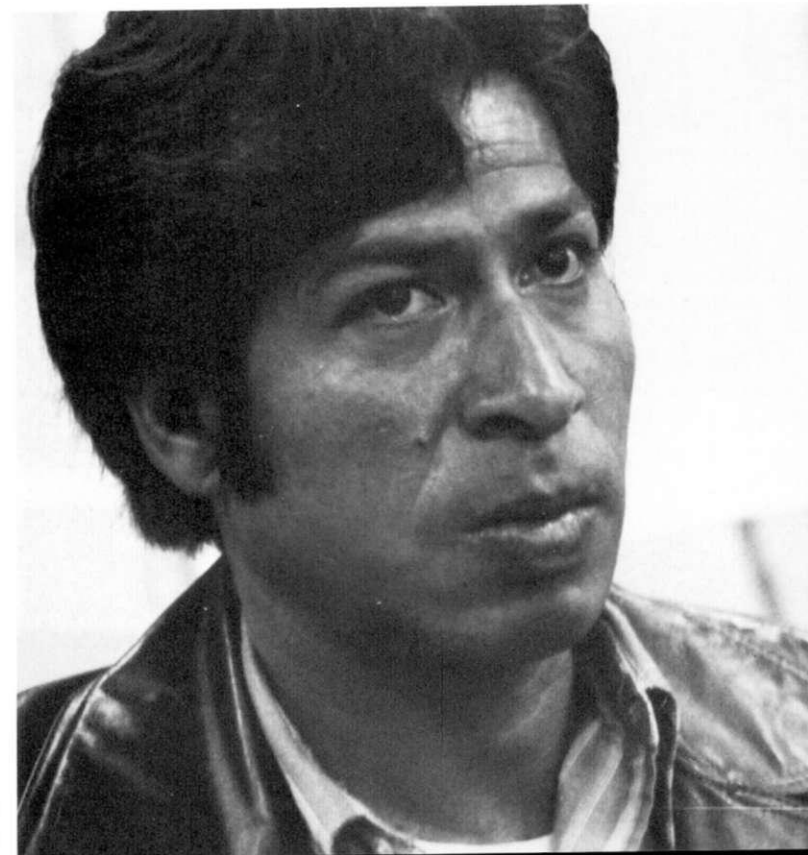
In the eighties we are going to see new coalitions emerge. People are going to get together, not necessarily because we want to care more for each other, but rather because we have to get together. New coalitions and new communities are going to come together because that is the only way we are going to survive. The inflationary and recessionary forces that exist in society make it important for us to understand that we are going to have to come together in new coalitions. We will do so because we have self-interest. Your survival depends upon my survival and my survival depends upon your survival. I am going to get with you because I don't want to go down. And you are going to get with me because you don't want to go down. We are going to get together in the eighties because none of us wants to go down.

The coalitions that I have worked with and organized have had several things in common. First, coalitions are often short-lived experiences. You don't get into a long-term coalition unless you want to take away from some of the things that you would otherwise be doing. Second, you generally do well to

set no more than three common goals. It is important to keep a tight focus to coalition efforts. Third, make sure that the first goal sought by a new coalition is one that you can succeed on. Once you demonstrate success, a lot of other people will want to be a part of your effort.

My final assertion is simply this: in forming the new coalitions of the eighties, don't abdicate your power. Don't give or resign yourself to somebody else's strategy or somebody else's self-definition. Learn from others and teach others. There are two constellations of power. One is money, and the other is people. Most of us don't have money. Pulling off what we need to pull off, therefore, is going to take a pooling of people resources. To the degree that we have unity, we will have liberation. We can come together and stay together, and work together, and care together, and know that in the eighties something is going to happen because you have decided that you are going to make it happen and I have decided that I am going to make it happen. My brothers and sisters, what more can I say except maximum danger means maximum hope? If we don't do it, it won't get done. We have to risk getting out there and fighting because that is how we both feel hope and win the battle. I look forward to a communion of effort between all oppressed people in the eighties.







Lessons We Can Learn from the Trade Union Movement

Eileen Luna
CWA, AFL-CIO Psychiatric
Technician Union

I would like to speak about power. Power, as far as I am concerned, is the only way that we are going to be able to get anything out of the state, out of the nation, or out of any establishment. The thing to remember about power is that power is as power is *perceived*. If the establishment thinks that you have power, then you have power. If you act like you have power, if you think you have power, if you look around and there are lots of people standing next to you, then you have power, and you will be dealt with accordingly.

There are a number of things that we have to realize if we are going to change the situation nationally and in California. One of the things to remember is that what benefits one section of us benefits all of us. I represent the psychiatric technicians of the state hospitals. As you may know, the state of California would like to get out of the human services realm. Many in state government would like to let everybody fend for themselves. The thing to remember is, who is your ally? Who can be made your ally? Who will begin to think in terms of standing with you? The psychiatric technicians, and in-

"It is very, very difficult to do anything on your own. . . . We need an alliance between the consumers of human services and the providers of those services."

deed the workers of the state of California, have an interest in standing next to you. This interest comes from a realization of what is in your self-interest and what is in their self-interest. You should carefully consider the potential benefits of an alliance with organized labor.

It is very, very difficult to do anything on your own. It is very, very difficult for the psychiatric technicians to do anything on their own. We need an alliance between the consumers of human services and the providers of those services. In the union I direct, we are attempting to educate our members to realize that we need to stand with the clients we serve.

One of the reasons I came here today was to share how you can support workers on their issues and needs. Our union is fighting for minimum staffing in state hospitals. Adequate staffing makes it easier to do a good job, and allows workers to go home at night. Service quality increases, staff time spent delivering services increases, and a much better situation ensues all around.

"Sitting Bull said that people are like the fingers of a hand. If they are spread out, they can be chopped off, one by one; but if they are joined together, they can make a mighty fist."

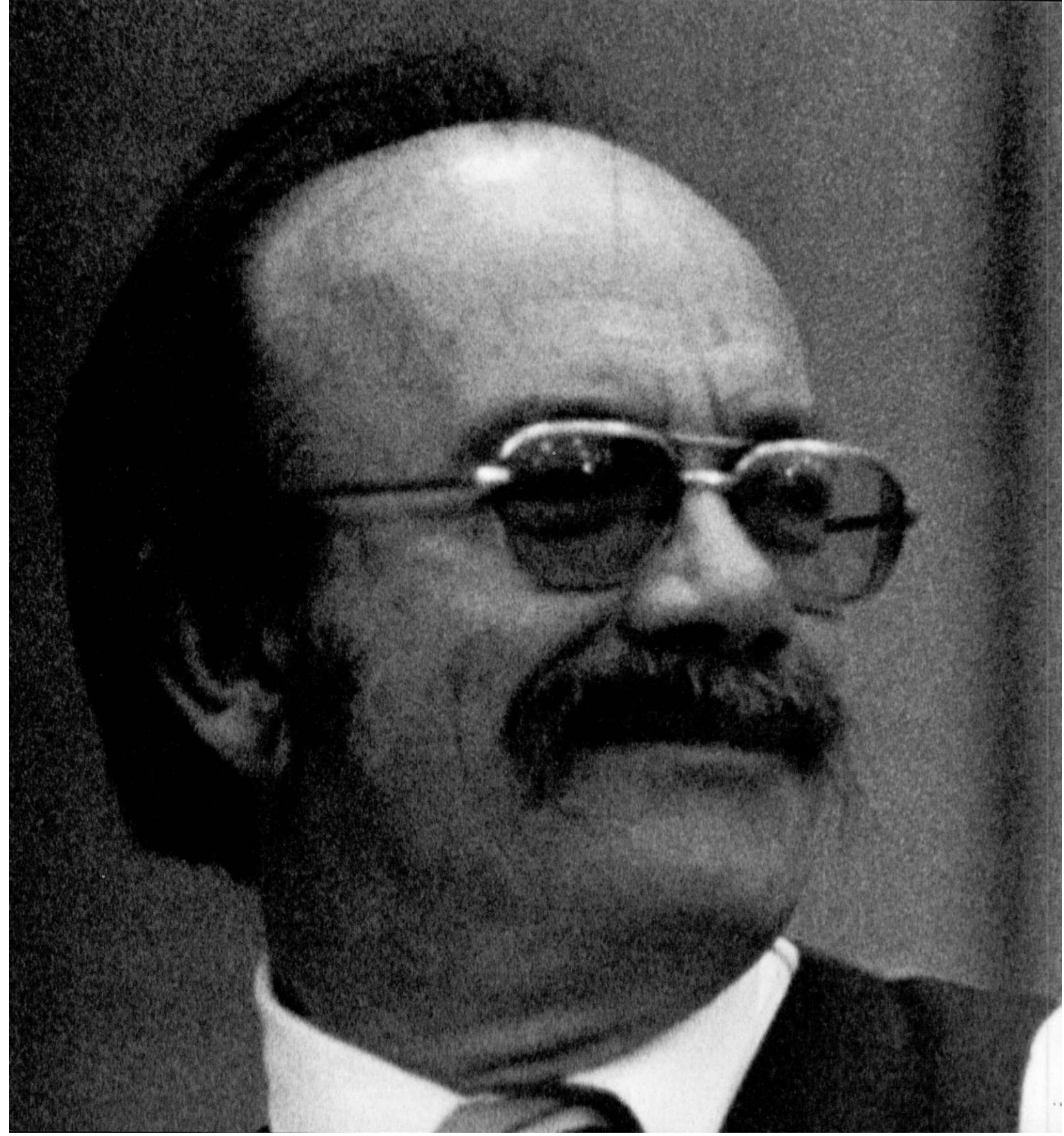
Consumer-worker unity must happen. Such unity will only come from an educational process. To me, this conference has been an educational process. I have never seen a group of consumers, activists and militants all in the same room and have never felt such potential for linkage between consumers and workers.

I hope that consumers will stand with state hospital workers when the struggles over representation and staffing demands occur. I hope that consumer groups will demand appropriate staffing ratios and better working conditions for psychiatric technicians and for all state workers, because otherwise we are all dead. A long time ago, Sitting Bull said that people are like the fingers of a hand. If they are spread out, they can be chopped off, one by one; but if they are joined together, they can make a mighty fist. I think that we have to look at how to build alliances, by conferences like this and by the People First organizations in the state hospitals.

The state is looking at massive layoffs this year in human and health services. It wants to be out of these businesses. We must stand together and demand no cuts in services. We must educate the public to realize that our services are critical to society, not an after-thought or something that can be done away with. We must work in terms of voter education and in terms of making alliances between consumers and human services workers. I don't know how we go about making these alliances. This conference is a start. I promise to find out how our union can plug into things that are important to the community of persons with disabilities and how your community can plug into the trade union movement. I think that the trade unions have a lot to offer you in terms of organizing ability, in terms of what we have done to influence public attitudes, and in terms of influencing public attitudes, and in terms of what we have done in the workplace to make jobs better. I sense that our future is together.







Lessons We Can Learn from Union Organizers

Owen Marron
Human Resource Development
Institute, AFL-CIO

Saul Alinsky once said:

"The major revolution to be won in the near future is the dissipation of man's illusion that his own welfare can be separated from that of all others."

Unfortunately, a lot of people have forgotten Saul Alinsky. Saul Alinsky was probably the greatest community organizer that ever lived. A lot of people are not aware that he recruited and trained a large number of the freedom riders who went down South. They agitated, they raised hell, they conducted sit-ins, and they forced Congress to take a look at the civil rights movement.

The Alinsky quote that I like is this one: "People don't get opportunities, or freedom, or equality, or dignity, as an act of charity. You need organization to make the other side deliver." Don't ever forget that. That is the only thing people in power understand: organization. People in power will never willingly cede power. You have to take power. It is like that in collective bargaining: we have had union meeting after union meeting where you hear a rank and filer get up and say, "I don't understand

"One of the ways that the establishment maintains power is to convince people that they are different and therefore do not have similarities with other oppressed minorities."

why the company won't give us this because it is only reasonable." My response is invariably, "You do not want anything the company gives you because anything the company gives you it can take away. The only thing that you want is what you take, because once you take something, you don't have to give it back unless you want to."

You are the last group to begin formally organizing, and you are the minority that is perhaps most oppressed and suppressed. There have been many groups prior to you. Working men and women have been oppressed since the beginning of time. If you read history—not the history taught in schools, unfortunately, because they don't like to teach real history—the first revolution in history was led by Spartacus in 79 B.C. It was ruthlessly suppressed. The whole history of mankind is replete with the struggles of working men and women.

You have got to understand that you are not unique. The only thing that is unique about you is that it's happening to you right now. It has happened to the

"What you are doing here by having people with different types of disabilities is emphasizing your similarities, and that is what you have to do, emphasize your similarities. Take those similarities and develop coalitions with other civil rights groups and with unions."

blacks; they have been exploited for two hundred years. It has happened to other minorities. You have got to understand that you are only unique in where you are at this particular point in time. You don't have to reinvent the wheel. Call upon the assistance of other civil rights groups and organized labor. We are more than willing; most of us are anxious.

In 1932 organized labor was at rock bottom. There were less than three million people who belonged to unions. Because of the red scares after the First World War and the depression, everybody thought that organized labor and the union movement were dead. In 15 years we built up to 14 million people. Organized labor in the public sector has grown in California during the last 10 years from less than 50 thousand people to almost 500 thousand union members. You can do the same thing. You are taking the first steps. What you are doing here by having people with different types of disabilities is emphasizing your similarities; and that is what you have to do, emphasize your similarities. Take those similarities and develop coalitions with

other civil rights groups and with unions. You don't have to give up your identity; you don't have to give up your goals. Maintain your self-interest. But work with us and we will build a coalition.

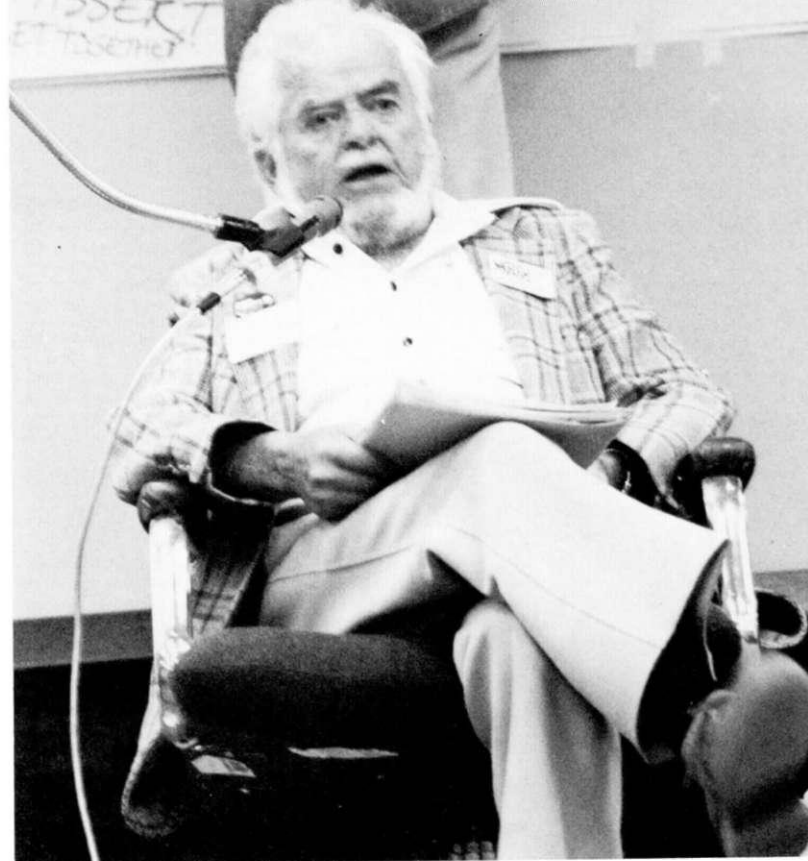
At the 13th national convention last November, the AFL-CIO adopted sweeping resolutions to assist the handicapped, to help them organize, to help them break down architectural barriers, to change attitudinal barriers, and to help you find jobs. That is the way you are going to get power.

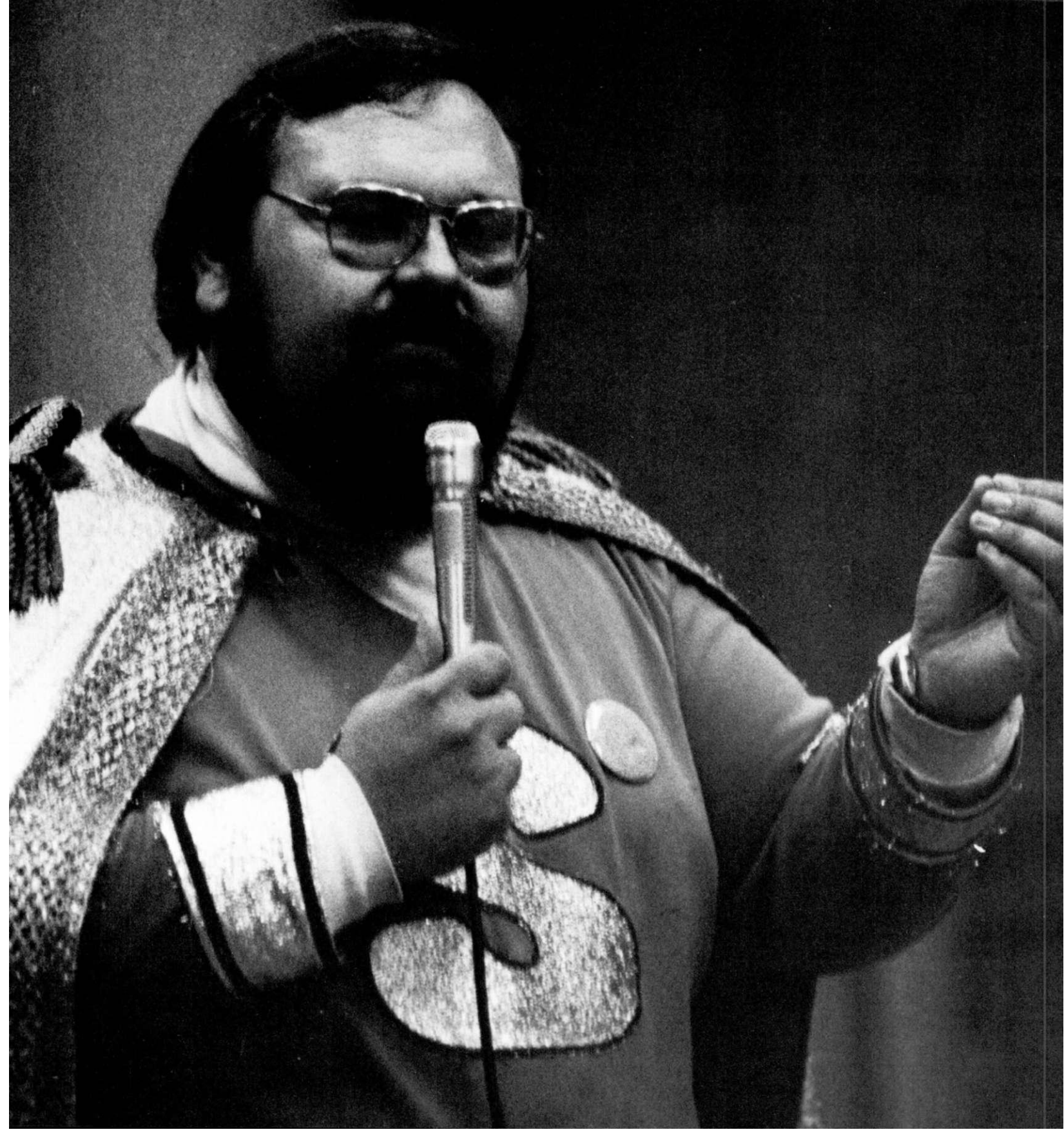
There are so many of you. You've got to organize. Please allow me to make a couple of practical suggestions. First, don't let this be a one-shot affair. Keep this organizing spirit going. Second, get involved at your local political level. Third, build bridges and linkages with community rights groups, civil rights groups, and organized labor. We would be more than willing to help. Fourth, take control of your own destiny.

You people know what your problems are; you've got to exert yourselves. You have got to build coalitions—that is the most important thing. You've got to understand that you are not alone. One of the ways that the establishment maintains power is to convince people that they are different, and therefore they do not have similarities with other oppressed minorities. Take a look at all the other minorities: they are all suppressed. You have got to band together. In today's society, with shrinking financial wherewithal, the government speaks of reordering priorities. We all know what Washing-

ton means when they talk about balancing the budget—they're going to cut out human services so they can build another aircraft carrier. And the only way you are going to convince government officials to do otherwise is to vote some of those turkeys out of office, and the only way that is done is through hard work. It takes a lot of hard work, a lot of effort, and a lot of risk. I celebrate the opportunity to support your endeavors.







Evening Festival of the Arts

At the heart of our movement lives a core of creative energy, liquid with heat and turbulence. Streams of the profound urge erupt to the surface as more and more people grow self-conscious and extend the community of concern. This growth in the quantity of people who are gripped by a vision of a new beauty among us generates a qualitative change in our human rights movement. Simply speaking or writing about justice, integrity, discovery, no longer can contain this growing imaginal energy. The normal relations of everyday waiting or partly learning or hardly working or barely touching each other... the experience of underdevelopment and oppression that we live with becomes the storehouse of memory and experience that fuel the eruption of art among us.

It is to rise above the monotony, the daily hopeless, the finite, the aloneness, the repetition, the struggle that the jets of poetry, theater, song, image, and dream arise.

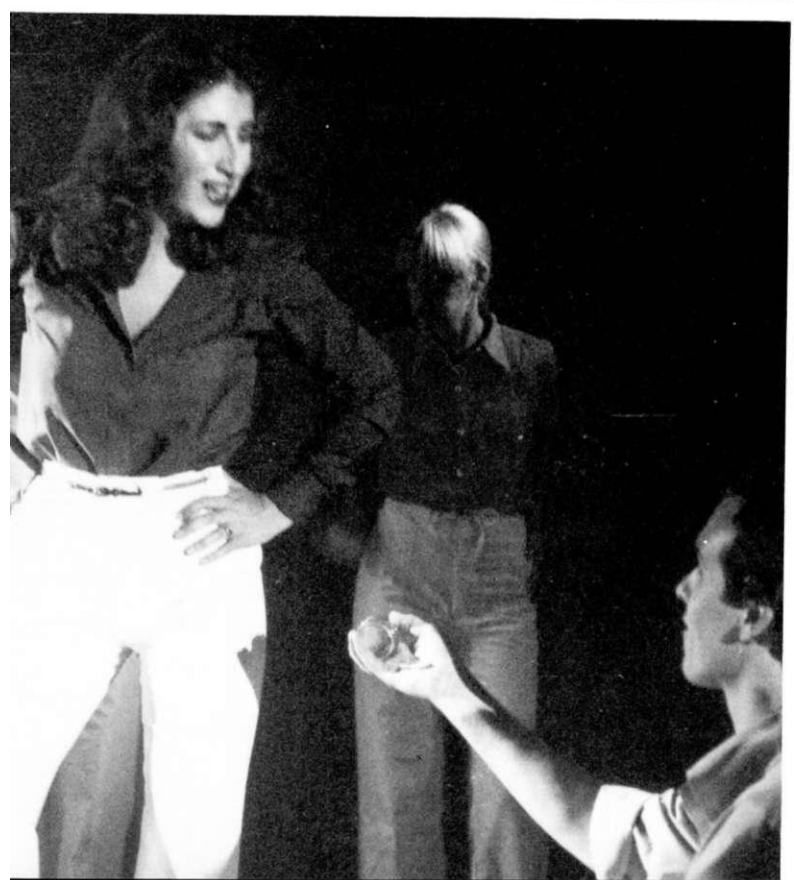
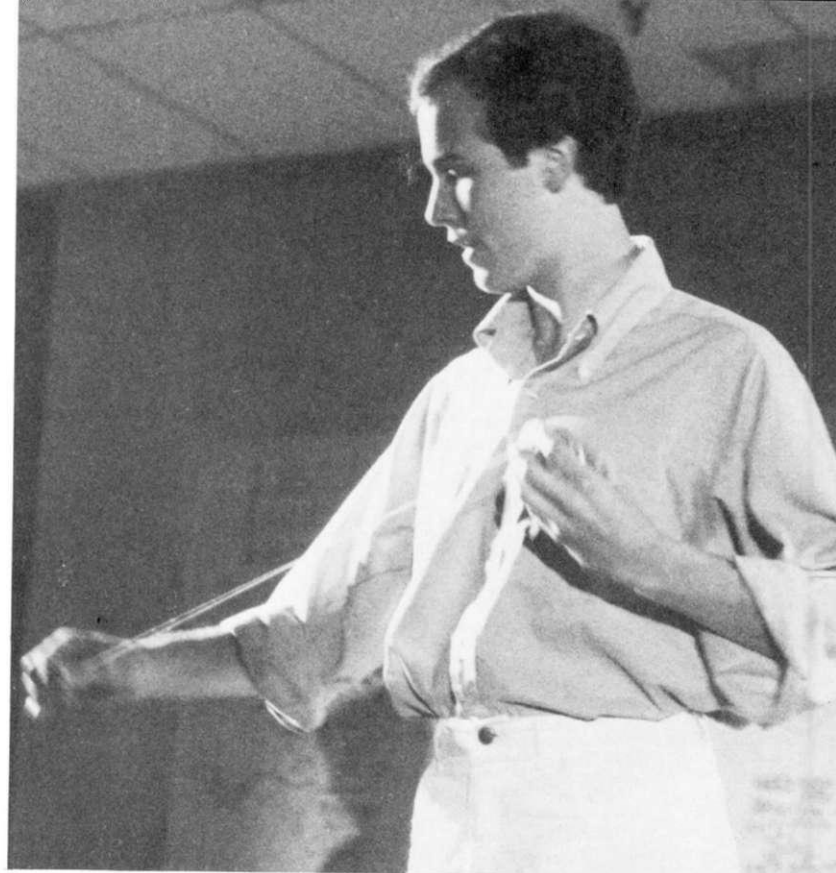
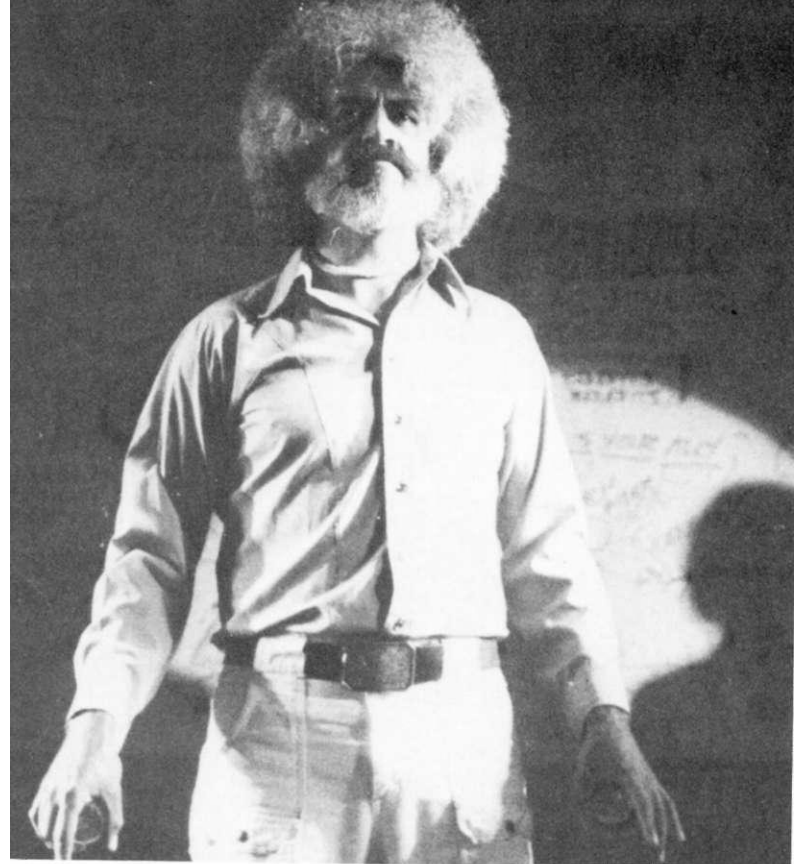
At a gathering of so many people with all possible learning and physical differences; at a gathering where we join together to see and grasp our destiny, the presence of the arts is as vital as oxygen. For an evening, between the piston pressure of the political days, the reminder and expression of beauty, love, humor, and theater flowed out and around and into us all.

The new musical YO YO's, by Joe Parente, about a young man who couldn't join up with the world because he was a yo-yo failure . . .

Then the poetry and music of Danny O'Keefe . . . then the magical songs of Danny Deardorff from his wheelchair through the strings of his mandolin, that were plush carpets through the spaces of tenderness, yearning, awakening, and feeling ... it was more that wonderful night—laughter, sensuality, pride. . .

It fused us into a new resource of good will, confidence and purpose.

We must have art. For without it, we will never see ourselves as we really are and never see what we must ultimately become.



He's A Sleeper

Music & Lyrics by Joseph Parente

From



*He's a sleeper, what can you say?
He's a sleeper, he wants it that way!*

*I don't think so, I think he tries,
He's not lying, look at those eyes.*

*We're just trying to help you,
We all know how you are,
I'll take all my time with you!
But your heart and head aren't
In it so far!*

*He's a sleeper, that much we knew,
He's a sleeper, what do we do?*

*We're just trying to help you.
You must do something, too.
Can't do everything for you!
Are you listening to me?
I'm talking to you!*

*He's a sleeper, we're wasting our time!
He's a sleeper, this is a crime!*

Please, be patient, he'll get it soon,

*Yeah! When hell freezes over and
We get a blue moon!*

*You know it is essential
For you to do your best.
You must reach your potential,
Put to the test,
You're not like the rest!*

*He's a sleeper. I wish I knew,
Something better, that I can do!*

*You see he's in fear,
He thinks they're attacks,
I know he'll get it,
When you all just relax!*

*We're just trying to help
Poor Duncan!
We all want you to learn
Poor Duncan!
We don't mean to be mean
Poor Duncan!
But you'll have to shape up,
To join our team!*

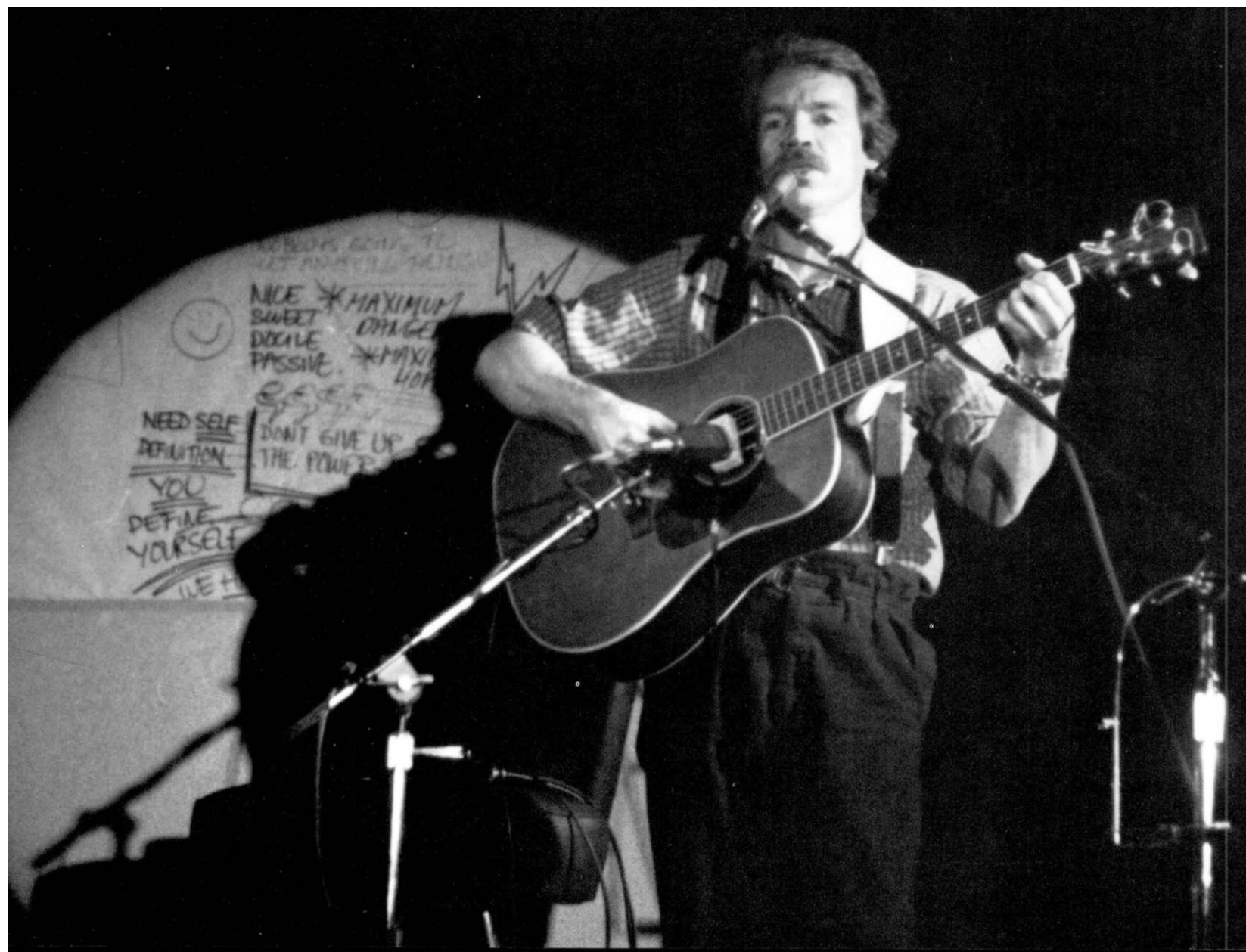
*He's a sleeper, I told you he was,
He's a sleeper, he can't make it 'cause,
A sleeper's all he'll ever be,
He's a sleeper, why can't you see?*

*We have nothing against you
Poor Duncan!
We know it isn't your fault
Poor Duncan!
It's not like you're one of those fools!
But you can't do it right,
And those are the rules!*

*He's a sleeper, we're sorry to say,
Perhaps the best thing is for him to pray,
He's a sleeper, he can't make the grade,
Even with our invaluable aid!*

*He's a sleeper, he's a sleeper,
Tell you what you have to do,
Don't call us—We'll call you.*

©Joseph Parente 1980



On Discovering a Missing Person

Lyrics Sung by Danny O'Keefe

*Long hair on my pillow
Lipstick on my shirt,
A woman's picture on the wall
Of a memory that still hurts;
It stabs just like a knife
That's been dull from over-use.
I can faintly hear her laughter.
And the tone of her abuse.
It always brings you down,
To the same place in the end,
A woman leads you to the edge.
And you fall in love again.*

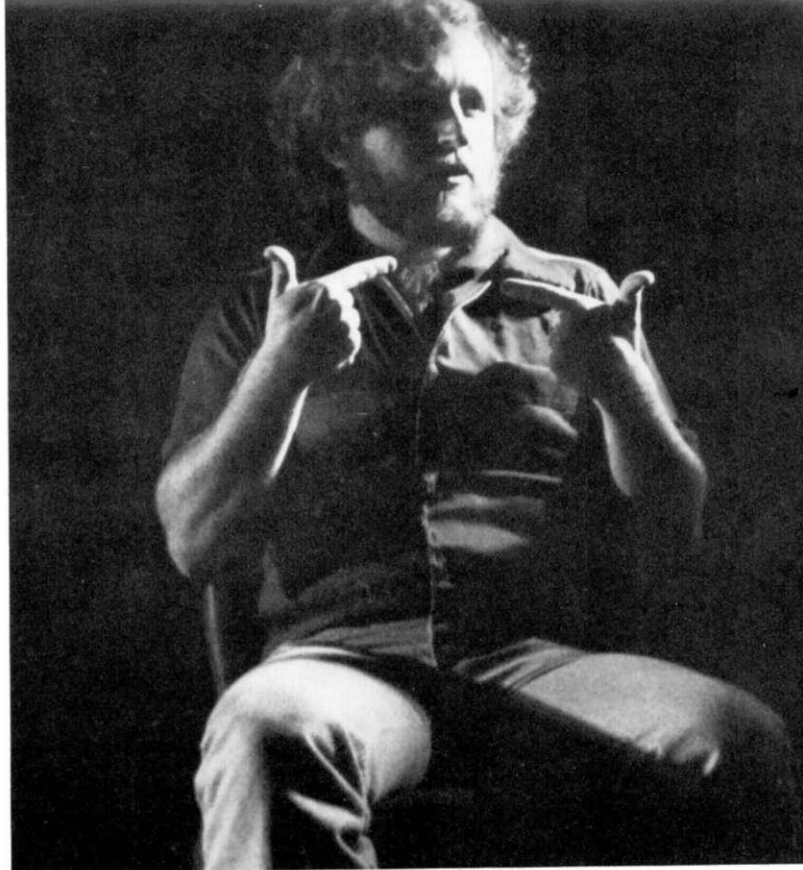
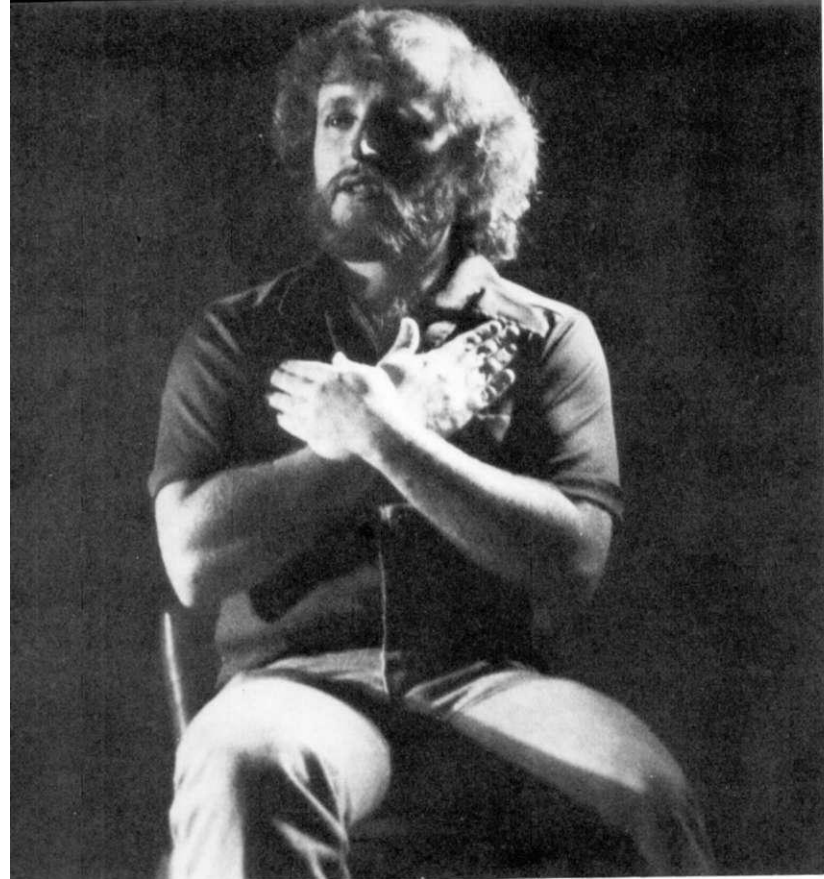
*I thought I was her partner.
When I heard the song begin,
I said, "This dance is taken,"
When someone cut in.
I know I'm not much different
From any other man.
We all believe in something
We cannot understand:
Always bring you down to the
Same place in the end.
A woman leads you to the edge
And you fall in love again.*

*Jealousy is a heavy price to pay,
But damn the cost.
Sometimes you don't know what
You found until you lost.
I don't know what it comes to
I don't expect I ever will,
But the feelings that don't die inside
Are the ones you cannot kill.
They'd always bring you down
To the same place in the end,
A woman leads you to the edge
And you fall in love again.*

*And if I really lost her,
Oh. I'd start the search again,
Longing for love's waters to
Wash me clean again.
Take me to the river,
Oh. I'm ready for the plunge.
There ain't been much water
Lately in my sponge.
It always brings you down
To the same place in the end,
A woman leads you to the edge,
And you fall in love again.*

©Danny O'Keefe 1977







The Little Kings of Earth

Lyrics By Danny Deardorff

*Oh the little kings of earth
Glorify the dust
Like kids in a sandbox
Tomorrow their kingdoms are gone*

*And the lives of little men
Glorify those kings
Placing their whole trust
In something that can't carry on*

*Lift your eyes above illusion
See the reason to your life
See it on the east horizon
The nightingale of paradise*

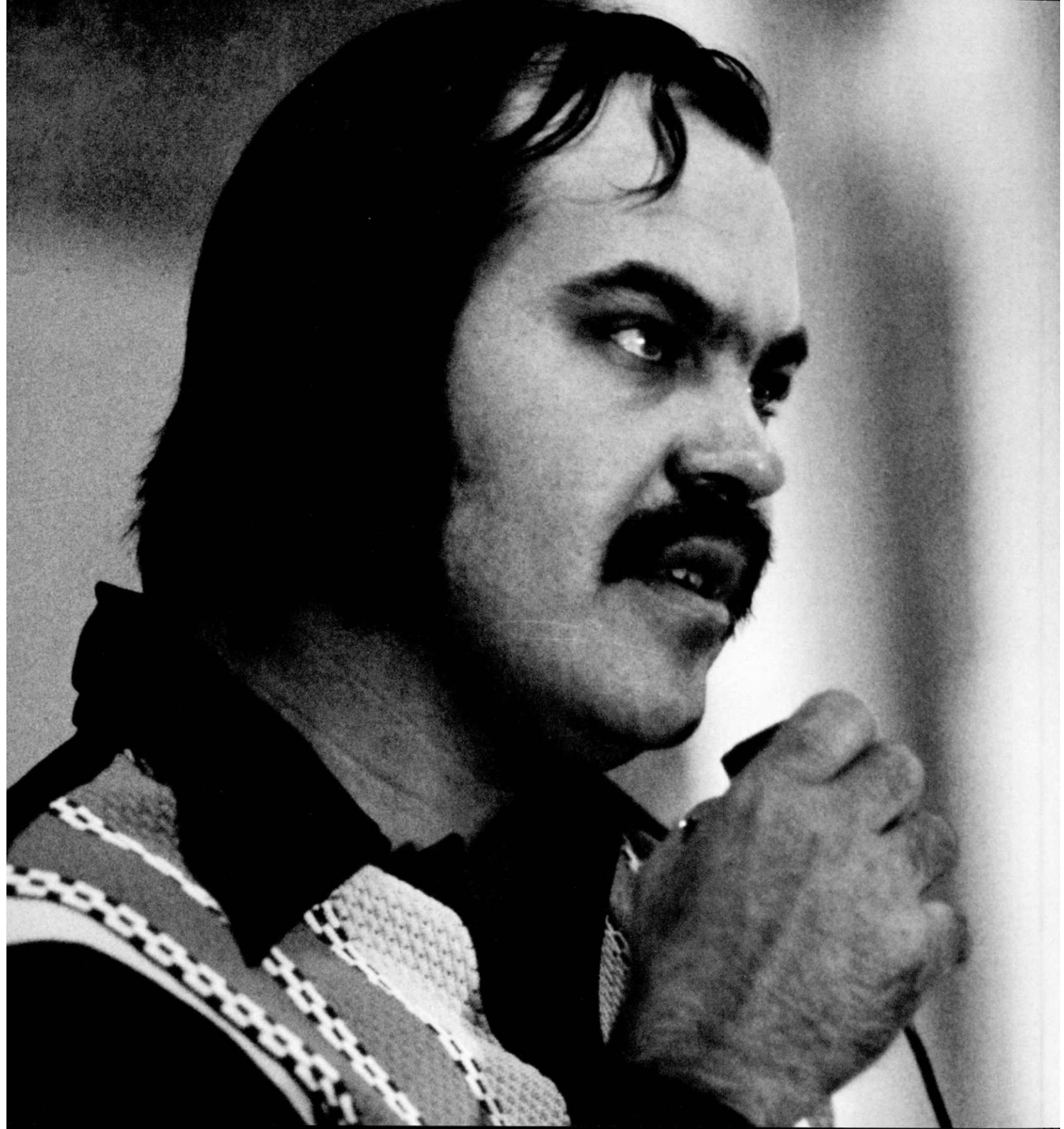
*What's your fancy What's your game
To glorify your name
The dust is your treasure
The things that you're holding on to*

*And though you cling with all your might
It's bound to slip away
You'd better start looking
For something to hold on to you*

*Lift your mind above confusion
Wipe the dust out of your eyes
See it on the east horizon
The nightingale of paradise*

*Lift your eyes above illusion
See the reason to your life
See it on the east horizon
The nightingale of paradise*

©Danny Deardorff 1975



People First: A New Force in the Consumer Movement

Jeff Goedecke
People First of California

My name is Jeff Goedecke. I am a member of People First. I am in front of you today as a person who is as good as you are. No more. No less. Treat me as you would have me treat you. That is the message of People First.

I feel that in the past we have been told what to do and who to be by hospitals, homes, even the news media. We are just beginning to tell people who and what we really are. We are just beginning to speak up for ourselves. That is why I think People First is so important. We know that our movement is struggling for a new beginning. We know that the fight is not over yet, and we know that we need you with us. We want our rights. And, with you by our side, we can work together to achieve those rights. But it will take all of us working together—no matter who we are, what we are able to do, or what our problems may be.

Those of us who are called slow learners or other names know that these names do not say who or what we really are. We do not want to be called "mentally retarded" or "dumb."

"By 1989 there will be a strong, national People First movement of persons with developmental disabilities who will function as an able and worthy part of the disabled community."

We want to be known for what we are doing. *We are standing up for our rights*, and for the rights of those who are more severely handicapped than ourselves. We feel that we can speak for them better than anyone else because we share a common label and a common experience.

People First is a movement made up of developmentally disabled people. We believe that all of us working together can and will change the way other people see and think of us.

Now, I would like to tell you what we have accomplished. We are seeing things happen. We have a head office located in San Jose. Locally we have chapters from Eureka to Los Angeles. We also have chapters in several states across the country. We give talks and speeches in order to start local People First groups. We have seen our members hired for serious jobs, and seated on boards of directors. We are seeing things grow. We are reaching out to our brothers and sisters and helping them to see themselves as strong and beautiful people.

"We need the one truly basic right that is granted to everyone: the right to be ourselves. Once we have fulfilled that need, then we can go on and talk about the other needs we have."

We are beginning to look people in the eye and tell them what we feel. Every day new people like yourselves are meeting with us and hearing our words.

People First gives us the knowledge that we are someone. *We are someone!* I can think of no better reason for self-advocacy than to teach our brothers and sisters that we are someone. We are people with *needs*. People with *rights*. We belong to an active part of this country. I believe in what we are doing. I believe in speaking out not only for ourselves, but for those who cannot speak.

We are no longer trapped by a society that would just as soon forget us. *We have a voice, a strong voice, one that we will continue to use long after the old ways of thinking about us have faded away.* As long as there are developmentally disabled people, there will be People First. We will continue to advocate for the rights of the developmentally disabled, and we will continue to make the politicians aware of our needs.

I have mentioned needs several times now and unless you are a handicapped individual I do not think you understand the basic needs we have. First and foremost we need people to be aware of what we represent, and we need people to be aware of *us*. We need the self-awareness that we are a part of this country. We need the one truly basic right that is granted to everyone: the right to be ourselves. Once we have fulfilled those needs, then we can go on and talk about the other needs we have.

In the past we were trapped in a box. One wall was our parents who did not know what to do with someone who was really different. One wall was employers who saw us only as janitors or workers in sheltered workshops. One wall was the board and care homes and institutions who saw us only as a source of income, and the teachers who saw us as special and different, people who should be hidden away. And one wall—one *wall was ourselves!* Yes, us! We were trapped by the way we saw ourselves.

Look at the person sitting next to you. Go on, say hello. Ask their name. Go ahead. We have time. That person is strong. *You are* strong. That person is beautiful. *You are* beautiful. This box is our trap. We need to break loose. What will it take? It will take parent education, so that our parents learn that we are people. It will take real jobs for real pay. It will take classes from grade school to junior college for slow learners and other disabled people, just like everyone else. And... we need to know ourselves.

I was asked to talk to you today about the 1980s, and what it will mean for us. We are now caught up in a flood of social changes and promise. But for all of us the tide started coming in during the 1970s: the Civil Rights Act of 1973, the Education Act, the 504 sit-ins, the beginning of People First in Oregon. And this tide started a wave, a tall, strong wave. We are now at the top of this wave and we are sweeping into the 1980s.

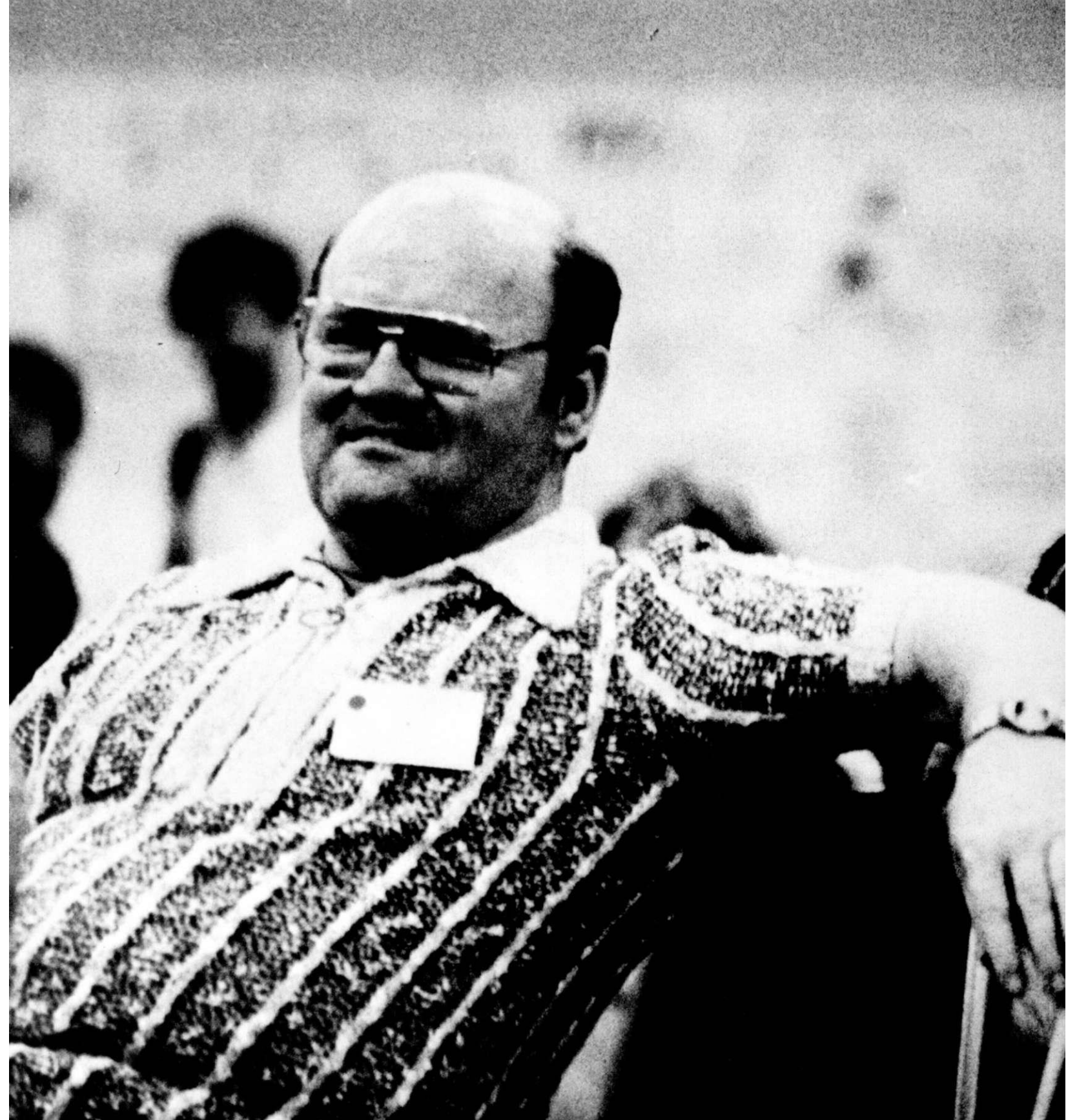
This wave will sweep away all of the outdated ideas of the 1970s. No longer will there be good handicaps and bad handicaps. No longer will there be little groups fighting each other for dollars. No longer will we allow ourselves to be seen as anything less than human.

I will not talk to you today about *needs*.
I will talk to you about *deeds!*

By 1989 there will be strong, national People First movement of persons with developmental disabilities who will function as an able and worthy part of the disabled community. There will be a strong, national coalition of disabilities so that our message will be heard and felt by every person in this country.

Look at the person sitting next to you. Look at your brothers and sisters. It is 1980, and the wave is breaking across the land!







Confronting Government Indifference

Judy Heumann
Center for Independent Living

I feel that Jeff Goedecke's speech was really exhilarating for me because he comes with a very positive perspective on what has happened during the past ten years and what needs to happen during the next ten years. People First, as far as I am concerned, is definitely one of the most liberating, exhilarating, and important organizations that has ever hit the United States. It is self-representation by a group of people that society as a whole, including most disabled groups, has basically put to the side and disregarded. The inclusion of people labeled "mentally retarded" and "developmentally disabled" into our movement helps bring our movement into proper perspective. There is nothing more important to me than disabled people speaking for ourselves.

In the last six months I have been confronted with the fact that the political structure in this country is not developing ways to meet the needs of people. While our major concern today is disabled people, we must recognize that our government is not developing ways to meet the needs of any of its disenfranchised people: the poor, elderly, disabled, dependent

"We are going to speak up for what we know is right and that means more money in social services, less money in the military budget, not tomorrow but today."

youngsters, etc. Over the last six months we have seen a number of instances wherein the President and the Congress are starting to talk about the need to take money away from social services in order to build the military budget. People who talk out against increases in the military budget are viewed as non-patriotic and anti-American. I personally maintain that talking about the need to provide human services in our country is not unpatriotic, but instead is very patriotic. It is about time that Americans started looking at the fact that we have no control over the majority of our money that get spent at the federal level. When Proposition 13 and Proposition 9 come, we scramble because money is being taken away from us. We also need to take a close look at the federal government because it is trying to take even more money away from us. There is less money for human services than we need, yet the Carter administration is proposing a reduction of \$16 billion in social services and an increase in military spending.

These issues have been very difficult for me to deal with personally. I have wanted to talk about the disabled

"And if we really begin to look at what's going on over the last year with the media, we certainly see that a lot of victories we have made are beginning to be torn apart."

movement as an isolated phenomenon. I have not wanted to get involved in talking about political structure, who controls the money, and where the money is going. The latter issues are rather overwhelming, to say the least. I don't know how much political influence I have over the fact that Mobil Oil, Texaco, Shell, etc., are earning more and more money. I feel guilty when I hear them say: "Well, we're taking your money and putting it back into making life better for you." Well, I don't know; maybe they are and maybe they're not. All I see is that my gas bill is going up. I have to use a personal van because I can't use public transportation. The head of the Muni system in San Francisco has stated that I no longer have a right to use public transportation, but no one is giving me an increase in support to pay a personal driver, maintain a personal vehicle in working order, or pay skyrocketing fuel prices.

The facts show that most of our federal government's money is already going to build guns and boats and things I really could care less about. I knew when I was in high school that the United States and Russia could kill each other a hundred times over. I

don't even want to die once, let alone know that I can die a hundred times. And we keep putting more and more money into building weapons. I want to see my brothers and sisters in this room, in institutions, and in family homes start to get some money. It is important for all disabled people, not just the leaders, to begin recognizing that when we talk about voting, when we talk about registering people to vote, we have to stop talking about registering people to vote on isolated issues. We may register people right now to vote against Proposition 9, but we must also begin to help people understand the effects of political decisions on people with special needs. We must begin to really analyze the societal perspectives of President Carter, Senator Kennedy, Ronald Reagan, and whoever else is running for office. We must stop asking them questions solely about disabilities because if we only ask questions about disabilities we won't get anywhere. They can't answer questions about disability because they don't know who we are. Let's ask them questions about where they want to spend money, on the military budget or on people. Because if they're talking about increases for the military you know they cannot be talking about increases for us.

I have been a proponent of utilizing the media, because I have been under the illusion that the media are effectively representing the people of this country. When I look at the fact that the *Chronicle* and the *Examiner* are owned by the same people and that there is also a television station owned by the same people, I begin to really question how much freedom of press really exists. If the *Examiner* decides to take a position against disability, do you

really think that the *Chronicle* is going to come out and take a position for disability? And that Channel 4 is going to take a position for disability? I really don't think so. If we really begin to look at what is on the media, we see that a lot of the victories we have made are beginning to be torn apart. For example, the *New York Times* is considered to be one of the most liberal, progressive newspapers in this country. Well, they are not liberally representing persons with disabilities. They do not have disabled people participating on their editorial board; they do not have many disabled people employed on their writing staff; but they are very liberally writing that we are asking for too much. They are maintaining that the New York City Schools should not have to ensure that all disabled children are educated in the least restrictive environment and that it is too expensive to integrate transportation systems.

There was a study that came out in the last six or eight months from the Congressional Budget Office regarding transportation for disabled individuals. The conclusion of this intellectual study was that it would be better for all disabled people who need accessible transportation to be given a car rather than integrate public transportation. This study, in all its wisdom, never talked about basic things like who is going to drive my car, who is going to pay for my gas, and who is going to keep my car running.

I guess my feeling is that disabled individuals have to really start analyzing the overall system. We can no longer call ourselves responsible and only look at our personal situations. We have a responsibility for ourselves

and we have a responsibility to all our brothers and sisters. Moreover, we have a responsibility to the communities that we live in to exercise our right to vote, to exercise it wisely, and to let politicians know that we are no longer going to vote for them just because they are a Democrat or a Republican or a conservative or an independent. We must demand to know their overall positions. We want to know if they support independent living, support assuring the least restrictive environment in school, support accessible transportation, support people being moved out of institutions into appropriate community services, and support full employment. We know all the things that need to be done in our communities to integrate people with disabilities: we need ramps, attendants, mobility instructors, interpreters, teachers. We do not need teachers being laid off; we need more teachers placed in classrooms. We don't need classes for 36 kids; we need classes of 15, not just for disabled people but for disabled people and non-disabled people alike. Education, housing, and people being fed have to be priorities in this country.

Those of us in this room are politically conscious or we wouldn't be here. We must begin to take broad social positions which benefit all people. We must no longer allow ourselves to be discounted and we must no longer discount ourselves. We must recognize that our gains are society's gains and vice versa. We must speak up for what we know is right and that means more money in human services and less money in the military budget, not tomorrow but today! Thank you.



What Are Their Positions?
Do They Support Us?





Menaces and Opportunities Which Loom in the 1980s

Tom Bates
California State Assembly

"It is not enough to beat tax cut propositions. What we need to do is start marching towards a program which recognizes that our society needs changing."

Judy Heumann really put her finger on it. It is time for us to look at what is going on in our economy. We've got to start looking at inflation, we've got to start addressing ourselves to cartels and multi-national corporations, because in my judgment this country is becoming nothing more than a marketplace for the multi-national corporations. They are going to screw us just as they have screwed the rest of the world. We are just beginning to see that right now.

Proposition 13 (the Jarvis-Gann Initiative) passed in California for a number of reasons. The most important reason that Proposition 13 passed was that people were living on margins. They felt pressed, and angry about what was going on around them. All you have to do is go to the market, to the gasoline station, to rent an apartment, to pay your electric or gas bill, and you realize why people believe that things are out of control.

The average individual is frustrated. Look at the pollution due to nuclear power around the world. We are poisoning the water and we are poisoning the air. What can the

average person do about it? Then along comes Howard Jarvis who says, "Politicians cannot solve the problems because they are the problem. All we need to do is send them a message, and they will understand that message and change." Well, that is just not the way it works. There is no question that property tax is an unfair tax. Progressive politicians have been talking about property tax reform for 15 years. The value of property goes up as inflation goes up and not as people's income rises. That is not a fair tax; it has never been a fair tax, and we should have gotten away from it a long time ago. The legislature failed. And I am part of that failure. The legislature failed to pass Senator Petris's bill which would have allowed us to do away with property tax. We would have changed to a fairer way of taxing. But we could not pass Senator Petris's bill. Along comes Jarvis, who says, it's time to cut property tax in half. People are being moved out of their homes and it is an unfair tax. People were on the margin, as they are today. People were angry and frustrated. A real movement emerged. People volunteered in great numbers to pass an initiative, and they succeeded. This is not the case with

Proposition 9. Proposition 9 is a totally manufactured movement. It cost Howard Jarvis over \$2 million to qualify Proposition 9. Proposition 9 does not have the gut-level support that Proposition 13 had.

Look at what happened when Proposition 13 passed. We worried that it was going to be a meat axe. Well, that is exactly what it was. We laid off people around the state. Human services were reduced. In my home area, police were cut back, fire protection was cut back, adult education was cancelled, public schools were cancelled in the summer, and 138 teachers were laid off. Today if you live in Oakland, it takes five days for a police officer to come to your door to check out a burglary.

Those of us who were opposed to Proposition 13 said, "What is going to occur is that the cuts are going to be unfair." Well, that is exactly what happened. The people who made the cuts, except one person I know, never put their names on the cutback lists. Services were cut back to people, but bureaucracy was not shrunk. Cuts in administration and in a lot of the waste that people were so angry about never

occurred. They never really got to where the problems were. Additionally, Proposition 13 transferred vast control to the state. State legislators now decide whether you have libraries, street improvements, etc., and that is wrong. These decisions should be made at the local level. The State of California will attach strings to the money it gives local governments. You watch!

I personally believe that we need to organize at the local level. I believe, with the conservatives, that we should allow local government control and responsibility, but I don't see it happening. I see the state legislature thinking that it knows what is best, and putting strings on funds to local governments. I will fight it, but I'm sure that power will transfer from local to state government.

Now let me explain Proposition 9 to you. It is a total fraud on the people and thankfully many people understand that. The Field Polls show that a couple of months ago 54 percent of people were in favor of Proposition 9. Fifty-four percent! Out of that 54 percent, 50 percent did not know anything about the issues involved. They were simply in favor of cutting their taxes in half. How could you be opposed to cutting your taxes in half? Now we have done some education and people are starting to recognize the facts. You may have seen the latest Field Poll. It shows that when people started hearing the arguments against Proposition 9, support for the referendum dropped dramatically. It turned around in two months.

We should start emphasizing the human element. We should start identifying ways to provide holistic health care on a long term basis, rather than crisis-oriented health care. We need to build new housing and to give renters a fair shake in our society. Renters didn't get any help from Proposition 13, and they are not going to get any help from Proposition 9. Eighty-six percent of people who rent, or about 40 percent of the population, will never own their own home. We are dividing ourselves on a class basis.

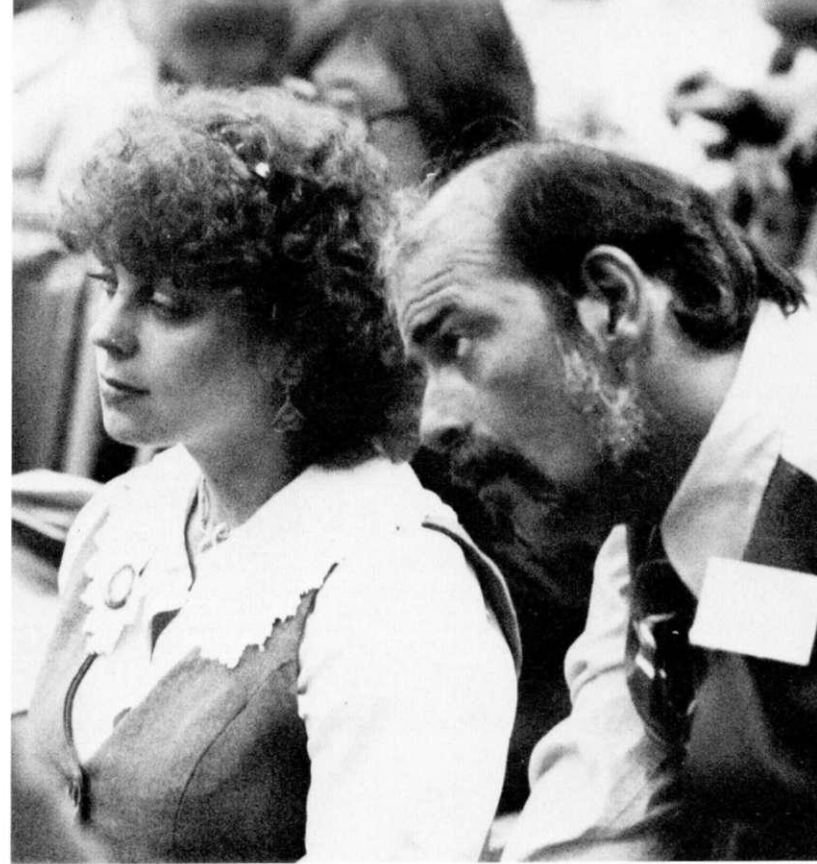
We need leadership in state government. There is absolutely no reason whatsoever that the State of California cannot be energy self-sufficient in five to seven years if we decide to do so. We have solar power and we have wind. We can entertain a program of conservation that will eliminate our need to import oil into this state. We have more oil in California, under the ground in the San Joaquin Valley, than they do in Alaska. We can be energy self-sufficient. We don't even need the foreign multi-nationals. We don't need oil from the Middle East. What we need is a goal and a program, a direction to move toward.

There is no reason why we should not embark upon a health delivery system in this society which is geared to prevention, which gets away from fees for service, which tries to deal with people in a holistic way, and not just during crises. The problem is not that we don't know how to do it—the problem is having the political will to do it, to fight the campaign, to fight the facilities.

We need to get people out of state institutions and into independent living. There is no reason whatsoever in the health care area and in mental health why the legislature cannot support planned personalization and decentralization. All you have to do is look at today's paper or watch last night's television to recognize that we have a crisis in mental health right now. People are being thrown into mental hospitals, spend about eight days and are then dumped back into the community without any follow-up, without any ability to deal with their transportation, housing, and employment problems.

There is no reason why the State of California cannot be a leader. We can establish a sound program. I have a measure up right now asking for a budget augmentation of \$110 million to assist the mentally ill. These monies would allow us to develop a balanced system over the next three years. I believe strongly in the commitment of the Center for Independent Living to get people out of state hospitals. I believe we can do it. I know we can do it. It isn't a question of whether we can—it's a question of priorities, and it is time to make quality community living for disabled people a priority. Please consider me an ally in your struggle for independence. Thank you.







Assuring a Decade of Deliverance

Alan Bergman
San Francisco Aid
Retarded Citizens

"Progress is a product of struggle; it has been a struggle, and I don't believe any of us thinks that struggle is going to end today or tomorrow. If you do, you are terribly mistaken."

I have been involved with the disability movement for approximately 16 years and in that time I have been involved with the people who are blind, people called the mentally ill, people with cerebral palsy and other physical disabilities, people labelled learning disabled, and those called mentally retarded. I have noticed a lot of common threads.

Before prognosticating about the eighties, I should like to begin by looking back at the seventies. It appears to me that the seventies gave us significant paper victories; that is, executive orders, legislative advances, and court wins. These victories were earned, very painfully in many cases, by consumers, parents, voluntary organizations, workers, professional organizations, and others—sometimes alone, sometimes together, and sometimes even working in opposition to one another. We now have clear, supportive written words. So, as I see it, the eighties offer potential for being the decade of implementation, or, if you will, the *decade of deliverance*. But for that to occur, we have to maintain our growth and our progress, increase our togetherness, and keep our objectives

in focus. Progress is a product of struggle; it has been a struggle, and I don't believe any of us thinks that struggle is going to end today or tomorrow. If you do, you are terribly mistaken. It is here and it is getting worse.

Cecil Williams did a marvelous job of emphasizing the importance of struggle. From my experience there are two critical factors associated with mounting power to win struggles: one, information is power; two, we as people, individually and collectively, have power.

It is very difficult to succeed in a struggle without good, widely shared information. You have to know what you are doing and what you are up against. We have increased our expectations tremendously but we have not experienced concurrent growth in our ability to communicate the social value of our increased expectations. There are some people who now say that our expectations are wrong, that they are too high, that they are too costly. The law, however, clearly guarantees equal opportunity. We are not talking about equal budgets. There is no doubt that in the

short run, at least, quality special education for people with disabilities will cost more than quality education for so-called typical or normal youngsters. But the law does not say equal dollars for education. What it says is equal educational opportunity in the most appropriate, least restrictive environment. We must educate the general public regarding both what our laws say and what benefits accrue to society by following these laws.

Unfortunately the paper victories of the 1970s have created an opportunity for many of us to sit back and become apathetic. Some think it is all done. This sense of apathy is a real problem, as I see it, particularly for the voluntary parent associations. Many of the parents who have been engaged in the disability civil rights struggle for 30 years, since the 1950s, are very tired. They think that it is time for somebody else to move in and help out, and that the next generation of parents is taking human services for granted. Here it is: PL 94-142, Section 504, AB 3274, AB 204, whatever, on a silver platter. But these victories did not occur due to the goodwill of Congress, the state legislature, or a court. They came from damn

hard work, persistent hard work.

That which constitutes an opportunity, and that which constitutes a menace in the future, is probably colored by our own perceptions. You may recall the story about the psychological experiment that dealt with optimism and pessimism. A psychologist took a youngster who was considered a pessimist and put him in a room full of brand new toys. The child said, "I'm afraid I will break them." He sat and looked at all the toys but never played. Then there was the youngster who was an optimist. The psychologist put him in a room filled with horse manure. The youngster immediately went in and started shovelling like crazy. The psychologist came in and interrupted him, saying "Child, what are you doing?" The child responded, "With all this horse manure there's got to be a pony under here someplace."

As we look at the eighties, there is great cause for pessimism and for optimism. It is all a matter of how we look at things.

One issue warrants special consideration. It appears to me that we have a potential menace in our internal structure, namely the labels we use, e.g., consumer, parent, worker, bureaucrat, legislator. Each one of these terms conjures up stereotypes which may be wrong. You just heard Tom Bates. He does not fit my stereotype of a legislator, but he is one. He is working damn hard for a lot of things which benefit the disabled movement and society. Mario Obledo was here yesterday and expressed an invitation to learn. He wants to learn more about our needs and aspirations. He feels he needs to learn more to do a better job. His attitude does not fit my stereotype of a

bureaucrat. I think we need to be careful of the categories that we apply to people. They don't necessarily tell us anything about the person. Personal understanding comes only from communication and getting to know one another better. I hate to use the terms good and bad, but I think if we looked around, there are good and bad legislators, good and bad bureaucrats, good and bad parents, good and bad human service workers, and good and bad consumers; bad in the sense that they are people who are not committed, who don't understand the issues, or who are resistant to change.

We have to improve our training, our organizing efforts, our leadership development activities; and more than anything else, in the long run, we must have better planning. Planning is probably the thing that we are worst at. One of the biggest wars in the developmental services field has to do with the issue of community services versus state hospital services. If this state could agree that by 1985 or 1986, or whatever year is deemed appropriate, every individual with special developmental needs would have those needs met in his or her home community, in the most appropriate, least intrusive, least restrictive way, and then we went about implementing a year by year strategy to reach this goal, we could unite people and liberate persons with disabilities. But instead we deal with six month or twelve month intervals, and we create divisiveness. We are probably our own worst enemy. We need to plan on a long range basis with clear, specific interim steps. In the case of altering state hospital utilization, we are talking about thousands of human beings and about reallocating hundreds of millions of dollars. You don't achieve such changes overnight, as much as

you and I would like to believe it can be done. I have learned the hard way that system change takes longer than one thinks it is ever going to take.

We are very good at lobbying support for initiatives advanced by Tom Bates, Milton Marks, and other progressive legislators. But the menace of the taxpayer revolt, especially via referendum, is a new ball game for us. Propositions 13 and 9 are based on voter power, not legislative and lobbying influence. Now, more than ever before, we have to get out and communicate our issues to the general public.

The taxpayer revolt is having some interesting fallout that are just coming out in the media. I learned this last week that because of reductions in mosquito extermination programs due to Proposition 13, the Health Services Department is predicting an epidemic of encephalitis in certain valley communities. As most of us in this room know, encephalitis can be a major cause of disability. We have a stake in communicating this issue to the public.

Let me tell you about Mr. Jarvis a little bit, and I would suggest everybody pick up the May issue of *New West* magazine, and the May issue of *San Francisco Magazine*. I am pleased that the media have found out that Mr. Jarvis is a demagogue and a menace. To paraphrase a quote by Mr. Jarvis, he is looking forward to the destruction of libraries, public schools, and social services, and the rapid dismantling of state and local government so that this country can return to a state of laissez-faire social Darwinism. Now for those of you who don't remember your history, Mr. Darwin described survival of

the fittest. There was another gentleman in the past, named Hitler, who used this as a methodology. If we allow people to draw artificial lines about who are the haves and the have-nots, who gets and who doesn't, who is appropriate and who is not appropriate, then we have violated the basic principles upon which this country was founded. The taxpayer revolt is an anti-people initiative. It represents a systematic oppression on behalf of white, upper-class, male supremacists. It represents sexism, racism, and anti-everything that I think most of us in this room stand for. It certainly is anti-social and human services.

As we move into the eighties, we must work together, we must look at every situation as an opportunity, we must evaluate the menace potential of issues such as the taxpayer revolt, we must develop trust, and we must divide the labor. No one of us, no one group, can do it all. There are too many issues out there. If we work together, however, we can and will be successful in making the eighties the period of deliverance and full societal integration for persons with disabilities. Thank you.





Organizing Tools to Get Power and Clout

Kare Anderson
Coleman Goff

My form of inspiration is going to be rather crass, opinionated, and corny, but I think the best way for me to help you learn to work together is to give you specific actions. My role as an able-bodied hired gun is to share tools that will help you affect decision makers in the ways you want. So philosophy is gone. Ideology is gone. I'll take it for granted that you believe in your issues. I am simply going to share some strategies that I hope will help you get more clout and power in support of the issues that matter to you.

I am going to offer my suggestions in terms of strategies to affect legislators, but I will be talking about means that you can apply to influence any decision maker. I am going to use corny titles because they help serve as memory tools.

I worked in the California legislature for a maverick, liberal Republican in the Senate: Senator Peter Behr. One of the errors frequently made by liberals, like me and many of you, is that in lobbying we look at some legislators as evil politicians, especially when they don't care about our issue. Of course, some legislators are evil, some are bought

"... Legislators are a commodity. We have to find a way to weight the scale so that it is more to their advantage to vote with us than against us."

off, and some are stupid, but that is irrelevant to what we are doing. The first rule I will propose to you is called the *Evil Politician And Your Righteousness*.

I was very righteous after working for the wire service overseas. I told Senator Behr how awful the political system was and he said, "Work in it for two years and then judge." For two years all I did was draft legislation and organize support for legislation. Now you and I know that there are some legislators that we don't respect. But I found a very surprising thing. Some of the most stupid, off the wall legislators found it to their advantage to vote with me on issues and some of the most charming, apparently ethical, thoughtful, considerate legislators killed bills I believed in. So what I am suggesting is that we cannot afford to decide that one person is awful and that another person isn't. I am suggesting that you should look at every public official as a potential ally on some issues.

Next, rule number two: *Legislators Are A Commodity. . . Weight Their Scale*. We have to find a way to weight the scale so that it is more to

"What I'm suggesting is for us to use our imaginations and find a way to draw our innate resources, our stereotypes, our sights, our situations, our products, anything that's visual, and make it something that the media will want to cover, because it's fun."

their advantage to vote with us than against us. That's all that counts. A lot of things happen to us when we go to the capitol and visit the center of power. The critical thing is not how important we are or how cool we are, but how to get our issue across, passed, and signed into law. I look at each legislator commodity by commodity. I look at them in terms of their needs, not mine, just as any vacuum cleaner salesman would do. What do they need? Certain legislators need certain kinds of support in their districts. Certain legislators, probably about 80 percent, don't care one way or the other about your issues. That's fine. It will take less on their part to weight it your way. They'd rather say yes than no. So I look at legislators and think, "How do I define my issue in terms of their needs, not mine?"

Next point, *Play Detective . . . Learn The Territory*. Be a research librarian. Do everything a muckraking reporter would do. Learn the territory. Many people came to Senator Behr's office to influence him to vote a way that he was already going to vote. They were wasting their time and his. So learn about legislators.

You can know whether someone is a Democrat or a Republican, what part of the state they are from, and what committees they sit on by reading the legislative handbook. These facts give you insight into the issues that are important to them. Their committee assignments alert you to where they choose to be an expert. If you don't know, other lobbyists will and you can prepare yourself by reading their newsletters.

I learn about legislators' interests, their backgrounds, and who their friends are. I find that legislators who went to Yale or Harvard think that's real cool. I really like to work with people who went to Yale or Harvard because it's easy to get to them. I also want to know where their spouses went to school and where their kids go to school.

Several weeks ago I worked with an environmental group in Southern California. They wanted to stop the dredging and filling on a certain eight-acre territory along the coast. The work underway was contrary to law and contrary to the policies of the local Coastal Commission. There was a legislator, a key coastal official, and a group of people on the Coastal Commission who could have stopped the dredging and filling. By playing detective, a consortium of environmental groups found that one of the Coastal Commissioners had children and that their school had an environmental education program. An environmentalist in the consortium located the children's teacher and enlisted her support. Suddenly a field trip was planned, a very comprehensive field trip that included a botanist and an ecologist. All of the children walked around looking at the dredging and filling. This is the way the mud flats used to be. That's

where eagles and herons used to come. Any questions, children? The children prepared their own notebooks. As you might suspect, there was quite an impact when the daughter of one of the Coastal Commissioners testified at the public hearing about why the attack on the mud flats should be stopped.

A second example: when working in Detroit we had a consortium of people living in rundown hotels. The plumbing was turned off at one hotel for several weeks. The tenants formed committees and did all the righteous things we are told to do in government classes. They wrote letters and called their landlord, but nothing happened. It was the next step that worked: they played detective. The holding company for the hotels had a holding company which had a holding company which had a holding company. And on the Board of Directors of that holding company were two men who lived in a very nice part of Detroit. The tenant group organized themselves and other people sympathetic with their issue. They printed a tasteful flyer and had one of the most friendly door-to-door solicitation campaigns that I have ever observed. "Excuse me, I just want to hand this to you. It's information about two of your neighbors. They have turned off the water in my building. I just want to give you this information." They got the media to come, and they succeeded. They never could have done it if they hadn't played detective. When you don't have a lot of money or extensive political connections, then all you have is your imagination. Try anything that's not a lie and that doesn't demean your issue.

The next step is called *Playing Your Stereotype To The Hilt*. There are three kinds of groups that I always talk

about in workshops, regardless of whom I am speaking to. One of them is gay people, the second is handicapped people, and the third is senior citizens. These three groups are valuable commodities for me to play a stereotype with because they follow through.

What am I talking about when I say play your stereotype to the hilt? I am a 31 year old, white, middle class, very shy woman. That's my stereotype. Within four seconds after you had seen me, some of you didn't feel comfortable with me. Others really liked me. Some people will like my friend Mary Regan and some people will like me. But if Mary and I both want action on an issue, together we have more clout.

Eighty percent of the decision making that any of us does is on a visceral, gut, emotional level and only twenty percent is based on facts. If I can get to you in your gut, then you'll use facts to rationalize support for my position. I want to get to you in your gut. If Mary and I can make someone uncomfortable or sympathetic, then we work together.

There was a time, when you first got militant, that you could make decision makers feel really uncomfortable. You were organized and you did it well. Legislators are now becoming more callous. You must add diversity. Mary is wonderful coming in with me, because she adds to my diversity, and vice versa. That's why I ask her help on nondisabled issues. Mary and I cut a deal to work together. Whenever you go talk to a decision maker, look to diversify yourself.

My next point to share is *Show Broad Community Support*. For each decision I am going to hit, I'm

going to bring on as much of the *appearance* of broad community support as I can muster. That doesn't mean a large rally. That means three people whom I have carefully picked. We bluntly exchange information about our stereotypes so that when we come to a legislator's office we are so compelling that he is going to drop his papers and watch us.

For example, I have been organizing with three different groups in Los Angeles. When they first met together they looked each other up and down and felt very uncomfortable. The first group, whom I will call the "matrons of the arts," were women wearing suits worth four months of my salary. They believed in placing art in public places; that was what turned them on. The second group were ex-convicts who had a huge federal grant to find jobs for newly released prisoners. The third group was the Gay Rights Alliance of Los Angeles, many of whom were people from Hollywood who worked on the set of *Mork and Mindy*. What raw material to work with! The key was that each group believed in the other's issue, but it was not their top priority. From a traditional standpoint, the three groups should have sat down and worked out a coalition. Six months later we'd have had guidelines and the process would have been extremely boring. Instead, each group already had its individual lobbying strategy mapped out. Rather than laboring to produce a composite plan, the groups decided to work together to assure success on one another's individual strategies. We said, here is each group's individual lobbying strategy, here are the decision makers, here are the sets of actions that should be implemented to affect decision makers. Here are the timetables, and

here are the three-person lobbying teams that would be good for each action. Together they mapped three plans: one for the matrons of the arts, one for the ex-cons, and one for the gay people. Next, they said that for this action we need these three stereotypes. As an example, one of the issues that was important to the ex-cons was placing a six-month limit on how long someone could be kept in "the hole" at San Quentin and Folsom. This is a very distasteful, unpopular issue. The hole at San Quentin is eight feet by eight feet by nine feet. It has a concrete floor and a metal latrine which is a grate on the floor. The bunk is metal with no cushion. The food comes through a door which opens both ways. That's it. Lights come on irregularly.

What we did in cutting a deal was to get the people from the Gay Rights Alliance, many of whom were doing set design and construction for *Mork and Mindy*, to reconstruct what the hole really looks like. Then, on a rather vaguely-worded parade permit, our model of the hole was set in front of the Federal Building in Los Angeles. We also had a wonderful poster of one of the convicts, and a brief written statement on how and why we wanted to change the regulations governing the hole. During the noon hour, when there was heavy foot traffic, representatives from the interest groups stationed themselves in front of the Federal Building saying to passersby, "Hello, I'm so-and-so, may I show you the hole? Here's a model of it; would you come this way, please?" They played their stereotypes to the hilt, and they realized the strength of helping each other on an action-by-action basis.

Work In Pyramid Style. I can't remember how many times someone came into Senator Behr's office and talked for two hours instead of saying, "This is the point I want to share with you." When I worked in the wire service there was a thing called a pyramid sentence. It means to be sure to state the where, who, what, why, when, and how in the top sentence. I was in Portugal, covering Spínola's coup, a dramatic world event, but not according to the *Sacramento Union*. If I wrote the story in 12 paragraphs, the most important facts had to come first with the rest in descending order. The newspaper was likely to cut the bottom seven paragraphs, and if they cut off the meat of my story I was out of a job.

Many times we go overboard preparing someone for what we're going to tell them. Here's the general framework, here are the qualifiers, here is the background, here is the history, and—where's your attention? I am suggesting that you get right to the point. Research me, know what my needs are, and get to the point. If you come into someone's office, say, "Look, we have this in common, there's a bill coming up next week, I would like this help from you. This is the way that I am able to help you. Can we get down to business?"

So we come to the next, related point. It is called *Perfect The Quick Hit*. I went to USC at a time when certain, more notable people were going to graduate school in marketing, including John Dean and John Erlichman. John Dean was the one who thought of perfecting the quick hit. I've since used it in many different ways. When we approach someone about an issue that's important to us, we may not have a half hour. If we want to be effective

advocates for our issues, we must learn to quickly share the essence of our position and our reasons for caring about it in a way that interests and involves the listener. It's our own little litany on *what matters to us*.

The next point is called *Hits From All Sides Mean Less Chance of A Miss*. There is another name for this strategy; it's called the "billboard effect." In journalism school they teach that if we all lived in the same eight-block area, and the same advertisement was on every billboard, the advertisement would have a 100 percent memorability factor. They say that familiarity breeds contempt. I don't think so. I think it breeds acceptance. The more our view on an issue, our truth on an issue, hits a decision maker from a variety of sides, from a variety of people, the more we are going to wear him or her down and the more weight we are going to give to our side of the scale.

When planning many-sided hits, try to get the targets on your turf, not theirs. A good hit on a legislator should occur in their district office, where they spend every Friday. Better yet, present your issue when they are completely on your turf. If you don't have an annual meeting, dinner, or award banquet, create one just for the purpose of making hits during them.

I learned one of my favorite techniques from a Gray Panther in Missouri. This Gray Panther had a newsletter which went out to 1400 people. He would talk to legislators who held key votes and say, "Thank you, Assemblyman, we appreciated your support last year on our issue. It was important to us. We highlighted you in our newsletter and even printed this picture of you. We

want to talk to you now because we have another newsletter coming out in two weeks and yours is a critical vote on one of our top issues." He offered the legislator something that was important and he made his support contingent on reciprocal support from the legislator.

Next, use *Plain Language, Not Glittering Generalities*. I attended Stanford, the University of Oregon, and Occidental College. I earned some degrees here and there but they haven't meant much in terms of helping me influence legislators. On the contrary, they have taken away my innate powers. My sentences are longer and more abstract. Brief, declarative sentences and specific, real-life details get listeners in their guts. As an example, I believe in government funding for abortions, a rather controversial issue. Six months ago, the anti-abortion people were in Washington. They canvassed the halls and made speeches. There were 12 microphones in front of them when they received nationwide coverage on the six o'clock news. The group's spokeswoman said, "We can no longer kill and murder babies. All of us are implicated in it, all of us. If you are involved in funding the killing of babies, you have to live with it. Go home and look at your kid and remember what I have said." Now that is good, specific, graphic language.

The next week, Eleanor Smeal of the National Organization for Women came on the six o'clock news. She gave a very carefully articulated statement about government funding of abortions and described how important the issue was. Nobody in my living room stopped talking. Nobody heard her. She lost an opportunity to put clout

into her issue. We lose power when we don't know how to graphically describe what's important to us. That doesn't mean yellow journalism and it doesn't mean demeaning our issue. But when I can't describe to someone from a different world what is important about my issue and give them a pictorial view of it, they are not going to listen when I give them facts and statistics.

The next point is called *Use Aikido*. As you may recall from John Wayne movies, if John walked into a scene and someone insulted him, it always came to blows and John always won. Well, sometimes you and I may not be physically strong, but we still need a decision maker's vote. Aikido refers to how I can leverage a person in power to use their energy my way.

A decision maker is more powerful than us because he or she has something we want, i.e., their support on our issue. Many times I've worked long and hard with well-intentioned people on a lobbying strategy only to lose our struggle at a legislative hearing because someone on our side failed to maintain control. For example, a sweet, conscientious person I'd been working with for months turned to a legislative committee member and said, "You know, Mr. Richardson, I know what you did on that health nutrition bill last year, and you're not going to get away with it in your district. You took away lunches for needy kids, and I think that's criminal."

Take the case of a legislator who asks a question that is completely irrelevant. Your first tendency may be to say, "Well, that's not actually related to what we're talking about." But you aren't going to say that, right? You're going to say, "That is an important

point," and then you're going to try to somehow draw it into the fabric of what you're saying. Now, if they say something that is false, you don't say, "I'm sorry, you're wrong, Senator, that is not the true statistic." You would say something that plays your stereotype of an earnest citizen to the hilt, such as, "I appreciate your perspective. Let me tell you how we arrived at our statistics because that might prove helpful." In other words, explicitly acknowledge what they had to say and keep on trying to share your point. Don't ignore their position; acknowledge it directly and go on.

The third kind of aikido is when a legislator says, "I don't know what you're trying to do. You were successful last year and now you're going to push for more and more, aren't you?" You say, in your slightly awkward, anxious fashion, "I'm sorry, sir, here's how we arrived at our perspective." Be as earnest as you can because you're playing aikido. The more belligerent they get, the more chance you have of getting another wobbly vote. Use their arrogance or belligerence, because you are playing your stereotype and setting your own standard of respect for yourself. You're saying, "I appreciate your perspective; can we tell you ours?" That's aikido; it is using their energy to their disadvantage and your advantage.

The last tool I will share is called *Making News*. We all know how important media coverage is and that we've got to learn more about how to get good media coverage for our issues. First, let's consider what we shouldn't bother doing if we want press coverage. In working with Channel 4, I found that there were 14 marches a day somewhere in their five-county

viewing area. KRON only cared about them if there was a possibility of "good TV." When the Iranian situation started and there was a good possibility that some windows would be broken, that created good TV. Now you can either get angry, say, "That's stupid," and try to reform it, or you can say, "Here's what the media want; we've got to give them something they value."

I used to walk out of the Capitol every day and pass people who were having a rally or march. Their medium wasn't the message. All rallies and marches look alike. A lot of you may disagree, but I firmly believe it after working in television for some while. Unless I consciously looked because I was engaged in a boring conversation while walking down the street, I never read the signs people held. Press conferences are also not generally very valuable.

I am suggesting that we must learn to use our imaginations and find ways to capitalize on our innate resources, our stereotypes, our situations, our products, anything that is visual. Do something that the media will want to cover because it is fun or interesting. For example, Senator Presley once prepared a bill that he was a little scared about. It legalized marijuana for terminally ill cancer patients taking chemotherapy because marijuana alleviates nausea. He didn't pick someone with long, curly hair to lobby on the bill. Instead, the person that he chose to stand with him when he introduced the bill was an extremely conservative Marine Corps veteran. The man's statement is one of my favorite speeches. I still get tears in my eyes when I recall it. He said, "I want all of you legislators, when you're ready to vote on this bill, and you are thinking

about your own mortality, to think of me. I have five years to live. I want to live them in as much pleasure and comfort as I can with my wife and my family. Please think about me when you're voting." And that was his speech. It was just that long. He had full media coverage. All they did was announce to the media that his appearance was going to happen. Senator Presley was imaginative. The Marine Corps veteran was the medium and the medium was the message.

When you're asking for news, find the medium that makes the message: ordinary people as well as extraordinary people. It's all a matter of who is appropriate to your issue. The most compelling thing that you can do to a legislator who is weighing the scales on an issue that is important to you is to take along people who are so unlike you in terms of appearance and style that the legislator is boggled when you and your supporters come into his or her office. Make sure that you look at each other and say, "This is my stereotype and here's what I have to offer. Now on this action, with this decision maker, here are the other two stereotypes that we need." The issue is what counts. Plan out ways to hit at legislators. There is nothing so intimacy-building and power-building as working with two people who are unlike you but who helped you win your issue. And down the line, you help them. It's worth twelve meetings to prepare by-laws for a coalition.

Thanks for the opportunity to share my experiences with you. I wish you the best in your struggle to achieve social equality and justice.



KARE ANDERSEN

TOOLS

TO GET POWER & CLOUT.

NOT
PHILOSOPHY &
IDEOLOGY.

DONT
PEMEAN
OR
LIE ABOUT ISSUE

1. EVIL POLITICIAN & YOUR RIGHTNESS

Some of the worse can support you... Best can oppose.



2. LEGISLATORS ARE A COMMODITY... WEIGH THEIR SCALE.



OR
THEIR NEED
} CONNECT UP

3. PLAY DETECTIVE... LEARN THE TERRITORY.



DEMOCRAT OR REPUBLICAN?
MR OR MRS
• VOTES
• FRIENDS

NEIGHBORS
• PROPERTY
• SCHOOLS
• FRIENDS
• SPOUSE
• SONS & DAUGHTERS

4. PLAY YOUR STEREOTYPE TO THE HILT.



MANY
DISABLED



Dont demean people!

5. SHOW BROAD COMMUNITY SUPPORT.

ARTS
MATRONS
LOBBY STRATEGY

EX-CONS

GAY RIGHTS ALLIANCE

(WE PRACTICED)

your neighbor turned off our heat

6 Mo. limit in Hole

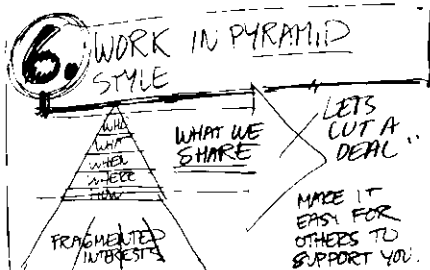
Work & Mindy

PICTURES

THE HOLE

Declaration Posters

RESPECT EACH OTHER & TIME.



7. PERFECT THE QUICK HIT

IF THEY GET INTERESTED, IT'S THEIR TIME

- WHAT I DO ON MY JOB →

8. HITS FROM ALL SIDES MEANS LESS CHANCE OF A MISS

Billboard effect... MAKE FAMILIAR
GET ON YOUR TURF

Plant people in audience

Group Panther story
Newletter Plot

See your picture

9. PLAIN LANGUAGE NOT GLITTERING GENERALITIES

Get Back to drawing

- DECLARATIVE SENTENCES

ANTI-ABORTION talk

If you are involved in killing babies... look at your kids

NICE, EDUCATED TALK DOESN'T WORK

STUDS TURKEL

peanut butter
coffee
wife

that driver

AD MAN... usually arrive at 11:00

critical dinner their turf not yours

"THE STRUCTURE OBSTRUCTS THE VIEWSHAPE....."

10. USE AIKIDO

HOW TO BE STRONG WITH THEIR ENERGY



- DRAW THEM INTO WHAT YOU ARE SAYING... ACKNOWLEDGE
- YOU ARE WRONG → ABSORB... USE THEIR ENERGY

11. MAKING NEWS

GOOD T.V.

BE FUN

- All rallies & marches look alike
- PRESS CONF LOOKS ALIKE

CRASH... FILL

MARINE CORPS MAN

GRADE SCHOOL LOBBIES

3RD

change

Emancipation Bill

BRICKS COVERED

DUMP MEETING

It's going to be a new one

Susan Seigle

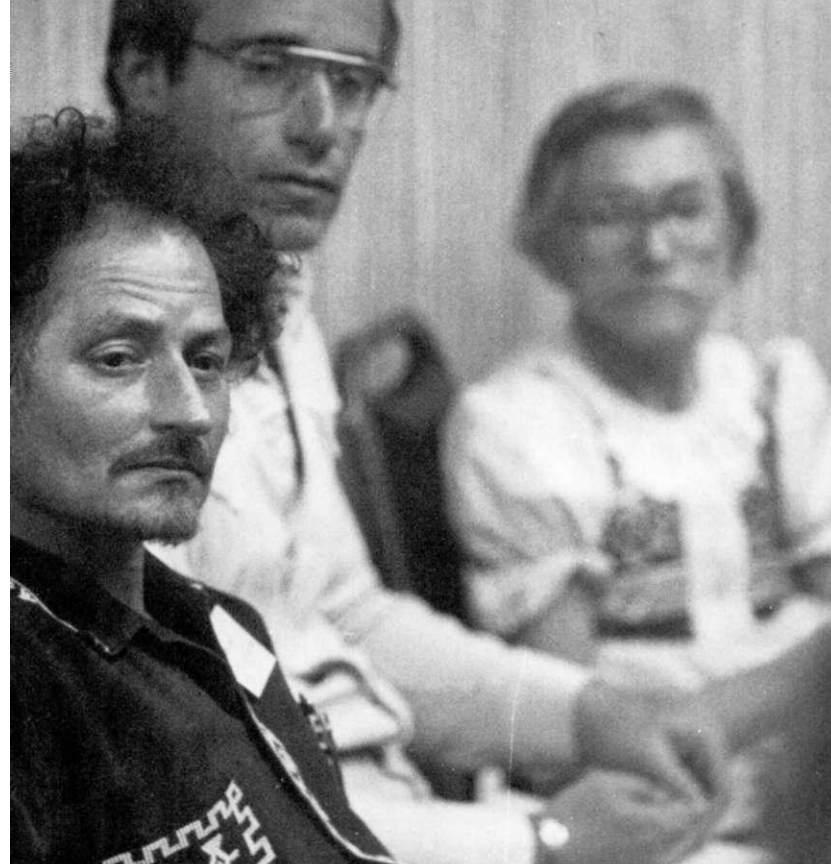
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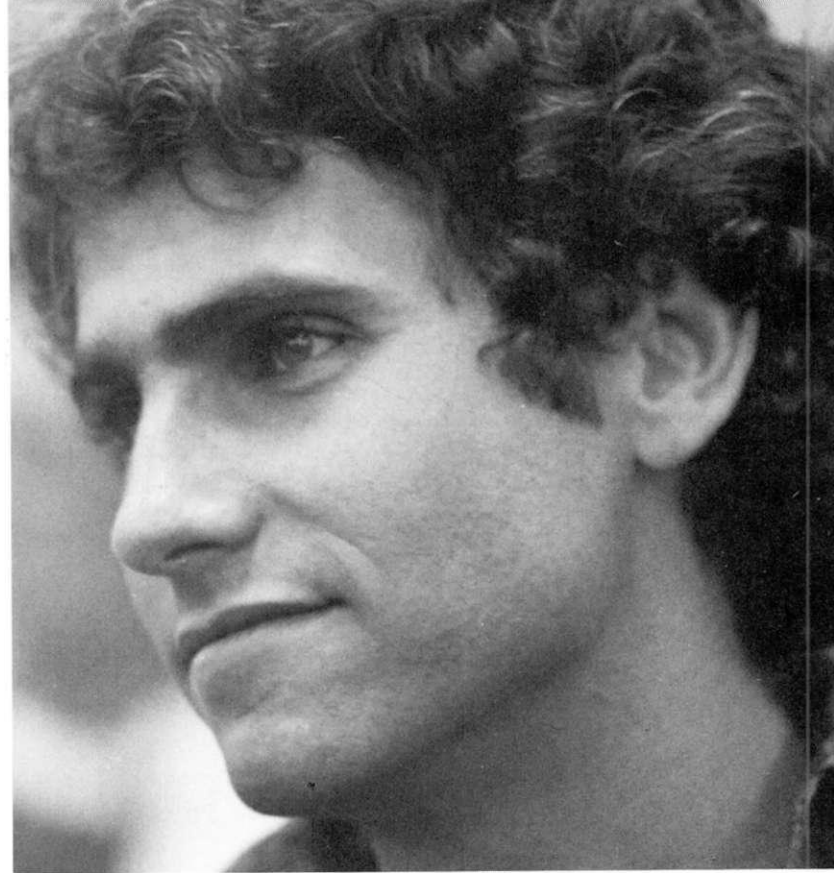
DE BEN CASE



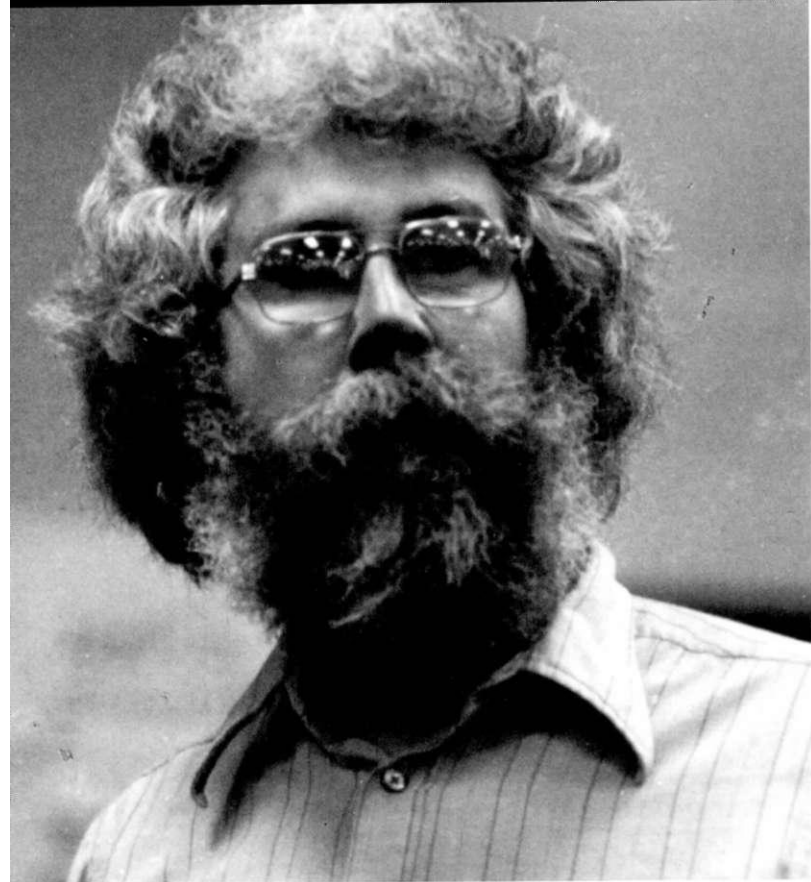












Conference Summary

Rich Santos

Center for Independent Living

Fran Smith

San Francisco Aid

Retarded Citizens

Consumers of rehabilitation services and friends in state government came together across the past two days to review our common history and to begin charting a collective vision of the future. We shared organizing principles and procedures among ourselves and with leaders from allied civil rights movements. Moreover, we detailed major problems and blessings predicted for the eighties and explored the status of the taxpayer revolt and how we may respond affirmatively. Finally, we discussed how to more effectively involve ourselves in the political process.

The major theme of this conference was unification. As Ed Roberts said, "Our future is together and our power is together. Together we are much stronger." Mike Thrasher emphasized that civil rights for disabled people will not fully move forward until consumers take control of the disability rights movement. Mario Obledo and Tom Bates stressed that people with disabilities are their own best protectors and advocates. Owen Marron and Eileen Luna, union organizers, declared that organization and unity are essential to take power, and urged the

formation of an alliance between organized labor and the consumers of human services. Conference participants committed themselves to increasing cooperation among various disability groups in order to help create valued futures for all people.

There is substantial cause for optimism as we enter into the decade of the eighties. Extensive new information and tools are available on how to effect social change. Legal mandates clearly guarantee equal opportunities. Groups such as People First are standing up and fighting for their rights. Other groups of people with disabilities are coming together, solving problems, forming alliances and fighting to increase the quality of transportation services, living arrangements, education and employment opportunities. Consumer groups know that constructive changes are unlikely to result from professionals and agencies in the human service field without extrinsic pressure. Conference participants and presenters stressed that the preconditions for effective pressure tactics are a unified consumer leadership, a guiding philosophy, sound management and organization, long range

planning, and consumer participation in all facets of our struggle.

Consumers do have the power to change the world in which they live. The Consumer Unity Conference was intended to be a catalyst for promoting consumer unification. We hope that this event is not a one-shot affair. All citizens deserve services which maximize their personal ability to lead satisfying, self-directed lives while contributing to the common good. Continuing cooperation, trust, and unified action are essential if we are to better the quality of life for all people.





The California Institute on Human Services is located on the campus of Sonoma State University in Rohnert Park, California. SSU emphasizes the liberal arts and houses numerous quality professional programs, some with histories of leadership activity in human services. The Institute provides a focal point for consolidating the activities of on-campus entities and of linking them with consumer, service provider, and government interests.

While the primary focus of the Institute is service system design, its specific functions include (1) provision of technical assistance; (2) facilitation of information exchange; (3) participation in resource development to increase California's fiscal, material, and personnel capacities; (4) refinement and expansion of forefront personnel development programs; and (5) promotion and acknowledgement of excellence in human services.

The outcomes of the Institute include (1) improved communication between consumers, practitioners, and scientists; (2) improved research, training, service programs and societal attitudes vis-a-vis persons with disabilities; and (3) technical-professional support for the initiatives of the citizen movement. The Institute is an experimental-demonstration project which stands as a California counterpart to similar institutes in Canada, the Caribbean, and Australia.

The Institute's primary mission is to stand at the midpoint between real community problems and opportunities and the application of knowledge gleaned through research and other accumulated experience.

The Institute strives to collect and analyze information important to consumers, service providers, and state departments and to translate their problems and opportunities into questions which are answerable through research and experience.

Viewed from another perspective, the Institute strives to translate knowledge about service design into real world programs which solve problems and/or capitalize on opportunities. Most importantly, the Institute acts to stimulate the actions of others, and avoids duplicating the functions of existing consumer organizations, policy boards, higher education programs, or service providers.

**The 1980s: Tasks for Creating
a Common Front**

Pulling Strength Together
Reviewing Our Common History
Forecasting Public Policy

Molding a Preferred Future
Kindling New Leadership

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