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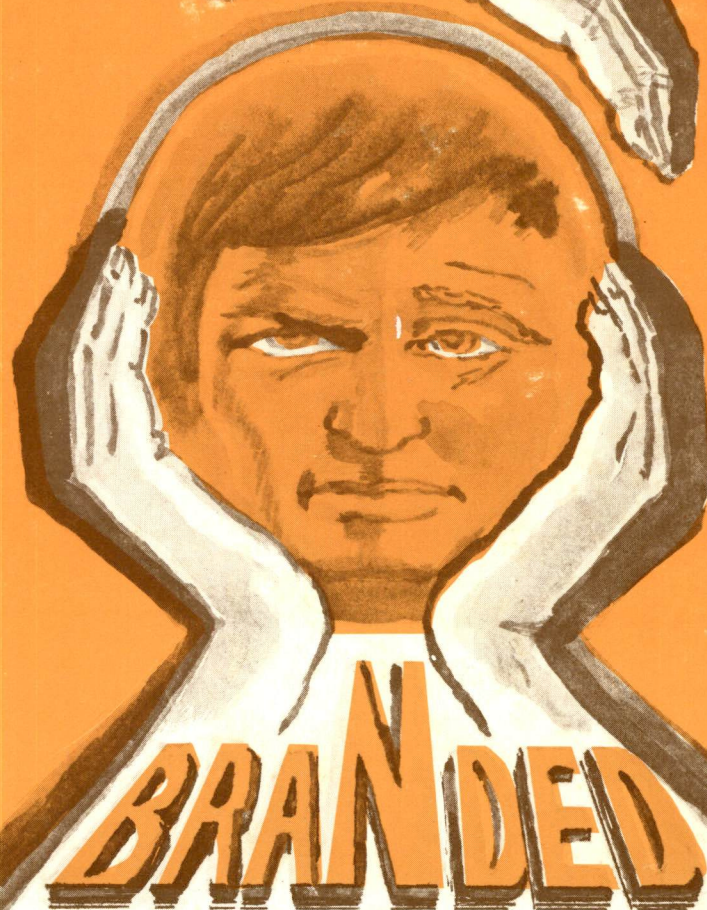
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DECEMBER, 1975

POLLING

MAGAZINE

VOLUME II, NUMBER I



John Bell Jr.

The Purpose of Polling



by
Daniel A. Poling II
Editor-In-Chief

POLLING MAGAZINE has been in existence for approximately 18 months. This is its third issue, but from now on it will be published quarterly, thanks to a federal grant from the Division of Developmental Disabilities (DD), Department of HEW. Under the mandate of this grant, **Polling** is to become a rapidly as possible the voice and advocate of the DD consumer movement.

Now, precisely what do we mean when we say, "the DD Consumer Movement?" By speaking of people with developmental disabilities, we are referring to those who have become handicapped in their childhood or early adolescence; the handicap has hindered the normal emotional and social development

of that person. Presently, developmental disabilities refer to three specific categories: individuals with cerebral palsy, epilepsy, or mental retardation. At this writing, however, Congress is considering a new DD act which is expected to greatly expand the formal definition of developmental disabilities.

Individuals with DD have always been at the very bottom of the totum pole within the disabled minority. We have traditionally been branded and treated like lepers both by the rest of our own disabled minority and by society as a whole.

This state of dehumanization has been poignantly described by Clinton Hilliard, a cerebral palsy victim who is the head of the speech pathology department at Crotched Mountain Center in New Hampshire: "'It' was born. I say 'it' as 'it' needed to be differentiated from the usual 'he' or 'she' that might have been born on March 16, 1927. 'It' was blue as a result of the then little known RF factor; 'its' skull was mishapen due to the use of forceps. The doctors were certain that 'it' would not survive, since 'it' could not swallow and barely breathe. The parents were advised to ignore 'it' and let 'it' go back to 'its' maker. This advice continued until 'it' was 11 years old; only the methods of termination changed."

The sole purpose of **Polling Magazine** is to get as many DD consumers involved in fighting for social change as is possible. Indeed, approximately one-third of each issue will be devoted to consumers within each of the three disability categories; mental retardation, epilepsy, and cerebral palsy. **Polling** will be a forum in which DD consumers can share their feelings, fears, and dreams, a forum in which the DD consumer can develop his or her own identity and locate the source of self-fulfillment, a platform on which DD consumers can organize and mobilize for decisive action throughout society.

The time has come for all DD consumers to stand and demonstrate to the rest of society that we are indeed living, breathing, feeling, human beings, people with great potential and tremendous promise.

Giving Credit Where Credit Is Due

Some disabled are noted for their sharp criticism of the system; and, to be sure, much of their criticism is justified. However, we should also recognize positive occurrences as we harp upon the negative ones. This magazine has just been through an extremely stormy financial period. We would have not been able to weather it without the unqualified backing of some key people within the system.

The system can be responsive to your needs if only you approach it responsibly and rationally! With this, we express our sincere gratitude to: Leo Hausman, President, UCP of NYC; Edward Reitman, Ass't. Exec. Dir., UCP of NYC; Clark Ross, Ass't. Dir., UCPA, Washington Office; Doris Haar, Chief, Program Development Branch, Division of Developmental Disabilities, HEW; William H. Staley, Office For Handicapped Individuals, HEW; James L. Buckley, U. S. Senator; Jacob K. Javits, U. S. Senator; Edward M. Kennedy, U. S. Senator; Jennings Randolph, U. S. Senator; Harrison A. Williams, U. S. Senator; Edward I. Koch, U. S. Congressman; John M. Murphy, U. S. Congressman; Peter A. Peyser, U. S. Congressman; Charles B. Rangel, U. S. Congressman.

POLLING MAGAZINE

"The Advocate of the DD Consumer Movement"

VOLUME II, NO. 1

Published under the auspices of the Epilepsy Foundation of America, Inc., and United Cerebral Palsy of New York City, Inc.

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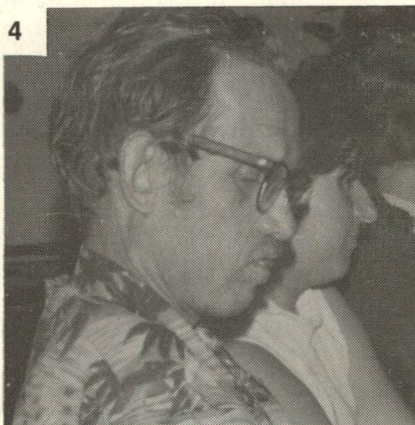
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Branded

by Daniel A. Poling II

My wife, Terry and I arrived in Denver on a dreary, chilly day in midsummer to conduct an interview with nine MR Coloradians. The Rocky Mountains were surrounded by fog. To the Airport Holiday Inn came a number of residents from state institutions. Pat Alire, Linda Jackson, Lance Solomon, and Shane Christianson came from the Ridge State Home and Training School; Donald Hinkle and Obedia Willia came from Clarkson State Hostel; Charles Dieterle came from the Kelwood House in Boulder; Michael Gregory and Christie Rothfuss, two who had once been institutionalized but who had recently been successfully integrated into the community, also came. Harold Knight, a member of the Colorado State DD Advisory Counsel, and his wife were with me for the interview.

We talked and listened for the entire evening, as these MR consumers gradually discussed their deeper feelings and thoughts. It became progressively clear to Harold and me that they were living with a staggering handicap that hung like a yoke around their necks, a handicap not of mental retardation, but rather of social stigma. They had been branded as deviants, freaks.

"Some people call us retarded. How do you feel about that?" I asked.

"We should be treated like men, that is, adults. We can do just as much as other people!"

"Because down deep when they say things like that, they probably got emotional problems themselves, but they just hate to admit it!"

To understand the psychological and sociological consequences of emotional branding, one must understand something of the "self-fulfilling prophecy." W. I. Thomas, the dean of American sociologists, set forth a theorem basic to the social sciences: "If men define situations as real, they are real in their consequences."* The self-filling prophecy begins as a false definition of a situation. The new behavior which results makes the originally false conception come true. Society has branded MR consumers as inferior, so they are treated as inferior; because they are constantly treated as inferior, they come to believe this false definition. The following sequence is an example of this:

DAP: Do any of you have any dreams - something you wish for?

ANS: Mr. Poling, there's things I wish I could do better. Sometimes I can't run as fast as the others, but I'm steady on a job, hold it down, but I wish I could do better.

*Social Theory and Social Structure, by Robert Merton, Page 424.

DAP: In what way do you wish you could do better?

ANS: I wish I could be like others.

DAP: Why?

ANS: I don't know, but I wish I could. I try to get along with everyone. I don't want to be different. I want to be the same. I want to be an adult, like everyone else.

Many MR consumers actually refer to themselves as, "us kids." At one point in the discussion, I tried to discover why by comparing an MR woman with Mary Betz, the citizen advocacy coordinator from Boulder. Mary was wearing a diamond engagement ring and had the appearance of a happy woman living a productive life.

MR Woman: Us kids can't do much. We're not allowed to do much on our own.

DAP: How old are you?

MR Woman: 24

DAP: Well then, that makes you an adult. You can do anything you make your mind up to do.

MR Woman: No. Us kids aren't allowed to be adults. We got to do what the employees (the staff of the institution) and our parents tell us to do.

DAP: Look at Mary, do you consider Mary to be an adult?

MR Woman: Yes.

DAP: Well, when I look at you and then look at Mary, I can't see any difference between the two. You are both extremely attractive young ladies.

MR Woman: Oh no! Mary is an adult. I'm not an adult; I'm a kid.

DAP: If Mary is an adult and you are a kid, what makes the difference between you two?

MR Woman: I live in an institution. Mary doesn't.

It seems that much of this feeling of inferiority is tied to living and being confined to an institution. Indeed, the primary goal of many MR consumers is to get out and become independent:

MR Consumer: I had a dream for three years. I wanted to get out . . . but they won't let me out of this . . . I'm not ready. One day I sat down on the stairs . . . and said, "I want to get out of this . . . to be on my own . . . I've been here too long" . . . It'll be nice when I have my own apartment, so I can come and go when I please. Nobody can tell me when to take a bath or when to go to bed. I'll be like everybody else then!

An MR consumer who had already integrated into the community confirmed this feeling:

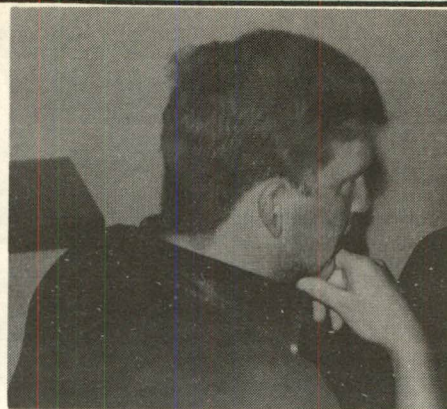
DAP: Have you ever lived outside of an institution before?

ANS: No, this is my first time.

DAP: I like it much better. I go out to work and I take my bath whenever I please — not when somebody else tells me to!

DAP: Do you recommend that everybody move out of the institution?

ANS: Yes, I sure do! That's the only way to live!



The problems of a negative self-image seem to permeate their lives. Unfortunately, and unwittingly, these feelings are often reinforced by the parents:

DAP: Some people say that we should not have sex and should not be parents. What do you think?

MR Woman: My mom says that us kids shouldn't do that. That it's bad. Us kids can't be bad.

DAP: How old are you?

MR Woman: 24

DAP: Do you realize most people your age are having both sex and babies? That it's all part of being an adult?

MR Woman: It's all right for adults to do that stuff, but us kids can't be bad.

MR Man: That stuff involves responsibilities. My dad says I'm not ready for responsibilities.

DAP: Why not?

MR Man: Because I'm handicapped.

DAP: That has nothing to do with it! Look at me. I look ten times more disabled than you, but I have sex and I'm married. Why shouldn't you?

MR Man: I live in an institution. You don't.

Regarding the self-fulfillment prophecy, Robert Merton, professor of sociology at Columbia, states:

"The application of the Thomas theorem also suggests how the tragic, often vicious, circle of self-fulfilling prophecies can be broken. The initial definition of the situation which has set the circle in motion must be abandoned. Only when the original assumption is questioned and a new definition of the situation introduced, does the consequent flow of events give the lie to the assumption. Only then does the belief no longer father the reality."*

It follows, then, that the only way to break this vicious circle is for society to change or be changed, so that an MR consumer is defined as equal, not inferior; as conforming, not deviant; as valuable, not worthless. One way to start this process is to offer him meaningful work and to pay him a respectable wage:

DAP: How do you feel about working?

ANS: I think it's good to work 8 hours every day and put in your time. There's not

*As quoted in Social Theory and Social Structure by Robert Merton, Page 421.



much to do around the house and I think you'd better get out and fight for your money and do things like that.

DAP: What about anybody else? Do you like to work?

ANS: Yes, I like to work. I put in 8 hours a day. I go to work at 8:00 and I come home about 4:00. I come home to take a bath and clean up and all that and this way, to work, is to keep your mind off and that's one way to do it.

ANS: Mr. Poling, my goal is to get out of pots and pans to get a better job and the better job I hope to be is an electrician's helper. I used to be an electrician's helper.

DAP: What is that?

ANS: An electrician's helper is to help out the electrician... like help do the wiring, go up in attics, to do things like that. I used to do that kind of stuff and I know a lot about electrical wires.

Another way to help change the self-fulfilling prophecy is to teach the MR consumer his rights and responsibilities as a United States citizen. He must respect himself enough to demand his human and civil rights. He must have the educational opportunities to understand that one way to protect these rights is by participating in the political process. I was dumbfounded to discover that these young adults didn't have the vaguest idea of what "voting" means:

DAP: How many of you know what voting is?

MR Woman: I know what it is. It's like a lady asked us one day at Safeway. Our name and everything and she wrote out a paper for us.

MR Man: Voting is like the Constitution and so, voting is like you have to vote for a president.

MR Man: Well, it means like Gerry or Nixon... it means for our president.

MR Man: Well, I think, voting is to me a privilege and you should get out and vote for our country.

Parents of MR consumers must force themselves to let their children think and not remain tied to emotional and intellectual apron-strings:

DAP: You don't want to vote?

MR Man: Well, I can vote if I want to. See, before I can vote, I gotta go through my parents. If my parents say I can't vote, I can't vote.

D. D. Consumers, Speak Out and Be Heard

Many disabled people love to criticize, but seldom have concrete alternatives to offer. If we want to be treated as mature adults, then we must act like them. **POLLING MAGAZINE** is the forum in which the right to criticize can be exercised, but this right must be used judiciously by offering concrete, realistic alternatives. Here are some specifics you should consider when writing an article for **POLLING MAGAZINE**:

Correspondence With The Editor: The Editor welcomes correspondence with DD consumers and others about manuscripts they may wish to submit for possible publication. First preference will be given to DD consumers; however, material by others will be considered if it is relevant. If a DD consumer requires journalistic assistance in the writing of an article, it is available.

Possible Topics of Articles: Articles on any subject of interest to DD consumers will be considered. Possible topics include: grassroots organizations, significant contributions to society, success stories, personal and/or group projects, and personal and/or group problems. In addition, we are looking for "how to" articles regarding problem situations that are commonly confronted by DD consumers. Finally, contents of this magazine may be commented upon in letters to the Editor. The Editor reserves the right to revise any article. Any article specifically written for this magazine may not be published elsewhere without acknowledgement of its source.

Preparation and Length of Articles: As a general rule, articles should be double-spaced and typed on one side of the page. If possible, articles should be submitted in duplicate. In the case of DD consumers, exceptions to the above stipulations will be made when the writer does not have access to a typewriter and other office equipment. Letters to the Editor should be approximately 200 words in length; other articles should be about 500 words in length.

Biographies and Photographs: A short biography of the author should accompany each article. Photographs are welcomed. Photos should be black and white glossies and can be on any subject relating to the article. Photos of authors are especially desirable. In exceptional cases, **POLLING MAGAZINE** will pay to have photos taken of a particular subject. However, prior consent must be obtained from the Editor.

Cartoons and Illustrations: Cartoons and illustrations on any subject pertinent to this field are greatly appreciated.

Tentative Deadlines for the Next Three Issues:

The tentative deadlines for the next three issues are:

March Issue deadline, Dec. 30, 1975

June Issue deadline, March 28, 1975

September Issue .. deadline, June 31, 1975

DAP: Do you mind repeating that? I don't believe my ears!

MR Man: Well, I have to go through my parents because, because I'm not old enough. They won't let me in, no way.

DAP: How old are you?

MR Man: 26. That's not old enough to vote, is it?

At least part of the blame for this situation lies with the parents. To be sure, their intentions are pure; yet they often do more harm than good. The MR consumer who now stands in his parents' shadows should be standing on their shoulders. Even a midget can see more than a giant if he stands on the giant's shoulders. That is how civilization has evolved, with each generation building upon the strengths of the one before. And that is one step in the process of bringing the MR consumer into the mainstream of society. As long as the parents remain over-protective, their children will be incapable of living normal, happy, productive lives. As long as their opportunities are stifled, they will continue to prove the validity of the self-fulfilling prophecy. As long as emotional support brings with it a lack of respect, they will remain a de-humanized element in society.

One Man's Contribution To Society

The most damaging stigma plaguing MR consumers is the widespread belief that they cannot function as productive members of society. Precisely what does this stigma imply? For any individual to live productively, he must develop and maintain a symbiotic relationship between himself and his society. Furthermore, any individual entering into a symbiotic relationship with society must possess the capacity to contribute to that relationship.

It is widely believed that most MR consumers do not possess this crucial capacity. Malcolm B. Brodie is now demonstrating the fallacy in this belief. Mac was a medical corpsman with the U. S. Navy in Vietnam, assigned to a Marine Division. While on patrol, he stepped on a booby trap, was thrown into a tree, and received a severe concussion. He was in a coma for six months. When he awoke, he had permanent mid-brain damage, which manifests itself in symptoms of short-term memory loss and frequent disorientation.

"I wanted to continue in the field of medicine. I especially enjoyed some phases of nursing," Mac said.

After his release from the hospital, Mac became a trainee attendant at the Texas Institute for Rehabilitation and Research. There, two and a half years ago, he met Lex Frieden, a C-4-5-6 quadriplegic, who broke his neck in an auto accident. Mac and Lex became good friends. Together, they developed the concept of a symbiotic

(Continued on P-7)

A Challenge For Colorado

According to the Federal DD act, one-third of the membership of each state DD advisory council must consist of consumers. In practice, most of these positions have been filled by the parents of consumers, and not the consumers themselves. The main defense of this practice is that qualified persons who are true consumers simply cannot be found.

This past August, while in Denver, Colorado, we met a highly articulate MR consumer, Charles Dieterle, from Boulder. Despite his having lived in institutions most of his life, Charles is a sharp character and a born leader. He now serves on the Advisory Committee for the Child Advocacy Project of NARC.

In evaluating Charles' performance on this committee, Ms. Jane L. Kolodziej, Assistant Coordinator of the Child Advocacy Project said, "He has insight into situations that are helpful to those of us working with staff people on the National Advisory Committee. He reminds us of the local program, and makes it easier for us to focus upon the problems that individuals working in the Citizens Advocacy Program face. More importantly, he has kept us aware of the population we serve."

Polling Magazine requests that Dick Lomm, the Governor of Colorado, consider appointing Charles Dieterle to his state's DD advisory council. Colorado is now faced with a challenge, with a chance to become a pioneer in the DD field.

There is presently great unrest and discontent within the ranks of the Colorado's MR consumers (they are, for example, still being paid 10 cents an hour for their work). Charlie could act as their ombudsman on the DD advisory council. Only an individual like Charlie can represent the true interests of his group. Charlie knows the problems because he has been there himself!

(Editor's note: The following is a recent letter that we received from Charlie Dieterle.)

Dear Mr. Poling:

One of my major problems is getting out of Kelwood. It is a residential care run by the Boulder County Board. I figured I learned all I can learn in Kelwood, but I don't have enough money at this point to move out. So I started doing pots and pans eight

hours a day. I get tired sometimes of doing pots. I hope to make my goal to get back as an apprentice electrician's helper cause I remember the good times in Grand Junction when I climbed and put up wires.

I don't like Kelwood. It's too run down and the rent's too high. I get sick and tired of the rules they've got there. Curfew . . . being in at ten thirty. Sitting at the table too long when we get through. I don't care for the houseparents . . . they're not there when you need them and are grouchy and all that. They keep medicine locked up and won't give it to you when you need it. The food should be better and the house should be fixed up. One of the good things they've done was put a sprinkler system in.



One other achievements I want to learn is financing money and doing budgeting better. That's one of the biggest achievements in the outside . . . to make money work in society.

I have a problem dating a girl . . . when I get up or come downstairs she asks if I want to go out. I don't have the money to take her out all the time. And she never pays.

(Signed) Charles Dieterle

We Are People First

The Handicapped At Work:

WE ARE PEOPLE FIRST is a group of mentally retarded adults who are learning to work for themselves. They have lived in institutions, have been talked for, planned for, and decided on in the past.

WE ARE PEOPLE FIRST helps them act, plan, and make decisions for themselves. They want to be known as "PEOPLE FIRST," rather than as handicapped or mentally retarded.

Their second convention, planned for this fall, will be given extensive coverage in our next edition. Five hundred and sixty persons attended their conference last year, at which they told Oregon they were ready to be of service to the community.

The president of PEOPLE FIRST, Ms. Valerie Schaaf, chaired the last convention. During the two days, she demonstrated considerable ease with the microphone — adroitly moving speakers along, prompting them, and relaying messages. Valerie says she has been turned down for jobs "because I'm slow;" she now works the graveyard shift at a cannery. Valerie received a phone call last year from Governor Tom McCall of Oregon, who sent his best wishes to the convention and invited the executive committee to visit his office.

The keynote address of the convention was given by Ms. Judy Cunio. Judy, in her mid-twenties, just received her high school equivalency diploma and is now attending a community college. She used to be institutionalized, but now she is enjoying an integrated life within the community. Below is the text of her keynote address.

I think it is good to hire the handicapped. It is good for both the employee and for the employer. In the first place, it will give the employee a chance to make something out of himself. And second, the employer will find that the handicapped person is often willing to produce more than someone else who has no handicap.

It has always been a mystery to me why thousands of students who really don't want to get an education are forced to go to school. But a handicapped person who might be willing to attend school is told, "you just don't fit in." It is the same in the world of work, and this should never be. It is especially not fair

Freedom of Speech

Editor's note: The following is a June, 1975 report from the President's Committee on Employment of the Handicapped.)

Do mentally retarded people have the right to express themselves? Sometimes they are deprived of that right by their parents. But parents are not always aware they are trampling on a human right, the right to speak.

John E. Winters, Executive Director of the Escambia County (Florida) Association for Retarded Citizens, has witnessed in his office a number of instances of this problem. Here are three of them; the names of the participants have been changed.

Scene I

Cast: Mother; Father; George, 17; John

Mother: Is there an opening in your workshop? You know, George is now out of school.

John: Yes. But George is going to need 16 weeks of evaluation, like everyone else.

Mother: Oh, he doesn't need it. We know he'll make a good worker.

Father: He likes to do things around the house.

John: [To George, slouched with his head down.] George, would you like to work in the workshop?

Mother: Of course he would!

Father: Of course!

Scene II

Cast: Mother, Father; Rose, 18; John

Mother: Rose has has excellent training. She's been in a workshop in Alabama.

John: [To Rose]. How did you like it, Rose?

Rose: I liked it fine.

Mother: She didn't like it at all. She had . . . uh . . . problems with boys. They bothered her.

John: [To Rose]. Do you have a boyfriend?

Mother: Well! She never would do a thing like that! [The father never spoke.]

Scene III

Cast: Mother; Corinne, 19; John. Corinne has had an illegitimate child.

John: [To Corinne]. How's your baby?

Mother: Her baby is fine. Now look, if she goes back to the workshop, I want to make sure she won't have any more contacts with boys. I don't want this to happen again. Corinne isn't really a bad girl. She's over-sexed.

John: [To Mother] Could I talk with Corinne alone?

Mother: Certainly not! Remember. I want a guarantee she will be constantly watched in the workshop.

John: I can't do that.

Mother: I want a guarantee.

John: What do you do when Corinne is home?

Mother: I make sure she doesn't go out with boys! [Six weeks later, Corinne had to be readmitted to the institution. Her mother claimed she was uncontrollable.]

ONE MAN's (Continued from P-5)

relationship.

Lex described their relationship at length: "The mentally handicapped individual helps his physically disabled roommate with such routine daily activities as dressing and undressing, transferring, cooking, and personal hygiene. He might be asked to accompany his friend to school, work, or just out on the town.

"The physically handicapped person provides his mentally retarded roommate with the direction and supervision necessary to effectively complete relatively complicated tasks. He is also available to advocate in his partner's behalf, whenever the need arises.

"In this arrangement, both partners enjoy the fruits of independent living. They share the joys of non-institutional living without sacrificing the care and security offered by the institution. This sort of interdependent relationship may actually result in better care for both individuals than either could receive in an institution, and it certainly leads to a more normal lifestyle."

This symbiotic relationship is working well. A year ago, they leased a 4-bedroom house and talked Robert (an able-bodied student) into moving in with them as their driver. Since then, they have both been more active and independent than before. They have traveled extensively together — something they could not have done alone.

Because of Mac, Lex is now extremely productive. He is in his fourth year of graduate school at the University of Houston and is writing his dissertation based upon a study of personal independence in the daily activities of quadriplegics. In addition, a beautiful young woman has entered his life. Joyce Nelson now lives with Mac and Lex, replacing their able-bodied driver. Joyce is 26 years old and a paraplegic, as a result of encephalomeningomyelitis. In addition to driving and cooking for the group, she is majoring in business administration at the University of Houston. Joyce enjoys the benefits of this symbiotic group relationship and contributes meaningfully to group welfare.

Mac contributes as much as he receives in this group relationship. While his personal function would be greatly impaired without the group, so too would the functioning of the entire triangle be greatly impaired without him. He has become a functioning, productive member of society.

Tomorrow's Challenge

by Judy Cunio

to the handicapped adult who, because of his life-long disappointments in jobs and in school, often has more will to excel than most others. He wants only to prove himself. I can say this because I speak from my own experience.

Sometimes, just because a person is physically handicapped, people think he doesn't have enough intelligence to do a job, but that is not true at all. Being handicapped does not always mean that you are mentally retarded. You would think everyone would know this, but it's not so. There may be millions of jobs the handicapped could do even better than a normal person. Even if his personality is not that way, the handicapped person has had to train himself to be more patient than the average person.

The employer who is boss to a handicapped worker will gain more because he will have better cooperation from his employee. On the other hand, by taking complete care of him and not letting a handicapped person take on the responsibility of supporting himself, the state is doing more harm than good. Everyone, no matter who he is, needs to have duties.

Take, for instance, our state institutions. Think of all the people that must be paid to take care of the many types of handicaps. That takes quite a bit of money. It is much cheaper to have the handicapped living in the community, working and supporting themselves. The state and federal government would save money all the way around, if the handicapped worked. The state puts us into training for years. And then instead of letting us go the whole way and support ourselves, they consider us good for only rest home care. We might sit almost idle for the rest of our lives. All of this care has to be paid for by the government.

We don't want to seem ungrateful, but all this makes us cold with fear.

This keeps running through my mind. Overlook the disability of a person and look for the ability, and you will find a lot more. In fact, you may find a gold mine or two.

To every employer I want to say: Hire the handicapped. We are not poor safety risks. America is a wonderful place. But we need to be free. All we want is a chance to prove that we have a lot to offer, with or without arms, legs, eyes, ears, and yes, even without a high IQ. So please give us a chance.

Retarded Citizens Speak Out

(Editor's note: In a rap session with Bernard Posner, the Executive Director of the President's Committee on Employment of the Handicapped, the following dialogue took place. This dialogue was published in a July, 1975 memorandum from the President's Committee on Employment of the Handicapped.)

"I'm going to ask you a pretty rough question. You don't have to answer it if you don't want to. Here all of you are: you're working, you live in your own neighborhoods. Do the people you work with, or do your neighbors, ever think about you as being . . . uh . . . different?"

I couldn't bring myself to say the words "mentally retarded." But the dozen or so retarded young men and women sitting in a circle in one of the rooms of an association for retarded citizens in a suburb of Washington, D. C., that night knew what I meant.

Silence. I sat on the edge of my chair.

Frances was first to speak. She's twenty, works in a sheltered workshop, wears thick glasses, and is excessively affectionate to everyone.

"I don't like it when people call me retarded," she said. "Retarded means you can't do anything. But I can do many things. I can work in the workshop in Rockville. I can handle my own money. I can take care of myself. So I'm not retarded."

Lester, thirty years old, well over six feet tall, spoke next. He had been silent at first, but when he started talking, it was as if a dam had burst. "Once my father sent me to a trade school some place in Virginia. He said I should learn a trade. It was a trade school for the mentally handicapped. I stayed there one day. I couldn't go back again."

"Why?"

"All those people reminded me of me."

"How do you consider yourself? What are you?"

"Oh, I had a birth defect," he said matter-of-factly.

Georgie was next, a blond young man with delicate sensitive features. "I don't like it when they call me 'gay'," he said.

"Do they call you 'gay' right in front of you?"

"No. But I can tell the way they look at me and talk about me. In the tire warehouse where I worked, one day I went up to a couple of the fellows and I told them, 'You think I'm gay, don't you?' And they said, 'You are, aren't you?' And I stood up to them and said, 'No, I'm not.'"

"Did that help?"

"No, they still talked about me."

"But what about the other thing . . . ?"

"You mean, like, retarded? Oh that doesn't bother me as much as 'gay' bothers me. I'm not 'gay'. I'm not."

Yet Georgie didn't get a job because of the tag, "mentally retarded." He applied for a job in a tire shop and, like all employees, had to take a physical exam. The personnel officer

was ready to hire him. But the doctor called. The conversation, Georgie said, went something like this:

"I don't think you should hire Georgie. He's mentally retarded, you know. The work might be too strenuous for him."

A young woman sat off to one side, the only one not speaking. I watched her. I wanted her to join the conversation, and turned to her:

"And how about you? Would you tell us how you feel when people look at you as be-

ing, uh, different? And by the way, where do you work?"

"Oh, I'm a special education teacher. I came here tonight to observe."

It wasn't that she looked like all the rest. It was that all the rest looked like her. Normal.

Bruce, in his twenties, slightly built, with a tiny moustache, summed it all up so well:

"Reject?" he asked. "That means the same thing as retarded, doesn't it?"

Who Ever Claimed MR Consumers Weren't Creative?

(Editor's Note: The following are excerpts from *Mental Retardation News*, May 1975.)

The poems below are some of those written by nine members of a poetry class at the Training and Rehabilitation Center, Nashville, Tennessee. The poems were published and edited by Tom Hibbett, a teacher's aide at the Center who conducted the class.

"I'd never taught poetry before," Hibbett said. "The teaching method just evolved from day to day. We would read the poems, talk about how they worked. Then they would compose poems of their own."

In the discussion of poems, Hibbett said he found a wide range of understanding — "Some stayed on the literal, overt level; other students went beyond the face value of the poem."

Limited Edition

the poems were published in a limited mimeographed edition called *The Windowpane*, which has virtually sold out.

Some of the poems tell of everyday activities — going on shopping trips, about friends, family, holidays; some are humorous; some take the form of recollections or wishes.

By permission of Tom Hibbett, we are reprinting a few of these copyrighted poems. Tom adds, "In my association with the people at the Center, I learned much more than I taught, not only about poetry, but also about the things of which poetry speaks."

TIME

*Time is for you and me
We have time to be happy
We don't have time to be blue
We have time to make other people happy
We have time to sing
People don't have to hurry
Animals don't hurry
People hurry
They hurry and hurry*

... Jerry Adams

BEACH

*As the girl was walking on the beach
The sea gulls swarmed above.
She threw them food within their reach;
They screamed at her of love.*

... Priscilla Dolan

RIVER

*Merry Christmas house
With a dog outside the house
Tied by the house
A house along the river
It's a beautiful . . .
Happy Christmas river
Happy river
People fishing
People playing in the water
Mountains near the river
And a happy house
Trees are pretty
Happy poem
Pretty river
The boat in the water
I love the river*

... Linda McServy

Standing on a New Frontier

(Editor's Note: A fresh challenge, a new frontier, effects everyone differently. Here is how two EFA Service Agents respond to their new experience.)

Last spring, I went to the Bureau of Vocational Rehabilitation in Pittsburgh in an effort to secure a job. In August, I received a call from my placement counselor telling me to call Mrs. Beth Korelitz from the Allegheny Plateau Chapter of the Epilepsy Foundation. In September, the grant for the project was given to the Chapter and Bess (as she likes to be called) was full of enthusiasm as she told me about my new job.

I am approaching this project with great

hopes and not a little trepidation. My first priority will be to understand the scope and limitations of my work and to establish a realistic, concrete goal attainable within the limits of my time and funds. I am especially anxious to talk with epileptics and parents of epileptics because I have been fortunate to have had an almost normal background, and I feel that I have an open, healthy personal attitude toward my epilepsy. I see my own attitude reflected in the attitudes of others. Communicating this self-image to others will make my efforts worth while.

Mary Beth Smith Service Agent
Western Pennsylvania

Epilepsy and Today's Society

by Herb Leavitt

Although we live in an age of technological and medical sophistication, we still treat epilepsy, a condition of neurological instability, as an illness of the dark ages.

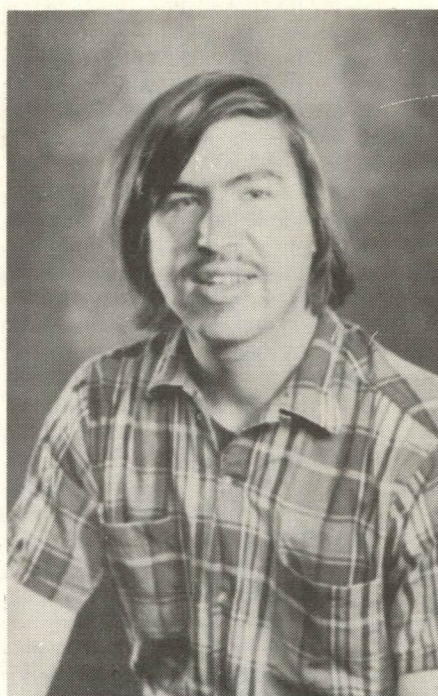
Maine alone has a total of twenty thousand epileptics (one fiftieth of the state's population); yet, few of them will receive the proper care and treatment necessary for the severity of their condition. For years persons with epilepsy have kept their affliction secret. Not until recently has the public awakened to the realities of treatment and counseling as alternatives to institutionalization and heavy sedation. The person with epilepsy has finally begun to come out of the woodwork.

While most epileptics are capable of leading normal lives with the aid of proper treatment, there still remains a small percentage who either are receiving no treatment or are psychologically incapable of handling the circumstances surrounding their condition. Those not receiving treatment, for the most part, aren't because they feel that their condition is demeaning; they do not want it publicized. Many times, this pride is the cause of serious injury and, in some instances, death. For if the epileptic had let someone know before hand what to do in the event of a seizure, injury could have been reduced considerably and, in some instances, avoided entirely. Those psychologically incapable of handling their condition are too often either institutionalized or heavily medicated so that their opportunity to understand epilepsy is greatly reduced.

The person with epilepsy should be made aware of the psychological and physiological dangers that come with rejecting the realities and responsibilities of the condition. Only too often, the condition worsens as a result of psychological stigma (tension, depression, etc.) or outside physical interference (colds, flu, over-tiredness, etc.), and the administration of powerful tranquilizers becomes the only alternative for restraint of the problem.

While extreme caution should be taken toward any physical or emotional strain, the epileptic should not become too physically lax, and should be encouraged to become involved in most normal forms of activity, such as taking walks and playing basketball. However, extreme caution should be exercised when the patient is involved in such activities as swimming, driving a motor vehicle, or anything else that might pose risks to the patient or to those surrounding him.

Although most forms of epilepsy are treated with proper medication, the disease still has its uncontrollable side. Such drugs as phenobarbital and dilantin are in most cases capable of treating and, at times, arresting the condition. However, even in an age when modern medicine has the capability to control much of the condition, there still remain many cases where the cause of disorder is never



discovered and the proper form of treatment never found. Even so, someone who becomes an epileptic does not necessarily remain one, for in most cases the patient will outgrow his disorder, the problem will correct itself, or corrective treatment is ultimately discovered.

There are times when the condition is not correctable, not just as a result of difficulties encountered in the disorder itself, but as a result of difficulties brought on by the patient himself. I have encountered persons with epilepsy who not only refuse to discuss their condition, but treat it as if they were perfectly healthy. The use of such stimuli as alcohol and street drugs, or even excessive amounts of caffeine to counterbalance the barbituates which control the condition, often cause petit mal and, at times, grand mal seizures. In some instances, minor brain damage has been reported as a result of mixing outside stimuli with anticonvulsive medications. Alcohol and drugs of any nature, except the specified medication, should be avoided entirely. If coffee is used, it should be decaffeinated. Such precautions should be followed whenever anticonvulsants are being taken.

Too often, epilepsy is incorrectly diagnosed and treated during a seizure due to the unavailability of specific and necessary medical information. As a result, the extent of damage is often worse than it might have been. It is because of such situations that identifying material like Medic Alert bracelets and/or necklaces should be worn, so that proper diagnosis and treatment may be undertaken.

I recently had a grand mal seizure in a local coffee shop in Augusta. As a result of the panic that ensued, I now have three stitches in the back of my head and have gone through several weeks of constant petit mal seizures. If somebody had only taken a coat or sweater, folded it up, and placed it between my head and the floor until the ambulance arrived, chances are that I would not have been injured.

In the event of an epileptic seizure:

1. Move all objects out of the patient's way so he doesn't become injured.
2. Insert something (spoon, tongue depressor, etc.) between the teeth so that the patient will not swallow his tongue.
3. Call the ambulance.

The last thing you should do is panic. Frequently, a person having convulsions becomes injured worse than he might have because somebody became frightened; the epileptic having a seizure is of no danger to anyone but himself.

Most epileptics are not looking for sympathy. But a greater understanding and acknowledgement of the nature of the condition is essential, for the person with epilepsy is still looked upon as one of society's outcasts. It is not unusual that an epileptic is unable to acquire gainful employment because the employer feels the nature of the condition is too great an insurance risk. As a result, it is only through state and federally funded programs that the person finally has the opportunity to become as successfully employed as his associates.

*I
love living
am a woman
enjoy my marriage
like to read
to run
to play tennis and ski*

*love living
find people fascinating
hate discrimination
try to live ethically
to constantly learn
to constantly grow
to understand my self and others*

*love living
am an epileptic*

Stephanie Grossman
Service Agent

Epilepsy Association of Central Maryland

Interview: Chris Brady, Houston Service Agent

(Editor's Note: On August 11th, my wife, Terry, and I travelled to Houston, Texas to interview Christopher Brady, the EFA's service agent for that area. With the campus of the University of Houston serving as a backdrop, Chris and I sat and talked.)

DAP: Before we begin, what's your name and background?

CB: My name is Chris Brady. I'm 23 years old. I was born in Texas up in the Panhandle, went through 3 years of college, and was accepted in Dental School here in Houston, at the University of Texas Dental Branch.

DAP: Could you talk about the first time you realized that you had epilepsy?

CB: On November 22 of my first year at dental school, my folks were down visiting. As I was waking up that morning, I had my first seizure. When I finally did wake up, I wondered what the firemen were doing in the apartment. I thought the apartment complex was on fire. I remembered my wife, Ronnie, was nearby, crying. That was when I went through a battery of tests. At first they thought I had a brain tumor or something. But the diagnosis turned out to be epilepsy. I was lucky enough to get stabilized on my medication fairly rapidly.

I was doing fine and finished my freshman year of dental school, and after I got out of school, I decided that I didn't have epilepsy, that there was nothing wrong with me, that I had just reacted to the pressures of school. And I quit taking all the medicine. On June 21, I had another grand mal seizure, and this time when I woke up the firemen had me halfway to the ambulance. Needless to say I got back in touch with my neurologist, got readjusted to my medication, and have had only two petit mal seizures and no grand mal seizures since then. I've been lucky.

About this time a year ago, a friend of my wife who works with the hotline for runaway children here in Houston suggested that we look in the yellow pages to see if the city had any organization where people who had epilepsy had banded together. We finally looked and found the Houston Epilepsy Association. We got in touch with them and scheduled some counseling. More than anything, it made me realize that I wasn't alone. It made me realize that doctors don't tell you a lot of things that the medical profession really knows.

DAP: Could you be more specific?

CB: Some people that were starting vicious rumors, saying, "Now you all won't be able to have kids because Chris has

epilepsy," and things like that, things that I now know are totally absurd. The counseling put my wife and I back on track. I was feeling sorry for myself at the time, very sorry. I kept wondering, why me? Why did this have to mess up my life? It knocked me down, but I was finally able to shake it through counseling and through the fact that I began to work with other kids. When you see a 13-year-old who has seizures three times a week and he's able to cope, you realize you have little to feel sorry for. The counselor at the Houston Epilepsy Association, Ellie Jacob, started a teen group, and asked my wife and me to help her with it. We've been working with them for a year now. We have a fantastic time. The group meets and exchanges gossip about what went on in the two weeks since they're seen each other. Then we break up into smaller groups — sensitivity sessions — and Ronnie, Ellie, and I each take one group with about 15 or 20 active members, and we sit and discuss things that are bothering us, like whether we share our medication with others at school, what peer group pressure is like from friends, whether we try to convince them to share our medication. We also talk of morality; whether we use our parents, whether we use our affliction to get something out of our parents, whether we use our brothers and sisters. We dig into dozens of things, and the kids get a lot out of it. In fact, we haven't had a meeting for about a month and the phone has been ringing off the wall. They all want to know when we're going to have another meeting.

DAP: Were you having any emotional problems before your first seizure?

CB: Not as far as I could tell. My wife and I had been married for almost a year and there were no real problems. Everything was related to the onset of my epilepsy. My wife didn't know how to take it. She went to the doctor — the first doctor we went to — and she wanted to know what to do when I had a seizure. He wasn't about to tell her — he didn't tell her anything — and she was scared to death. She was afraid I was going to swallow my tongue and turn blue in the face and die, or chew my tongue up. She didn't know whether to stick a pencil in my mouth or what. Finally, my neurologist talked to her and the counselors talked to her and we now know what to do when I have a seizure — if I have a seizure — and how to handle it.

DAP: Are you ashamed of your epilepsy?

CB: No, I'm not ashamed of it at all.

DAP: What about after you first found out?

CB: After I first found out I was . . . we were very frightened. We thought it was a brain tumor or something similar, but after it was diagnosed as epilepsy, I was

mostly confused. I didn't know what it was, I didn't have anything to relate to it. I could only remember a student at college who had epilepsy. He had a seizure in the cafeteria, and he dropped his tray and his food went flying everywhere. I can remember how everyone laughed and how sick it made me feel, and I thought, now I've got what he's got, but I didn't know fully how to accept it, and . . .

DAP: Did you feel like a freak?

CB: I then felt as if I was the only one who had my affliction. Yes, I guess I felt weird, I felt different, I didn't feel . . . after it began I didn't feel . . . it put a definite strain on my wife and me and our relationship.

DAP: Did your wife reject you for a time?

CB: No, I don't think she rejected me. I think she was scared most of all. I don't think it was an out-and-out rejection. She didn't know how to react to the situation as it stood. But after the counseling, when she found out that I wasn't the only person in the entire world who had epilepsy, she became interested and is now taking an active part in the group and in working with the kids.

DAP: Do you think your disability has made your relationship with your wife stronger?

CB: Definitely. It brought us together, because we've gone through a time of trial together, sailing through this storm in our small boat. We've weathered the storm, and we're still together. Our relationship is stronger for it. We're both active in the Houston Epilepsy Association.

DAP: What do you want for the future?

CB: I have several dreams. I hope to be able to go to a smaller community to practice dentistry and not have people look down on me simply because I have epilepsy. At one time I was worried about handling people who looked down on me, made me feel small, especially in a smaller community where I might be the only dentist for 3 or 4 thousand people. How would the people react to me if I had a seizure in my dental office? Would I lose all my patients? Would they all start going to someone else? I was worried about that, but my wife and I talked about it and decided that if it happens, it happens. I'm not going to change. Hopefully, some people are going to realize that it doesn't make any difference one way or the other. You have to have faith in your fellow man, and that's what we're basing the entire concept of our future on right now. I went through a trial at the dental school after I got back from the hospital, after my first seizure. I was in the hospital for about 2 weeks, trying to catch up in school. The Dean of the College called me in and talked to me. He was concerned about my ability to study dentistry while I had epilepsy. I

didn't know what to do, and he said he would talk with me about it at a later time. I caught up with my school work and we started going to the Houston Epilepsy Association. When he called me back into his office in August of last year and I talked to him, I was on my feet. I knew what I was talking about. I was able to put up a good defense. He was pointing out some things that I hadn't recognized about dentistry and epilepsy, the possibility of having seizures, and he was trying to suggest alternatives. I wouldn't have anything of it. Nothing else has been said, and I don't think anything will. I think I am accepted for what I am, for the fact that I can do it. As long as I continue to succeed, everything will be fine.

DAP: Do you try to conceal the facts from your patients?

CB: I don't make an issue of it. I guess most of the people at the dental school probably know I have epilepsy, because I missed two weeks and they asked me about it.

DAP: What about when you start your own practice?

CB: I'm not going to conceal it, no. It's me, it's a part of me — I'm not going to be a phony. They can accept me for what I am, for what I have, for the quality of work that I do, or they can go to another dentist. If they do, I'll go out and dig ditches, I guess.

DAP: Do you plan to have children?

CB: Yes, definitely. My wife and I have talked about it and we've found out it's not necessarily a clear-cut case of genetics. I have epilepsy, my children may not. I found that certain states still have laws forbidding people who have epilepsy from marrying or having children. I had a similar problem at school, where some of my friends gave me a bad time about my marriage.

DAP: I never knew a seizure was the equivalent of a divorce proceeding!

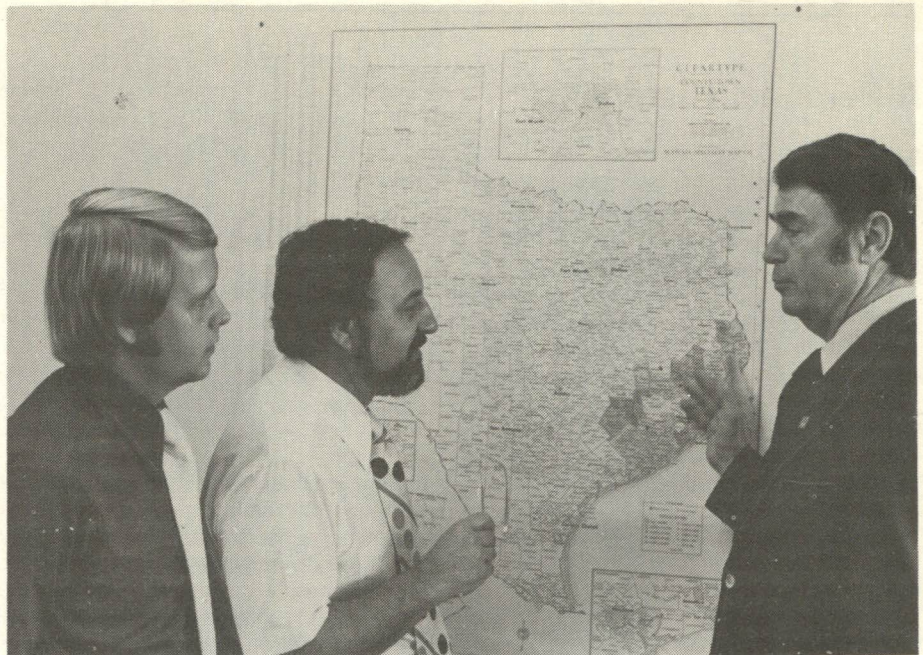
CB: Well, one so-called friend said that if I had children, my wife and I would be bringing down "the overall genetic character of America," and I was ready to fight. I compared him to Hitler, trying to inbreed the population for a certain strain. I was really upset. I can look back on it now and see it as funny, but at the time I was really upset about it. It just shows ignorance that exists — that even sophomores in dental school, who supposedly had absorbed some medical information, had such a concept of epilepsy.

DAP: That is so pathetic it is funny.

CB: It is, it really is and I feel sorry for the person who said that — he just doesn't realize what he is saying.

DAP: Tell me now — what do you like about the HEA service agent program?

CB: The thing about the overall concept of the program is that it permits the person with epilepsy to work with others. It



Chris Brady with Don Franis and Fred Ross, Executive Director of Houston Epileptic Association.

gives him total exposure to other people, as well as giving non-handicapped people the chance to see us, to see that there isn't anything really wrong with us, that we're able to function within society. And that's what we want, after all. To be accepted for what we can do. We don't want to be given a free ride for anything. That, plus the fact that we have a chance to try to start a really reliable consumer group, is something that is a challenge to me. I pulled a few strings and we now have a parents' group in addition to the teen group that we began. And the parents are really interested. They're waiting to start the sessions. It's not just the person with epilepsy, or the child with epilepsy, it's everyone. If we start with the parents of the teen-agers, we can expand to the entire community.

DAP: Do you have any reservations?

CB: None that I can see. I was thinking at first that we were going to build a consumer organization of three or four thousand people and touch bases with everyone who has epilepsy, but I'm coming to the realization that that is probably impossible, that many people are not going to want to take an active part in it, even though they may have epilepsy. We found several people here in Houston who have epilepsy and are scared to admit it. They're afraid that it's going to hurt their careers, or knock them out financially, or whatever. If we can pull five of them over, influential people, I'll be pleased. Let the people know about the agency, let them know what we have set up, and let them know that we are here. It'll be tricky — but that might be my only reservation — the

fact that I don't reach as many people as I would like to.

DAP: Why will it be tricky?

CB: Because a lot of the people are afraid of the stigma attached to their handicap. A business man, who has been out in the community for 20 years has epilepsy, but nobody knows it, not even his wife. She just knows that he takes medication and she doesn't question him about it . . . he's going to be very, very leery about coming right out and saying, "Hey, I have epilepsy. Accept me for what I am." I mean, he's been living in the dark and hiding. Because of his attitude, he is going to turn around and put off anyone with epilepsy twice as fast as he would someone else because he's afraid that that person will see in him what he has. That's where the challenge lies, getting these people to accept us. I think we can do it, but it's going to be hard. I really don't know what means we're going to use.

DAP: One more question. What do you have to say to others with epilepsy?

CB: That's a big one! There's so much I'd like to say. I suppose the most important thing is to accept the fact that you have epilepsy. Begin to form groups. Get in touch with the National Epilepsy Foundation of America, and work for a reliable consumer organization for those who have epilepsy. This is the only way we can make our needs known.

You can see how racism is, how it hasn't changed completely, even though integration was ordered long ago. In a sense, we're fighting the same kind of fight. To be recognized. And that is the biggest thing we have to strive for.

A Personal History

by Annette L. Pitre



As an epileptic myself, I know the need for research on this misunderstood disease. Epilepsy can strike anyone at any time. It makes no distinctions among its victims. Yet society brands seizures as "fits" and those of us with epilepsy as outcasts. In the hope of encouraging further research, I wish to enlighten the public about my disease.

I was born in 1936 in Southern Louisiana. My birth was hard, and I had my first convulsion at seven months, a problem which was not then diagnosed as epilepsy.

In the second grade, I was taken out of school, because my doctor feared that it was too much of a strain. But thanks to a wonderful teacher and my family, I made high grades at home and graduated.

I began taking medication and the convulsions disappeared. I finished high school with honors, graduating second in my class. After graduation I quickly went to work, finally finding a position I loved, as a legal secretary.

Then it hit me. I was in an automobile accident in 1958, and just barely pulled through. It was then, for the first time, that I was told I had epilepsy, either as a result of my difficult birth or from the automobile accident. Fortunately, I was able to return to work.

Within a year, the seizures began to worsen. I had to give up driving, even though the seizures were mainly petit mal, and I never had any after effects. In 1968, I had a nervous breakdown and was finally forced to stop working; the doctors related it to my epilepsy.

There are those who try to bury their problem through shame or embarrassment. But I tell anyone I am with that I have epilepsy so that if I have a seizure, they will know what to do. To me, epilepsy is simply another disease; because of my medication, my seizures are infrequent and the restrictions on my activities minimal. People are generally understanding, and, as they learn more of my problem, seem to want to spend more time with me. I have learned that epilepsy is not an unusual liability; as long as I take the necessary precautions, I can carry on as well as anybody else who is afflicted with one of nature's lesser diseases.

A Bitter-Sweet Life

(Editor's Note: The following is reprinted from the **National Spokesman** of EFA, February, 1975.)

It was more than twenty-one years ago that epilepsy hit our family. To keep up with the expenses of a family with six children, my husband was working two jobs. I remember very well; it was the day before Thanksgiving, 1953. I was in the basement doing the laundry, trying to get everything done before the holiday, when the phone rang. I was told to come to the hospital at once as my husband had been injured, but what had happened to him had all the doctors puzzled. After many, many days in and out of the hospitals, many tests, X-rays, and EEG'S, they finally found that my husband, at age 38, had had a grand mal seizure; he had epilepsy.

It seemed like the end of the world to us. My husband went on medication and didn't have the second seizure until 11 months later. He had the car running that morning and was getting ready to leave to take the boys and get some work done on our old car. He came back in to kiss the baby goodbye, then went back out. I suddenly wondered why he hadn't left yet, looked out the window and there he lay, face down in the cinders of the driveway! It was my first experience of a seizure, and I thought it was horrible. We had to call the emergency squad and get him to the hospital. Thank God he heals quickly!

That was only the beginning. Since we had a large family, my husband had to continue working. He never had a seizure on the job, but many, many elsewhere. Each time he wouldn't be able to work for several days. I went to work when my youngest of six was four years old (1953), and have been working, sometimes part-time, sometimes full-time, ever since.

My husband worked, (and I might add, did a good job of it) until 1960. In October 1960, he was critically injured, through no fault of his, but from company negligence. His back was fractured in five places, his kidneys were damaged, and there were many more external and internal injuries. I was working at the time in a wholesale drug house full-time and expecting my seventh child. Again, I got the phone call my husband was critically injured and in the hospital.

When my husband was able to talk, he informed them he was an epileptic, so he could have medication. The company he was working for used this information against him.

Finally, after several years, he did get Industrial Compensation and Social Security. For several years, it was rough. I had to condition our children to be big enough to live with what had happened to us, to go on and live their own lives, to look ahead to their own futures. Living with epilepsy is like living over a bomb, not knowing what minute it will explode. As the years have passed, my husband's seizures have increased. Sometimes he has three in one day. Once he had a seizure in the bathtub with the water running, I found him just in time! I'm not tossing bouquets at myself, only explaining.

My husband is very, very bitter about it. He says "Why me?" He is one of a family of nine, and even his brother and sisters have shied away from him. So is it any wonder people who are afflicted or their families don't care to broadcast it?

My husband would like to work again — but he knows that is gone forever. He enjoys the summer time when he can get out. He does cut the grass and take wonderful care of the yard, as much as his back will let him. He has lost five inches in stature and has a kyphosis on his back, which is also crowding out his lungs. So every seizure he has tears up his back; he is months getting better, and he lives in constant pain. In November, 1972, I had to rush him to the hospital again. This time, it was a perforated bleeding ulcer. He wasn't expected to live through the day. They couldn't possibly operate because of his extremely weakened condition and chronic emphysema. However, after they froze him and gave him 13 pints of blood, he started getting better. He was in the intensive care unit for four days.

I have cited just a few incidents in the life of my husband. There have been many, many more. I thank God, humbly, for my seven wonderful children — six of whom are happily married. Their husbands and wives all know of "Dad's condition."

Our oldest son is a paramedic and saving lives. Our youngest is now 12, has never missed a day since her first day of kindergarten and is doing fine in school. She has grown up with her Daddy's "condition."

You're welcome to my story, but don't use my name (because of those seven wonderful kids.)

Epilepsy Foundation Consumer Action Groups

(Editor's Note: Last spring, the Division of Development Disabilities, HEW, requested the Epilepsy Foundation of America, Inc., United Cerebral Palsy of New York City, Inc., and Polling Magazine to cooperate in developing a DD consumer movement. The following is a description of the joint efforts of EFA and Polling Magazine towards this end.)

The Epilepsy Foundation of American (EFA) has recently received funding for the development of a nationwide network of self-help consumer groups composed of those afflicted with epilepsy.

The overall objective of the project is to establish groups attached to and growing out of existing EFA chapters. Until now, chapters have not had the capacity to expand the pool of vocational opportunities or to exert influence upon providers of relevant services.

The program has several goals, all of which serve to strengthen the concept of group action:

a) employment of individuals with epilepsy as service agents to the consumer groups.

The service agent is to organize and mobilize consumer interest through the development of a broad, prognostic effort. The goal is to establish a nucleus, convening a committee to arrange a general assembly of consumers. The service agent is to start a group process organized around the most pressing issues, to identify the procedures that govern human involvement in service systems, to stimulate and maintain greater cooperative efforts with service providers on a broad front, and to establish regular entry into the service systems for the consumer group.

b) emphasis upon consumer input within a program format, a concept consistent with EFA policy;

c) development of a newsletter, **Polling Magazine**, to disseminate self-help group ideas and innovations, including those related to consumer action;

d) creation of a self-help model at the local level as a permanent, functioning bridge between the consumer and EFA, the service agency.

The new project hopes to create access to existing services, and presents an alternative design for the disabled consumer. The first design, already in existence, retains the service agency as the main determinant of both consumer needs and services. The second is EFA's innovative program, which sees the client as more than a passive consumer. This new model suggests a more aggressive approach. From the outset, consumers obtain and mold services to meet their own needs through group action.

Such a program is not entirely without precedent. Short-term groups established in experimental programs in Chicago, Atlanta, and San Antonio demonstrated the need for such a design among a multiple disabled population with extremely limited prior vocational experience. The study led to an increased desire on the part of some states to provide more and better services. Furthermore, correspondants from many areas have conveyed a sense of isolation, confusion, and uncertainty in their vocational options, and have expressed a desire to associate with other persons who have similar problems.

Functions of the Self-Help Groups

The self-help groups will have two functions. They will focus upon the nature and extent of the personal problems confronting the members; and they will critically assess available resources, expanding to meet whatever needs arise.

In doing so, the groups will become particularly important for the individual. The person with epilepsy is frequently stigmatized, forced to withdraw and isolate himself from society; fear of rejection may cause him to avoid using even those services which are presently available. The group can provide a sense of support and confidence, not only by encouraging him to interact with others, but by preparing him vocationally and improving his knowledge, motivation, and commitment to move into the mainstream.

The plan also assists the service agency by increasing the visibility of the consumer in an organized and economically feasible way.

The EFA project evolved from the observation that the disabled consumer needs a more permanent structure for self-help and social action. The most conspicuous lack in previous studies has been the dearth of opportunity for continuous association on mutually distressing problems.

The final goal of the new project and, indeed, of consumer-oriented rehabilitation as a whole, is to strengthen and expand group effort to achieve a wider, more relevant range of goals and the permanent integration of the disabled into society.

The Pioneers . . .

The following is a list of the EFA fifteen service agents and their respective Chapters.

1. Pat O'Keefe
Service Agent
Minnesota Epilepsy League
529 Jackson St., Suite 225
St. Paul, Mn 55101
2. Dan Collins
Service Agent
Western Washington State Epilepsy Society
145 North West 85th St., Room 203
Seattle, WA 98117
3. Donald Paddock
Service Agent
Epilepsy League of
Metropolitan Portland
718 West Burnside
Portland, Or. 97209
4. Jane Huson
Service Agent
Epilepsy Association of Franklin County
137 East State Street
Columbus, OH 43215
5. Robert Bruce Yelton
Service Agent
Epilepsy Society of San Diego
1612-30th Street
San Diego, CA 92102
6. Rose Snyder
Service Agent
Epilepsy Society of San Francisco
693 Sutter Street, Room 318
San Francisco, CA 94102
7. David Fabian
Service Agent
San Antonio Epilepsy Association
1119 South Alamo Street
San Antonio, TX 78210
8. Christopher Brady
Service Agent
Houston Epilepsy Association
2472 Bolsover, Suite 286
Houston, TX 77005
9. Minerva Garza
Service Agent
Georgia Chapter, EFA
2779 G-1 Clairmont Road, NE
Atlanta, GA 30329
10. Judy Goodman
Service Agent
Big Bend Epilepsy Foundation
1005 East Park Avenue, P. O. Box 1515
Tallahassee, FL 32303
11. George McKay
Service Agent
Palm Beach County Chapter
c/o Seizure Control Clinic
2935 Australian Avenue
West Palm Beach, FL 33407
12. Stephanie Grossman
Service Agent
Epilepsy Association of Maryland
2518 North Charles Street
Baltimore, MD 21218
13. Charles Vogel
Service Agent
Washington D.C. Area Chapter, EFA
1328 South Dinwiddie Street
Arlington, VA 22206
14. Mary Beth Smith
Service Agent
Allegheny Plateau Chapter, EFA
438 Union Trust Building
Pittsburgh, PA 15219
15. Linda MacNevin
Service Agent
Epilepsy Society of Massachusetts
3 Arlington Street
Boston, MA 02116

I Cannot Do What I Want To Do Most — Work

(Editor's Note: The following letters are reprinted from the **National Spokesman of EFA**, September, 1974.)

It Is Ironic

It is my belief that productive work has true value in life and contributes to one's self-esteem, which increases as we produce for others.

For many years, I have lived in the hope of being able to produce in my society. While earning my M.S. through part-time employment, I hoped for the day when I would be able to apply my education. However, employers are still reluctant to accept the handicapped and let us both build our self-esteem and produce for them.

When I apply for a position, I must admit to a physical handicap which would in no way hinder the performance I could and would render. This admission causes me to be classified as "over-qualified" or given some other excuse for not being hired.

It is ironic that I am not seriously enough handicapped to qualify for DVR services or for Social Security benefits, yet I cannot do what I want to do most — work.

E. Louise Woods
Oak Park, Illinois

I AM A VICTIM -

I am a victim of petit mal epilepsy. I use the word "victim" only because of the ignorance of other people.

I've been on medication for a number of years and am perfectly healthy. I've been in the service, driven a cab, driven a school bus, been in sales work, and been a security guard. I've done all these things because I didn't reveal my secret.

It's a shame that it had to be a secret, but I know what prejudice can do.

No one would have ever suspected if I hadn't cut down on my medication without consulting my physician. I hadn't had any attacks in years.

Shortly after, I passed out at work. You know the rest. My physician explained, but things were not the same. I quit and went elsewhere, but they were advised by my former employer; it didn't work out. Now I've just become unemployed again. I find some people will not accept me, even though I have only had one seizure in over 16 years, through my own carelessness.

E.R.W.
Missouri

NOT BEEN HIRED

Every time I pick up a newspaper or turn on TV or radio, I hear, "Hire the Handicapped." Well, this is one irate "handicapped" that has not been hired for many years, although I've applied many times.

I have almost two years' experience working as a medical secretary-receptionist, but this doesn't seem to count for much. I lost that job because, while at work, I suffered a grand mal seizure, witnessed by my stunned physician boss. After a neurological workup the next day, my condition was diagnosed as

A Portrait Through Poetry

(Editor's note: Many times, the deepest feelings are best expressed through poetry. This is true of the following two poems. The first, "The Shelf," expresses a serious problem which confronts all epileptics. The second, "Teamwork," suggests the solution.)



THE SHELF

*Why can't I truly be,
Myself — and no one else?
Why must society shove me,
An epileptic, upon a shelf?*

*Why is it that society
Rejects me as a whole,
And my friends disown me,
Once, the truth, they know!*

*Why can't people understand
That I am just like them?
That I have their same feelings —
Plus the longing to have friends!*

*Why can't people accept me —
Accept me for myself?
Why must society shove me,
An epileptic, upon a shelf?*

— Martha Jean Smith



TEAMWORK

*As we demonstrate our Teamwork
And recognize the need
Our sincere cooperation
Will help us to succeed*

*With faith and confidence in self
We willingly face facts
Appreciation we will earn
Resulting from our acts*

*The least hopeful to succeed
A challenge unexplored
Can lead to benefits untold
And reap its own reward*

*Potential for a better life
Is here within our reach
We use this opportunity
To learn much as we teach*

*If we courageously accept
This challenge that is ours
As we do our part, we will find
Strength from higher powers*

—Joan A. McDonough

.....
epilepsy. When I told my boss, he hissed, "Well, what did you think you had!"

My latest neurologist suggested that I not put down on an application that I have epilepsy (I have gone four years without a seizure). If I had a seizure while at work and was dismissed, at least I would have worked for a brief time. But why should I be forced to lie all my life?

Ms. B. E.
Arizona

EVASION —

My seizures have been in check since March, 1955. I had worked for a restaurant for six years and then, knowing they were going

to change ownership, started to look for another job. When I typed my resume, I said that I had a brain injury problem that had been in check since 1955. Only one was even answered, and when I went for the interview and explained the problem was epilepsy, the man actually had to struggle to keep his composure.

My neurologist said if I planned to get a job, I had to change the resume. After three weeks of no work, I did. I went to work in a matter of days, but an epileptic cannot live a normal productive life if he or she must evade the truth.

Ms. M. N.
California

Where Is UCPA Headed?

by Bruce Oka

(Editor's Note: On August 14th, 15th and 16th of this year, John Bell, Bruce Oka, and I met in Fort Smith, Arkansas to discuss matters of mutual concern. The following article is a result of that meeting.)

At times, an adult with cerebral palsy looks at United Cerebral Palsy of America and wonders where on earth this organization is headed. Its official name implies that it is an organization of people with cerebral palsy, run by people with cerebral palsy. In reality, however, such is simply not the case, and the time has come for adults with cerebral palsy to stand back and examine precisely what this organization is all about.

The pamphlet, "Report To the Community," published by the Fund Raising Division of United Cerebral Palsy of New York City, Inc., states: "Doctors and the public scarcely understood cerebral palsy only a generation ago. Concerned parents of handicapped children went from doctor to doctor before finding one who could diagnose the condition. Often, they prescribed no treatment, counselling parents to put their children in institutions.

"Unwilling to accept hopeless, empty lives for their children, some of these parents banded together to give one another mutual strength for helping their children and themselves. They were the beginning of United Cerebral Palsy."

UCPA is in the midst of an evolutionary process; our criticisms are thus intended to be constructive rather than destructive, for growing pains are not only normal but also healthy.

UCP has reached the stage in its evolution where adults with cerebral palsy should have a greater voice in determining its basic policies and where parents and other non-disabled volunteers should play a far less active role. Although a non-profit organization does not have any monetary stockholders, UCPA does indeed have stockholders of a very unique type: those with cerebral palsy. Without this unique stock, the entire association would be rendered null and void. So, let's stop playing games! Not only should we control the majority of the shares of stock within the company, but we should also be receiving dividends, in the form of quality programs. Since we are the only ones who are in a position to adequately judge which are and which are not quality programs, to deprive us of our voice renders the entire national organization a farce.

With the above as our motivation, John Bell, Dan Poling, and I are organizing a Caucus of Adults with Cerebral Palsy. The Caucus must become the active advocate of those with cerebral palsy, both within UCPA and outside of it. It will also be run by democratic principles.

The rationale for the operation of such a Caucus is given in the following article by Marie Moore. We are greatly disturbed by how

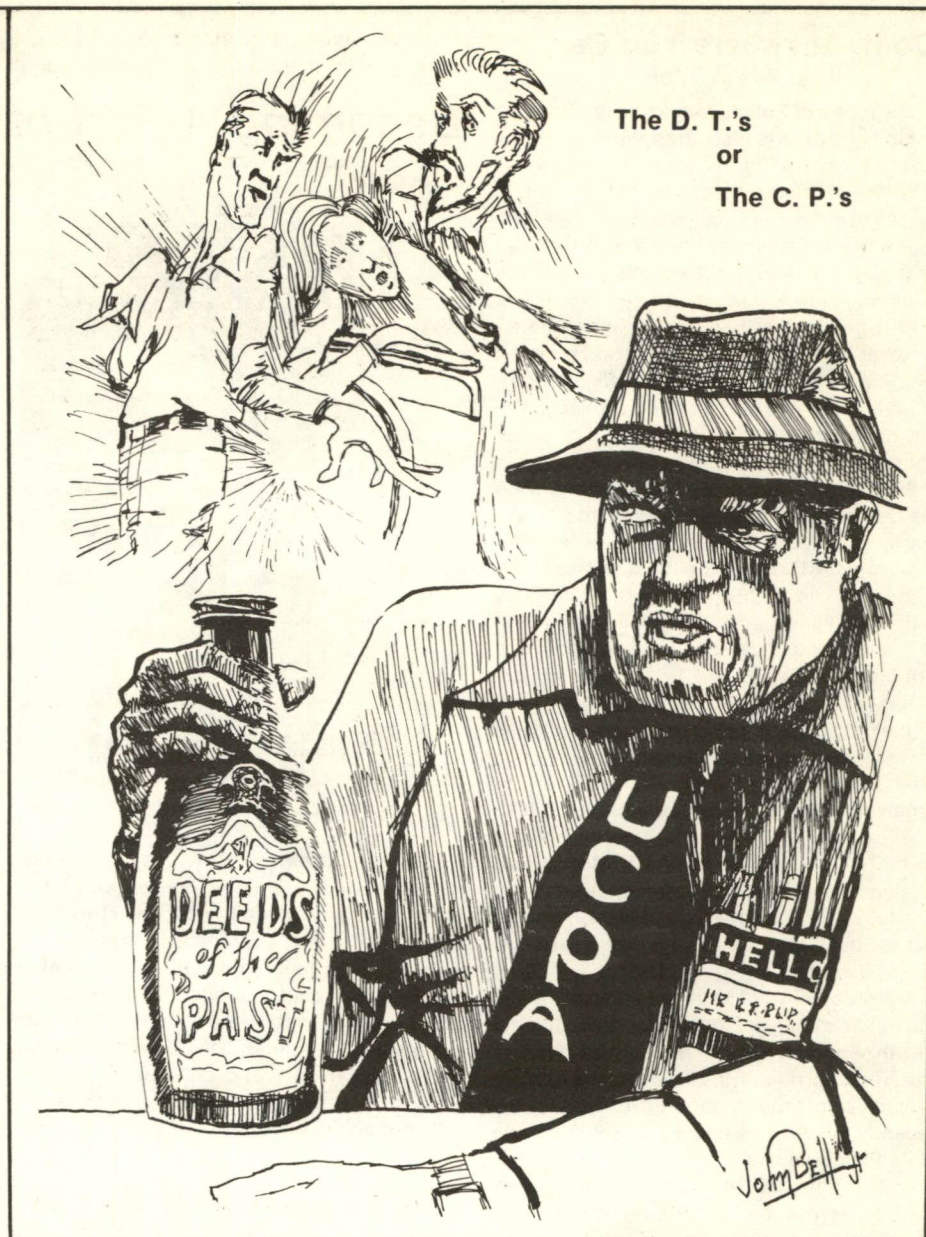
few adults with cerebral palsy are appointed to the standing committees of UCPA and by the way in which these appointments are made. Take, for example, the appointment of Tom O'Brien to the Chair of the Consumer Activities Committee, which makes him a vice president of the corporation and enables him to sit on the Executive Committee. We consider Tom a good friend and applaud his professional integrity and honesty. But his disability is polio, not cerebral palsy. Indeed, while he was being considered for this position, Tom raised the same objection himself, and the reply was always the same: "Unfortunately, there are no adults with cerebral palsy in the entire nation who are qualified for this position."

If this is not outright bigotry and prejudice, we are at a loss to know what is! This attitude seems to permeate the thinking of a substantial number of key individuals in UCPA. Therefore, at least one consumer from each affiliate should be sent to the National Convention in Pittsburgh in April; National should

pay for one-half of each consumer's expenses, with the other half to be borne by the local affiliate. We are also calling for these consumers to observe both the Corporation and the Board of Directors meetings. Finally, we are calling for a mass meeting of consumers afterwards, to evaluate the performance of both the Corporation and the Board, an evaluation which will be published in a subsequent edition of **Polling Magazine**.

Outside UCPA, the Caucus will act with complete autonomy. It will take an aggressive role in the Federal DD structure and in the American Coalition of Citizens with Disabilities, Inc. The disabled minority is just starting to organize into a viable political force, and the Caucus intends to work hard in this endeavor.

During the next fiscal year, there is a strong possibility that the Caucus will receive funding from the Division of Developmental Disabilities, HEW. With this in mind, a grass roots organizational plan will be developed for the



The D. T.'s
or
The C. P.'s

Do It: Anywhere You Can

by Rita A. Varela

The motto of **Polling Magazine** is "Strength in Unity." There is also strength in diversity, and the two are not necessarily opposed.

We've all heard ourselves tell friends, "I don't know how you can work with so-and-so," and can remember times when they've said the same to us. Because people are different, some will succeed where others fail. And right now, it really doesn't matter whether a consumer action group is formed within a United Cerebral Palsy affiliate or independent of it; the main thing is to organize disabled constituents and to receive help and concessions from everywhere possible.

Some critics charge that we are mobilizing faster than the Association expected or will allow, for it is trying to control the consumer movement. They argue that we should withdraw from UCPA and work exclusively with nonaligned activist organizations. But C.P.'s with speech problems sometimes have trouble being accepted in activist groups. Other disabled people are not always willing to make the effort required to insure that all voices are equally respected. This can change. But it is important for C.P.'s to organize, both to be effective in disabled politics and to become a creditable force within UCP. Even if your affiliate isn't as responsible to consumers as it should be, the Executive Director may be able to help you get in touch with adult C.P.'s in your area. That's a start.

A key objective of adult C.P.'s is to change the public's image of the disabled. Traditional health service organizations have to an extent fostered unproductive stereotypes. But these prejudices belong to another America; more recently, UCPA has helped disabled people state their own case:

- Through UCPA, Denise Sherer has traveled across the country, presenting a far more realistic and dynamic view of the young adult C.P.

- C.P.'s want a greater role in determining policy; Daniel Poling has convinced a large portion of UCPA's current leadership that consumers must be consulted.

- Robert Brown, both in his Pittsburgh affiliate and in national forums, has stressed the need for more adult services. Pittsburgh's UCP offers educational assistance, training for independent living, personal guidance, and other programs.

- Young activists, through local chapters of Concerned Youth for Cerebral Palsy, have fought against architectural barriers, sponsored voter registration drives, and, most significantly, initiated campaigns to elect C.P.'s to affiliate boards of directors.

As the UCPA Consumer Activities program expands, and as some of the people currently spearheading this effort move on to other interests or to other disabled organizations, local leaders should fill the openings, for we are best served if our options and institutions are flexible enough so that consumers who cannot work in one organization can fulfill

their commitment in others. By all means, contact activist groups in your area. But don't

write off the local affiliate until you determine for yourself where they're at.

Becoming A Part of the Action



by Marie Moore

In the past twenty-five years, minority groups used a number of organizational structures to draw attention to their problems, their needs, and their right to equal opportunities. They have gained the attention of the majority through public demonstrations, economic boycotts, public education campaigns, and litigation. Less dramatic methods have also been used, such as activism within established organizations to bring about desired social change.

Whether the United States Congress, a national voluntary agency, or nationally organized associations for business, professions, labor, or trades is the place to influence decisions, minority groups have found effective ways to show their strength. They have evolved from using outside pressure to exerting internal influence.

A fine example of cohesive internal influence upon an established organization is the black Congressional Caucus. The Caucus meets as a body to identify needs, establish priorities, and develop strategies for influencing the Congress. Caucus members use their membership on standing and ad hoc committees to spread Caucus information on all issues.

Similar activities have been organized in the Young Women's Christian Association, the National Education Association, and the two major political parties by blacks, Chicanos, women, and other special interest groups.

Within the United Cerebral Palsy Associations, Inc., adults with cerebral palsy are beginning to organize such a Caucus to influence UCPA and its standing committees by informing them of the concerns and priorities of disabled adults. This structure has the potential to create opportunities for more adults with cerebral palsy, to make them a part of the action that controls their destiny.

It Is Amazing What We Can Learn To Live With Once We Make Up Our Minds

(Editor's Note: The following article is a reprint from the **National Spokesman** of EFA, January 1974.)

People complain, in this modern day and age, about how others still regard epilepsy as an illness of incurable horror. I just wish people with epilepsy — both rich and poor — would stop for a minute and ask themselves how they feel about it.

I feel epileptics are just as much at fault as the general public, because they keep it a secret. And self-pity is one of the worst things they can have.

It's like the old saying: "I cried because I had no shoes, but then I met a man who had no feet."

I have learned through experience that if I take the time to look around me, I can see people who are in worse shape than I am.

Daily, I take the time to thank the Good Lord for my blessings. The right mental attitude is more important than the physical disability itself.

I have learned that a greater part of our happiness, or misery, depends on our dispositions and not on circumstances. It isn't the condition but one's mind that can make one miserable or happy.

The best thing someone with epilepsy can do is to acquire an ability and overcome his disabilities. It is amazing what we can learn to live with once we make up our minds. I know I did. With experience, I have also learned to know my fears and make them my tools. No one is without fear, and the best way to eliminate fear is to do the thing you fear most, to look it squarely in the eye.

I just hope this letter will help others with epilepsy open their eyes and see the light. May the Good Lord bless you all, and give you strength and courage.

Mrs. E.V.O.

(Editor's Note: Women are now acting to discover their own identity and their proper role within society. This is especially true of disabled women, for the disabled woman is a member of not one, but two minorities. The following three articles are written by women with cerebral palsy. The first, by Gretchen Menn, describes the role of the disabled woman in the women's liberation movement. The second two, by Kay Jennings and Audrey Benson, describe exciting projects in which they are involved.)

The Role of Disabled Women in Modern Society

by Gretchen Menn

The women's liberation movement has a special meaning for the handicapped woman. It provides her with the hope of a more open and less superficial society, a society in which she will no longer be judged as a woman or a handicapped person, but, with her brothers and sisters, on a more complete basis. Women who have physical disabilities share many things with all women. Handicapped women are often denied employment for which they are qualified, both because of their sex and because of their physical disabilities. If a handicapped sister is also a member of an ethnic minority, she has a third barrier to overcome.

Society expects both women and handicapped people to be submissive and to avoid initiating relationships with members of the opposite sex. A woman with physical disabilities is often humiliated when men can not see beyond her disability, when she knows that friends are desperately looking elsewhere for dates for out-of-town cousins, when people offer to "fix her up" with the only handicapped man they know.

One focus of the women's movement has been the consciousness-raising group. The group provides a supportive and sharing atmosphere in which women remember, share, face, discuss, and examine incidents in their lives which have been painful, stereo-typing, humiliating, or dissatisfying. In such groups the handicapped — sometimes for the first time — are able to share their experiences as a group further oppressed.

Few people born with cerebral palsy can remember not feeling different. A cerebral palsied adolescent has many memories of rejection, humiliation, misunderstanding, and condescension. Many physically handicapped teenagers feel the need to prove to the world that they are not retarded and are worthy of being members of "the group". They can be snobbish or cruel to teen-agers who are mentally retarded, or who have not had many normalizing social experiences. By sharing and re-examining our experiences, we can begin to realize that, as teen-agers, we sometimes felt this need to prove ourselves because we were often segregated from activities, partly because of our physical disabilities and partly because of the inability of non-handicapped teen-agers to accept differences in others.

The women's liberation movement has created an atmosphere in which all people can free themselves from stereotypes, roles, hang-ups, and prejudices, and will continue to do so. By sharing experiences, han-

dicapped and non-handicapped women can learn of each others' similar fears of rejection, failure, and humiliation. Through the sharing of these experiences and fears, they can reach points of commonality and tear down superficial barriers of race, religion, sex, social class, and handicap.

M.I.C. and the Disabled

by Kay A. Jennings



The needs of disabled people in Duluth, Minnesota and Superior, Wisconsin are under study by physical planners in the area. One of these planners, this writer, is a disabled individual. About 2 years ago, I started working for the Head of the Lakes Council of Governments (HOTL COG), a voluntary organization of local governments in the Duluth-Superior metropolitan area which conducts metropolitan-wide planning activities in such fields as housing, transportation, and environmental quality.

The Duluth-Superior metropolitan area has a population of about 155,000 with a disabled sector of seven to ten per cent. The task of fulfilling their needs is being met by a number of facilities, organizations, and services, but many critical needs remain.

Our first consideration has been housing. High rises for the elderly contain specially constructed units for those disabled persons who are capable of living independently. Group homes throughout the area provide training in independent living for many mentally retarded young people. While these are meeting the needs of some of the retarded, we need more to provide for both present and potential demand. One group whose needs are not being met at all is composed of physically-disabled persons capable of semi-

independent living (individuals who need some degree of care, but who are able to function for the most part by themselves; for example, a person who needs help in dressing or cooking, but who is otherwise able to care for himself.)

We are now strongly recommending the construction of semi-independent and independent living facilities for physically disabled persons. These facilities, whether they be homes or apartments, should be fully integrated into normal community neighborhoods and should be of two types: temporary semi-independent living situations for training purposes, and permanent semi-independent and independent living situations.

The transportation situation in our area is crucial. While bus service is available, it is inaccessible to many elderly and disabled persons; they are forced to rely on friends, relatives, or volunteers to transport them. One solution under consideration is the establishment of a door-to-door "dial-a-ride" service, utilizing specially-designed vans with hydraulic lifts. Additionally, greater cooperation and sharing of equipment between those volunteer organizations who already provide transportation could augment the public services and provide almost total mobility for the disabled.

Another area under study is employment. Disabled people are employed throughout the area at all professional levels. Sheltered workshops exist in both Duluth and Superior, as do Goodwill Industries and the Lighthouse for the Blind. More cooperation between these agencies would be beneficial. A number of private industries are very receptive to employment of the disabled as well; an excellent program for civilian personnel at the Duluth Airbase provides employment for about 80 disabled persons.

Existing problems are complicated by architectural barriers, which are abundant. Several proposals have been made for their elimination. In addition to stricter law enforcement, all public buildings, including the Arena-Auditorium and Superior Public Library, should be made barrier-free. In Duluth, the situation is compounded by the many hills upon which the city is built. Further, rural Wisconsin and Minnesota townships have barriers to available transportation because of their isolation and their distance both from each other and from Superior-Duluth.

Recently, the HOTL COG has been phased out and replaced with the Metropolitan Interstate Committee (MIC). Under the agreement, the region has given the MIC the powers to do research and analysis on metropolitan issues, to aid local units of government, to review federal grants, to comment on plans and policies of local governmental bodies, and to prepare and adopt comprehensive plans for the metropolitan community. The disabled will,

(Continued on P-19)



The United Handicapped Federation

by Audrey Benson

"We have all the issues but we don't have the organizational vehicle by which to address these issues," the parent of a handicapped person said before a weekend seminar on Action Leadership Techniques. After the Seminar, the parent began looking at the possibilities of organizing the handicapped, just as many other minorities had been organized.

After locating and identifying grass roots leadership in the handicapped community during the summer of 1973, we organized an Action Leadership Techniques seminar in October of that year. The seminar searched for insight into the problems of effective organization, analysis of the characteristics needed for creative leadership, and the development of practical skills. Our instruction ranged from discussions about institutional power to how to write a news release.

On Sunday, a steering committee was formed; by January 1, 1974, we had raised enough money to hire an organizer, himself a handicapped person, both to help bring to our organization more groups of handicapped persons and to assist in preparing us to work effectively for the issues at hand.

On September 7, the United Handicapped Federation held its Constitutional Convention. We became duly constituted and incorporated according to the laws of Minnesota so that we could more easily influence stands on issues which affect our self-determination and the quality of our lives. We are an action group, working for social change.

In the past, able-bodied people have been in control of our way of life. Virtually every aspect of our lives — health, education,

employment, rehabilitation, financial aid, transportation, fair compensation — is governed by a specialized system of bewildering complexity. Able-bodied people are in control of these systems. For example, a handicapped person on welfare cannot receive money to buy a pair of shoes without a doctor's prescription, even when the old shoes are completely worn.

There are many examples of the control that others have over our lives. More often than not, it is the system and not the disability that infringes upon the right of the handicapped person to deal with his own affairs.

The United Handicapped Federation proposes to change this situation. Our society has entered the age of "consumerism." Agencies in the business of rehabilitation and service for handicapped people know that they must have consumer representation on their boards, councils, and committees. But they still retain the power to choose. And their choices are people who have had no real connections with the grass roots.

The United Handicapped Federation wants true consumerism. We must choose among our representatives and spokespersons those who have had the same kinds of experiences with the system that we have had: those who are unemployed or underemployed; those on medical assistance or SSI; those who have leadership potential waiting to be tapped.

The United Handicapped Federation is a coalition of some 36 groups of handicapped people in the Minneapolis-St. Paul metropolitan area. We are a vehicle for achieving the rights that are, by law and morality, ours — rights that permit us dignity and give us control of our lives.

The UCPA Election Process

If UCPA is to continue its steady growth and evolution, it must seek the best possible national leadership through an open process of selection.

Although the next national election is almost two years away, it is time for C.P. consumers to become involved in the selection process. UCPA National Officers are our officers. They direct policy and actions that effect our lives; it is therefore crucial that we begin to make ourselves heard.

To insure a fully open election, the present board of UCPA should:

1. Make public the methodology of the nomination process;
2. Make public the potential candidates;
3. Disclose the criteria by which the candidates are considered;
4. Heed the voice of consumers in the nomination and election processes.

Polling Magazine is ready and willing to become involved both by action and by endorsement of specific candidates, but only if its readers agree. We therefore urge every consumer who cares to tell us to what extent we should become involved.

The results of this poll will be published in future issues, along with biographies of the various candidates for office. Endorsements of specific candidates and details of the election process will also be published, if our readers so desire.



(Editor's Note: The following articles both support and criticize UCPA's commitment to consumer activities.)

Adult CP's Are Critically Evaluating UCPA

by Bill Kiser

As a cerebral palsied adult in my late forties, I have been greatly encouraged by United Cerebral Palsy's effort to promote consumer involvement within its organization. Every organization devoted to helping the handicapped should have a strong consumer representation. I hope the talk of consumer involvement is something more than a toy for us to play with. True consumer involvement cannot only help those of us who have cerebral palsy, but can do much for the entire United Cerebral Palsy organization.

However, we must remember that consumer involvement is a two-way street; there is much to gain, but involvement brings with it the obligation to make the best use of each opportunity.

Contributions Reconsidered

by Harold V. Knight

To write, without being trite or maudlin, of the contributions disabled persons can make to society is not an easy task. The usual pat statements — that a disabled individual can be an inspiration to others by his fortitude and courage, or that a disabled individual should be thankful that he is better off than someone more handicapped — are patently inadequate.

On occasion, I have remarked that everybody has some disability, but mine is simply more obvious. After mumbling, fumbling, and stumbling for more than two-thirds of a century I am not certain that the whole cockeyed world does not, in some way, mumble, fumble, and stumble. In fact, our social order seems to manifest various symptoms of cerebral palsy: the wild movements of the athetoid, the rigidity of the spastic, the lack of balance of ataxia, and the trembling of the tremorous.

Now, I don't want to carry this analogy too far, for, like any figure of speech, it does not stand up under close analysis. But we live in an imperfect world and we must not fear to become involved in it just because our bodies are less capable than we would like. Our contribution lies in what we accomplish, large or small, in spite of our disabilities and not because of them.

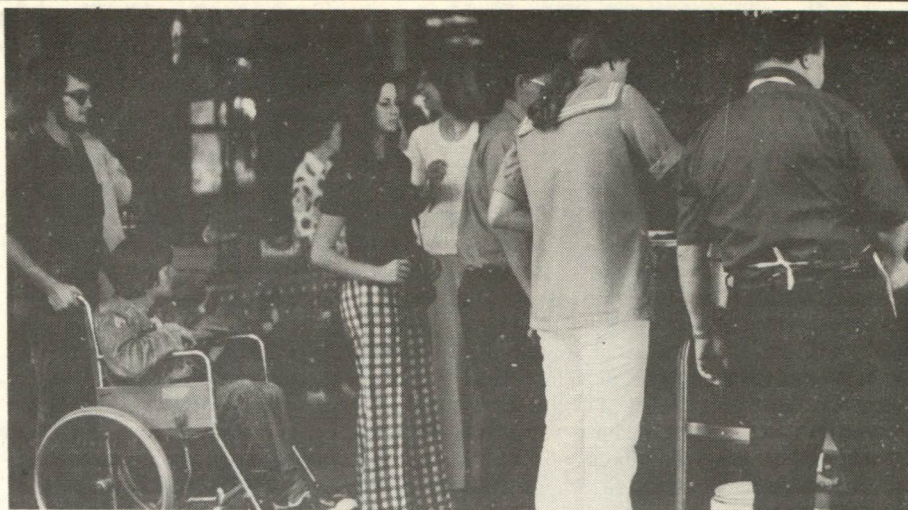
One reward for a disabled writer is that those who read his work do not know he is handicapped — unless he writes about himself. Those who seek to help people with disabilities similar to their own, such as writers, teachers, psychologists, or physicians, are to be highly commended. Those who choose fields unrelated to disability contribute to the understanding of the non-disabled with whom they come into contact simply by being themselves. We do not need to write or speak to communicate. The more we participate in society, the more we communicate.

We must let others know that our abilities, however circumscribed, are as good as theirs. Just because we cannot do everything does not mean that we cannot do something well.

M.I.C. (Continued from P-17)

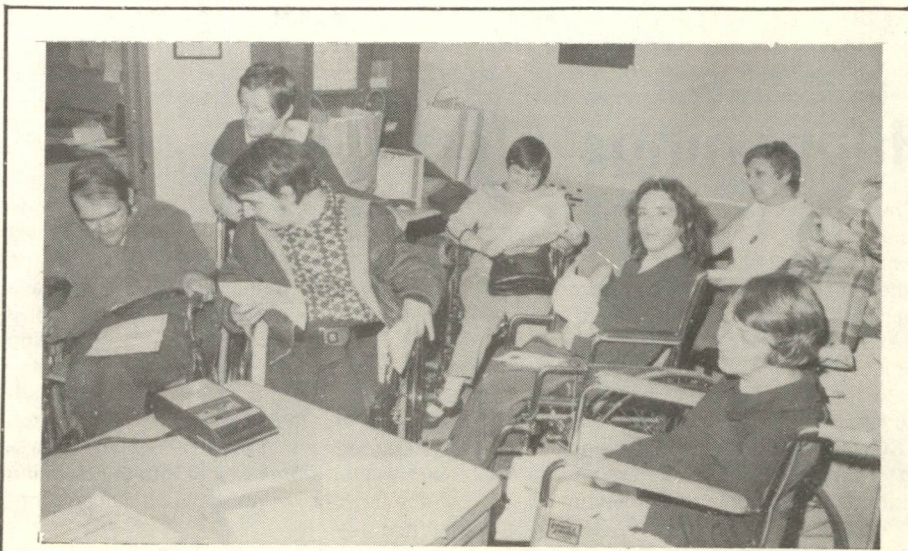
of course, be included in this comprehensive plan.

Our future work will provide for disabled people in the planning processes. Specifically, we have included provisions for disabled people in the Transit Development Program. A proposal is being written for the hiring of disabled persons to work with area building inspectors to ensure compliance with barrier codes. The report is intended to serve as a guide for the review of those projects which affect the disabled. We hope to encourage the construction of more barrier-free housing and are considering the possibility of assessing the need for such housing.



One of the strongest groups of adults with cerebral palsy in the entire nation meets in Iowa. Under the dynamic leadership of Calvin Jondle, it has held statewide bowling tournaments and has traveled to the Grand Old Opera in Nashville, Tennessee. The above picture was taken on the day its members sailed down the Mississippi River.

An adult council session of United Cerebral Palsy of New York City, Inc. UCPNYC services approximately 653 adults with cerebral palsy and has about 10 separate programs. An adult representative from each of these programs is elected by his CP colleagues within a specific program to serve on the adult council. The primary function of the council is to represent the interests of its constituency within the agency.



MY FIRST TWO NACDD MEETINGS

(Editor's Note: The basic function of the National Advisory Council for the Developmentally Disabled is to advise the secretary of HEW on broad issues of program implementation. In the past, it has had the same problem of representation as the state councils. However, just this year, two true DD consumers have been appointed to the NACDD: Jim Stearns of Washington, D. C. and Tom Johnson of Iowa. Both Jim and Tom have cerebral palsy. In this article, Jim Stearns tells of his first impressions of NACDD, and he requests reaction from other DD consumers.)

by James Stearns

As a member of the National Advisory Council on Services and Facilities for the Developmentally Disabled (NACDD), I was struck by one fact during our recent meetings in Washington, D. C. — that, to do their job

well, members of the Council very much need and appreciate help from consumers.

The NACDD advises the Secretary of HEW on how to better run programs which provide services to the developmentally disabled, to

those of us who are cerebral palsied, mentally retarded, or epileptic.

During the meetings, I often asked myself two questions: Are there any needs of the developmentally disabled to which we, as Council members, have not given enough study? Are the present programs working as well as they could to meet those needs which we have seen? When disabled persons, speaking from the audience, gave advice to the Council, I understood just how important it was to listen.

Dan Poling, for example, spoke about the need for more disabled persons to sit on the state boards that supervise DD programs, since only those who have been through the programs know whether they function.

As Dan spoke, I remembered a time when my doctors told me to perform some therapy which neither I nor most of my friends wanted to do. If we had had some way then, as we did not, to talk to the doctors, perhaps they would have seen that the therapy was not working; for no matter how good the therapy sounded in the textbooks, I had no faith in it and would not follow the program. As a Council member, I realized that the most important question was one that was answered in part by Dan's idea: how do the consumers feel about our work? Do they have any faith in us?

Another consumer heard by the Council was William Adrian, a disabled government worker, who asked the Council to help the disabled find jobs. William uncovered an area of which the Council had been less aware than it should have been.

Disabled people, then, had a hand in Council business during these two meetings in two ways. First, the Council learned that disabled persons must speak up — in meetings and in letters to Congressmen and others who run the programs that touch the lives of the disabled. Disabled persons must also communicate through radio, television, and newspapers, so that others can learn about their needs. Second, what is said by the disabled will now be heard by the National Council.

So that the voice of the disabled becomes even louder, I hope that readers of this article would respond to the following questions in letters to **Polling**:

1. What needs of yours have not been met by the government?
2. What needs of yours have been met in part, but have not been met as well as you think they might have been?
3. What projects have you been working on that might better the lives of other DD consumers?

I believe that, with Council members working together with disabled persons, we can reach our common goal: to give to the disabled every possible benefit that is enjoyed by the able-bodied. It is to this end that we all must work.

The Federal DD Structure — What Is It?

As DD consumers, it is vital for us to have some understanding of what the Federal DD structure is so we can effectively relate to our power base. After months of Congressional deliberations, President Ford signed a new DD Act into law on October 6, 1975, over the strong objections of the Office of Management and Budget, who claimed that the bill was too expensive, and with the endorsement of the Department of Health, Education, and Welfare, who argued that the bill was much needed and long overdue. The new Developmental Disabilities (DD) Act continues and revises three existing programs — University Affiliated Facilities (UAF's), State Grants, and Special Project Grants — and creates a new statutory mechanism to establish and protect the rights of persons with developmental disabilities.

Because of the new DD act, the Federal DD structure is about to undergo some substantial changes. Superficially, however, this is the present structure:

The developmental disability program is a joint Federal and State endeavor, in which the Federal government gives grants to the 50 states in accordance with an established matching formula. That is, the individual States put up a certain percentage and the Feds match it. In every State, there must be a designated State Agency to administer the DD monies. There also must be a statewide DD planning and advisory council in each of the 50 States. One third of the membership of these State Councils must be DD consumers, individuals who do not have a vested interest in maintaining the status quo of the present DD structure.

Because the DD structure cuts across Federal department lines, directly including 8 or 9 Federal programs and indirectly including a number of others, DD consumers can potentially gather significant and substantial power by gaining membership to state DD planning and advisory councils. By "power", I mean gaining direct control over many of the Federal State programs which affect our lives.

In the past, however, parents of DD consumers have been defined as "consumers" themselves, and have been allowed to represent the consumer interest on state councils. Although many parents are no doubt well motivated, this creates an obvious conflict of interest. If the DD consumers of this nation are ever to be considered first class citizens, we must be granted the undisputed right to control our lives.

Happenings Alert . . .

The following events are of crucial importance to each DD consumer. Both deserve our attention and assistance.

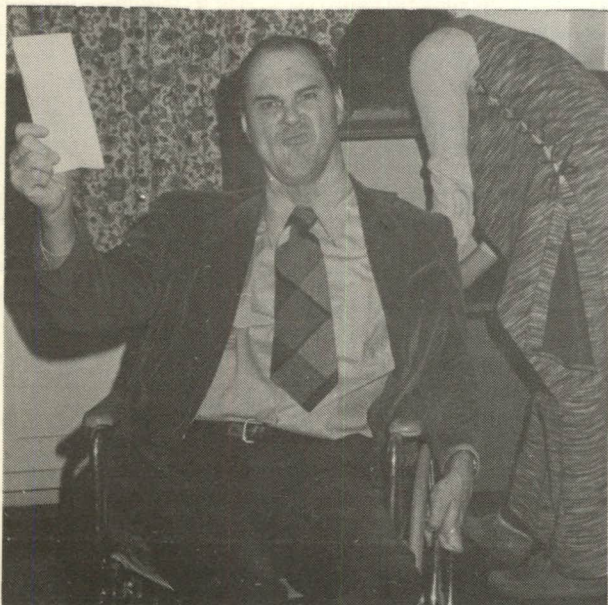
The American Coalition for Citizens with Disabilities, Inc., (ACCD) is in its second year of existence. ACCD was established to promote the social and economic well-being and to assure the full exercise of human constitutional rights of citizens with disabilities. ACCD is endeavoring to work with individuals and groups of all types of disabilities. We should be heard within this coalition:

Sometime in the next several years, a White House Conference on the handicapped will be held. The Conferences will explore the problems faced by handicapped Americans and will develop administrative and legislative recommendations for solving them. **Polling** has already been in contact with Mr. Wallace Babbington, Director of the Office For Handicapped Individuals, HEW. Mr. Babbington has assured us that the DD consumer movement will have direct input into the planning and execution of this White House Conference.

C.P's in San Diego In The Process of Voting . . .



C.P. Consumer Clint Hilliard Voting In New Hampshire



Biographies of DD Consumers Contributing to This Issue

General

James Stearns lives in Washington, has cerebral palsy, and is in his final year of law school at Georgetown University. He is presently a law clerk at the Georgetown University Health Policy Center. He also serves on the National Advisory Council on Services and Facilities for the Developmentally Disabled and is a member of the UCPA Governmental Affairs Committee.

Clinton T. Hilliard, who has cerebral palsy, has considerable experience in the field of Speech Technology and is the Director of the Speech and Hearing Department at the Crochod Mountain Foundation in Greenfield, New Hampshire. He holds a B.A. in National Science from Muhlenberg College, Allentown, Pennsylvania, and an M.A. in Speech from the University of Alabama. Clint is married and has one daughter, who is 14 years old.

Daniel A. Poling II, 38, has cerebral palsy and resides in New York City. He has a B.A. in Sociology from Hunter College and has done graduate work at both Dartmouth College and Columbia University. He is married, has two stepchildren and two grandchildren. He has done extensive social work in New York racial ghettos and is currently the Editor-in-Chief of **Polling Magazine**.

Epilepsy

Annette L. Pitre, 39, is a graduate of a trade school. She was born in Southern Louisiana, where she has lived all her life. She has been a legal secretary and the deputy clerk of her county court.

Herb Leavitt, 22, lives in Augusta, Maine. He has his high school equivalency diploma and does voluntary work at the Maine Chapter of the Epilepsy Foundation of America, Inc. He is an active member of the Winthrop Street Universalist Church.

Martha Jane Smith, 27, who has epilepsy, is a current resident of Florida. She has done undergraduate work at Texas A & I University in Kingsville, Texas, where she was majoring in American Literature. She dropped out of school to marry. She and her husband have an 18 months old daughter.

Joan A. McDonough, who is an epileptic, resides in Columbus, Ohio. She is a board member of the Epileptic Association of Franklin County.

Mary Beth Smith, 30, who has epilepsy, is a graduate of the University of Dayton, Ohio. She is married and the mother of 2 children. She is an EFA Service Agent.

Stephanie Grossman, 23, has epilepsy and resides in Baltimore, Md. She has a B.A. in Psychology from Stanford University in California and has done graduate work in Clinical Psychology at Rutgers University in New Jersey. She is an EFA Service Agent.

Cerebral Palsy

Bruce Oka, who has cerebral palsy, is a resident of California. He has extensive experience in the field of community rehabilitative workshops and is currently majoring in social work education at California State University. He is second vice-president of the United Cerebral Palsy Association of San Francisco, Inc., and a member of the California State DD Board Number Five.

John Bell, Jr., a distinguished artist, has cerebral palsy. He is past President and present Chairman of the Board of United Cerebral Palsy of Arkansas and a member of both the Arkansas State DD Council and the Arkansas DD Grant Review Committee.

Bill Kiser has cerebral palsy. He has his own syndicated column, "The Handicapped Mailbag," and has just written his first book, **A New Light of Hope**. He is a recent recipient of the President's Award of United Cerebral Palsy, Inc.

Harold V. Knight, 68 years old and in semi-retirement, has made his living for 44 years as a writer. He was born with moderately severe athetoid cerebral palsy. His newspaper credits include a Jamestown weekly, The North Dakota Union Publication, and a column called Statehouse Drama. He has written five books and is working on a sixth.

Marie Moore is the National Advocacy Coordinator for UCPA Child Advocacy project, sponsored by the Bureau of Education for the Handicapped. Ms. Moore is a certified occupational therapist and has her M.A. She is also a black woman and an activist.

Gretchen E. Menn has cerebral palsy and is now a developmental disability service specialist at the Region VII Information Center for Developmental Disabilities in Kansas City, Kansas. For 13 years, she attended a school for orthopedically handicapped students and has a B. A. in History and English from the College of Emporia in Emporia, Kansas and an M. A. in SOCIOLOGY FROM THE University of Missouri at Kansas City.

Rita A. Varela, who has cerebral palsy, now resides in Zephyrhills, Fla. She has a B. A. from the City College of New York and a M. A. in Political Sciences from New York University. She is presently a free-lance writer and is active in the Polk County United Cerebral Palsy affiliate in Lakeland, Florida.

Audrey Benson, 38, who has cerebral palsy, presently resides in Minneapolis, Minnesota. She has a B. A. in Social Work from the Moorhead State College, Moorhead, Minnesota. She has been a counselor for Goodwill Industries and is now the President of the United Handicap Federation in St. Paul, Minnesota.

Kay A. Jennings is a 25 year old cerebral palsied resident of Duluth, Minnesota. She received her B.A. Degree in Biology from the College of St. Scholastica, Duluth. She is presently employed by Head of the Lakes Council of Governments, conducting research on various projects, including the needs of the disabled in the Duluth-Superior Area.

Mental Retardation

Charlie Dieterle, in his mid-twenties and an MR consumer, is currently a resident of Boulder, Colorado. He now serves on the Advisory Committee for the Child Advocacy Project of the National Association for Retarded Citizens, Inc.

Judy Cunio is in her mid-twenties, has cerebral palsy, and is a resident of Oregon.

Caucus. Each district will have an interim chairman who will select six additional people to form an organizing committee within that particular district. John Bell, Dan Poling, and I will supervise the organization of 2 districts each; the Southeast and Southwest districts will be John's responsibility; the Northeast and Midwest districts will be Dan's; the Midwest and Western districts will be mine. If you are a C.P., and if you and your group would like to become members of the Caucus, fill out the membership form in this issue and mail it to **Polling Magazine**.

Our criticism of UCPA is meant to be constructive rather than destructive. These are rapidly changing times; if UCPA intends to remain a viable and creditable force, it must remain flexible. We believe that UCPA can and will change. Indeed, a number of local affiliates are taking the lead in promoting greater consumer involvement. We would like to thank those affiliates by listing their names and the names of their principle offices below:

Leo Hausman, President, UCP of NYC; John Bell, Jr., Chairman, UCP of Arkansas; Thomas O'Brien, President, UCP of Metro Boston; John L. Davis, President, UCP of New Jersey; Mrs. Martin Eaton, Vice President, UCPA, NY State Past President; Elmer Lux, President, UCP of New York State; John E. Migliaccio, President, UCP of Rhode Island; Miss Elizabeth R. Schantz, President, UCP of Delaware (consumer); William E. Laughlin, President, UCP of Illinois; Mrs. Richard Karon, UCPA Director; Clifford J. Girompiny, President, UCP of Colorado; Mrs. Robert O. Walters, President, UCP of Colorado Springs; Joe L. Childs, President, UCP of Kansas; Mrs. Walter Gill, President, UCP of Greater Kansas City; Harper V. Orth, President, UCP of Oklahoma; Jules Dunes, President, UCP of San Francisco; Glen R. Ecklos, President, UCP of Santa Clara County.

Caucus Membership Application

As described above, the Caucus of Adults with Cerebral Palsy is now being organized on a nation-wide basis. There are two types of membership: Individual or Group. Individual members must be 18 or over and have cerebral palsy. Member groups have voting strengths equivalent to the number of members who are 18 or over and have cerebral palsy.

To apply for membership in the Caucus of Adults with Cerebral Palsy, fill out the following form and mail to **Polling Magazine**, c/o United Cerebral Palsy of New York City, Inc., 1430 Broadway, New York, NY 10018.

A Caucus Representative from your district will be in contact with you.

NAME

STREET ADDRESS

CITY AND STATE ZIP

For What Type of Membership Are You Applying?

Individual Group

If you are applying for a group membership, what is the full name and address of your group?

.....

NAME

STREET ADDRESS

CITY AND STATE ZIP

Name of your Group's Principle Officer:

If you are applying for Group Membership, how many of your members are 18 years old or over and have cerebral palsy?

According to UCPA's breakdown of districts, which of the six districts are you in?

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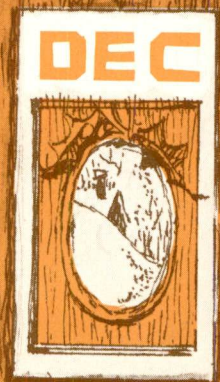
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**For more information,
write to:**

**EDITOR
POLLING MAGAZINE**

**c/o United Cerebral Palsy of NYC, Inc.
122 East 23rd Street
New York, N.Y. 10010**

Rates available upon request.



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