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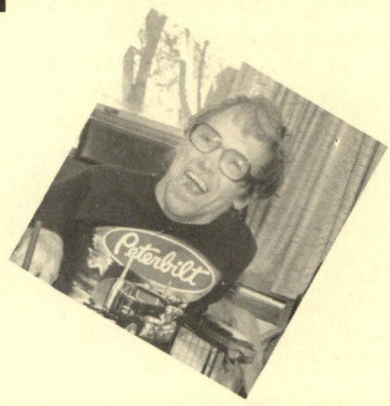
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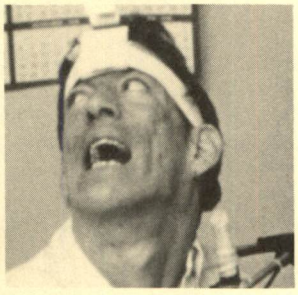
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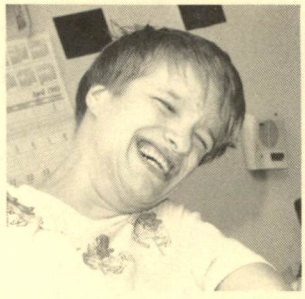
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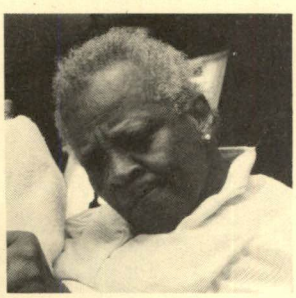
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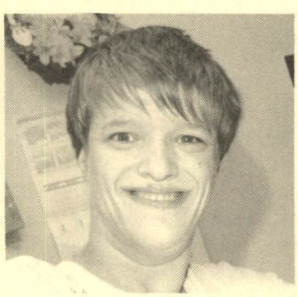
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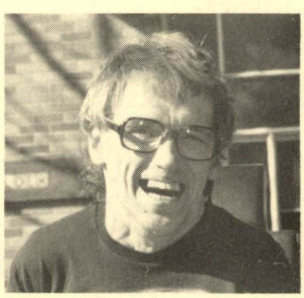
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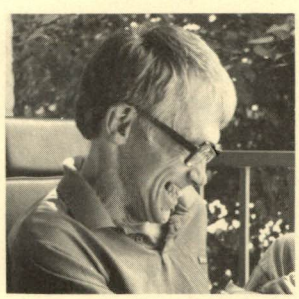
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A NEW WAY OF DOING

by Jim Hollahan

This special edition of the **NETWORKER** explores the topic of community living for men and women with severe physical disabilities. In these pages, we have attempted to capture not only a new way of thinking but a new way of doing—providing the support services necessary for people with disabilities to live in their own homes.

These pages contain the stories of individuals, told in their own words and in the words of the local media in Springfield (IL), Portland (OR), and Birmingham (AL). John, Don, Anna, Mary and Jessie are only a few of the thousands of persons with severe disabilities determined to find their own homes. Their stories document their struggles and accomplishments, their belief in their own abilities, and their determination to gain their rights.

This issue is about changing attitudes, stereotyped images and belief systems. It is about progress being made and personal goals fulfilled. We capture here but a glimpse of the excitement involved in moving into the community and the quality of friendships so vital in supporting people who for so long were told "the only place for you is a nursing home."

The newspaper accounts reprinted here reflect exciting changes as well in community attitudes about people with severe physical disabilities. Reporters are listening to, and writing about, real people. Stereotypes and labels are beginning to break down. Changes in language often lag behind changes in attitude, however, and even in the most empathetic newspaper articles, words like "victim," "afflicted," "crippled" and "the handicapped" crept in. Words and phrases like these were edited out of the articles reprinted here, but we are reminded again of the need to portray persons with disabilities as just what they are—persons.

John Sanford addresses this issue in his editorial, "Label Jars...Not People!" as does Brenda Yarnell in her article about the impact Project SPICE has had on the staff at UCP of Land of Lincoln. As Project SPICE participants moved from congregate settings into their own homes in the community, she notes that when staff talk about their plans for the day, they no longer say they are "going over to Dirksen House," but instead say "I'm going to Mary's house." Mary is no longer "Mary-the-client" but "Mary who lives on Schrader Street and has a dog named Cubby."

Changes in attitudes such as these signal a major change in all of our perceptions and beliefs about the people we serve. They reflect changing beliefs and perceptions of what is possible for persons with disabilities. These changes mark real progress in our goal of assuring that people with cerebral palsy and other severe disabilities gain their rights and the opportunities to live, work, play and learn in their communities. As we celebrate these accomplishments, we also commit ourselves to redouble our advocacy efforts on behalf of people with physical disabilities.

Jim Hollahan is Director of the UCPA Program Services Department.

THE BOTTOM LINE: Label Jars . . . Not People!

by John Sanford

The word stigma and the concept of rights are polar opposites. Webster defines stigma as, "A mark or token of infamy, disgrace, or reproach. A mark indicative of a history of disease or abnormality, a brand." This definition describes the way in which our society, in far too many instances, has treated and related to persons with developmental disabilities and persons labelled mentally ill.

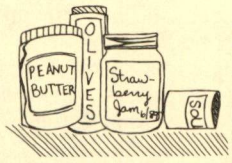
History makes it clear that both of these populations are perceived to carry a mark that indicates we often see them as having a history of disease or abnormality. In simple terms, persons with developmental disabilities and persons with mental illness have been branded. However, we tend to deny this perspective because the stigmatizing references are seldom conscious and purposeful.

The media, electronic and written, have also unwittingly contributed to the branding of these populations. It doesn't make a difference whether it's an article about a "mad" gunman or a movie in which a person with a disability (or anyone else for that matter) is referred to as an "imbecile." The branding is the same, and the effect is dehumanizing.

This stigmatizing has extended to many labeled groups but especially to persons with developmental disabilities and persons labelled mentally ill. By doing so, we have relegated them to being perceived as less than fully human. By consciously or unconsciously classifying them as less than fully human, it has been easy to justify not extending to them what society has said citizens are entitled to—civil rights—and what human beings are entitled to—human rights.

Turning to Webster again, we find "rights" defined as, "Something that someone has a just claim to." It is clear that, in society's eyes, neither of these labeled populations has ever had a just claim to their full rights.

If stigmatization of labeled persons destroys their ability to be recognized as persons entitled to full rights as citizens and human beings, they can continually be denied the right to decent housing, the right to employment, and the right to live in dignity.



The time has come for the mass media, and indeed all of us, to take a different approach in how persons with developmental disabilities and persons labelled mentally ill are presented. This will require a careful review of imagery and labels. Stories about "crazed" gunmen and forever hopeless "imbeciles" must cease to be communicated to the public. Even if an actual murderer has a characteristic of mental illness or if a person with developmental disabilities actually needs much assistance to perform an otherwise simple task, stigmatizing labels must not be used.

The responsibility of the media is to portray persons with labels as just what they are—people. People with hopes, fears and desires. Individuals with the same wants and concerns as others. In other words, the responsibility of the media is to begin to correct some of the mistakes of the past and make a commitment to no longer depict and portray these people as being less than human.

It is only through the zealous efforts of all of us that we can elevate persons with developmental disabilities and persons labelled mentally ill to their correct status within our society—as people first. Then, as people who are full citizens of this country, they can have a just claim to their rights.

John Sanford lives in Lansing, MI. He is a lawyer who is Director of the Office of Recipient Rights in the Michigan Department of Mental Health. John is on the Board of Directors for UCP of Michigan and the Detroit Center for Independent Living and was formerly on the Board of the Michigan Protection and Advocacy Service. He is also a member of the Michigan Indpendent Living Council. Each issue of the ***NETWORKER*** *features a guest editorial by an individual with cerebral palsy.*

HIDDEN POPULATION OF DISABLED LANGUISHES

Reprinted from *The Post-Herald*, November 18, 1989
by Michelle Chapman, *Post-Herald* Reporter



Andre Chung, Birmingham *Post-Herald*

Johnny Geisen awaits the day when he can move from the nursing home into a place of his own.

Man with CP wants to follow friend to independence

Mike Holsombeck and Johnny Geisen have been friends since childhood.

But they share much more than laughs about teenage pranks.

Both are severely disabled by cerebral palsy and moved into nursing homes in their mid-teens, when their care became too difficult for their mothers.

Holsombeck and Geisen are also examples of the hundreds of Alabamians with disabilities who have been forced to live in nursing homes because they have been offered no alternative.

At a time when other teenagers were cheering at football games, going to proms and worrying about dates, they began spending their days surrounded by sick, elderly people.

"It gets lonely and you feel like people don't understand what people with CP are like," Geisen said, using an outdated communication method he utilizes because his speech is very difficult to understand.

He points his right thumb at a plexiglass-enclosed sheet of paper with the alphabet, numerals and several dozen frequently used words on it. To convey his thoughts, he must spell out most words letter by letter.

He spends his days in a wheelchair that he propels backward through the nursing home. Although he can handle much of his own care, poor control of his hands makes him dependent on someone else to feed and bathe him.

Geisen, 36, who has been in nursing homes since 1969, has a dream. He simply wants to live like other people do. His desire to be independent has increased recently as he has watched Holsombeck live out that fantasy.

Holsombeck, 33, spent 15 years in nursing homes but was one of the first persons with a disability to apply when United Cerebral Palsy of Greater Birmingham opened the Gerry Fullan House, a transitional home for people with physical disabilities, in 1986.

Although Holsombeck has little use of his limbs and also has great difficulty talking, UCP personnel decided he was capable of living independently if given the right support and training.

He took classes at the Independent Living Center to teach him about apartment living and was given computer training to enable him to find a job. He became adept at typing with a pointer hooked to his forehead with straps.

Holsombeck also has a computerized voice synthesizer to speak for him and an electric wheelchair with devices that let him control lights and appliances--things Geisen does not have because Medicaid will not pay for them.

UCP officials were determined to find Holsombeck a job as well and took him on as a participant in the agency's supported employment program, which provides intensive on-the-job training for new workers, offers continuing support services and provides workplace modifications and specialized equipment they need for their jobs.

Earlier this year, the Jefferson County Personnel Board hired Holsombeck as a data entry operator. His job, which involves putting information on job applications into the board's computer system, is full time.

Then, last month, Holsombeck moved into an apartment. He shares a two-bedroom unit in Center Point with his 21-year-old sister, Leslie, and her friend. Like many young people moving into their first apartments, the three pool their resources to pay rent and utilities.

An aide visits him twice a day to help him with hygiene, cook for him and feed him. He said the state Vocational Rehabilitation Services pays the aide $3.60 an hour for 20 hours a week. He pays an extra 90 cents an hour and for additional time.

The only other government service he now receives is transportation to and from work in a special van for persons with disabilities.

Holsombeck said the government is saving hundreds of dollars a month now that he is independent. And he is paying income tax as well. In fact, he is excited about filing a tax return next year; it will be his first.

And Holsombeck could hardly be happier. "It's a whole different world," he said. "I have control of my life now, not other people, not the government."

Asked what advice he would give the government about offering alternatives to persons with disabilities, he said, "Get them out. It is a whole lot cheaper, plus they deserve to see how life is outside a nursing home."

Jubilant about finally being on his own, Holsombeck said, "I didn't give up. I started to give up several times, but something kept telling me to keep going."

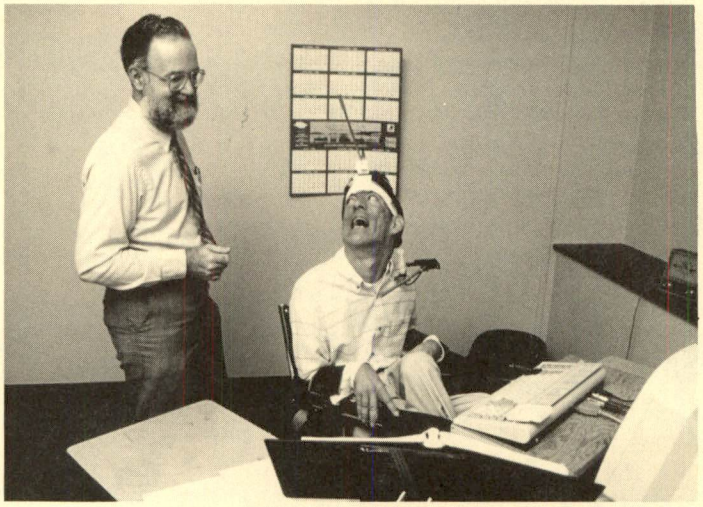
Geisen said he will not give up either. Before he can move out, he must convince his mother—who also is his legal guardian—that he is capable of independent living. He said her belief that he needs 24-hour care has been softened somewhat by Holsombeck's success.

He said some state workers who are reviewing cases of persons with disabilities residing in nursing homes visited him last week.

"They asked me why was I in a nursing home," he said. "They told me that I didn't need to be here."

HE DEMANDS TO BE HEARD . . .

These are the words Employment Specialist Brenda Carson uses to describe Mike Holsombeck, a young man with cerebral palsy who put himself into a nursing home when he was 15 because he felt he was too much of a burden to his mother. Although he has extremely limited mobility and relys on a communication device for speech, Mike refuses to allow himself—and his abilities—to be discounted. When UCP of Greater Birmingham opened the Gerry Fullan House, a transitional living center, in 1986, Mike was among the first to apply. At the Fullan House, Mike began keeping a journal. Reprinted below is the part of the journal that Mike shared with Employment Specialist Brenda Carson when presenting himself as a candidate for the UCPA National Supported Employment Project.



Bob Farley, Birmingham *Post-Herald*

Mike Holsomebeck shares a joke with co-worker Joe Kerr, chief personnel officer, at the Jefferson County Personnel Board.

MY BACKGROUND HISTORY

by Mike Holsombeck

I was born on March 11, 1956. I lived in Oak Grove until the age of ten before moving to Birmingham. I started to school at Elyton Charelane at the age of three. When I was sixteen I was transferred to Lewis-Slossfield where I attended until I was twenty-one in 1977. In 1979 I took my G.E.D. at Jefferson State.

In 1980 I started at Jeff State but only went one quarter. In December 82, I started back at Jeff State and went until November 1984. I mostly took basic subjects during this time.

After living with my mother until I was fifteen, I decided myself to move into a nursing home. I lived in different nursing homes until 1986, when I moved into the Fullan House. In March 1986 I went to Lakeshore for evaluation for speech, P.T. and O.T., paid for by the Homebound Program. After being evaluated, the recommendations were to get me a power chair and a Minspeak Light Talker, which were also paid for by Homebound.

Since living at the Fullan House, I have attended classes such as money management, food nutrition, cooking, communication skills, human sexuality, time management, shopping, several P.C.A. [Personal Care Attendant] classes, basic computer, and pre-employment.

The number one goal that I have completed was when I moved out of the nursing home. Other goals completed were getting a power chair and learning how to drive it and being more involved with the disabled population by being an advocate. In March I was able to buy my own computer. My goals now are to get a job and to be able to move out into my own apartment and be independent.

My income is S.S.I. of $354.00 a month. I also have Medicaid, and I am on my Dad's Blue Cross. Out of my income I pay $72.00 for rent; $90.00 for food; $10.00/month transportation; $30.00/month for phone; and $25.00 to $30.00 for P.C.A.

My physical abilities are: push manual wheelchair with one foot; type with a head pointer; operate a computer with a head pointer; dial a telephone with a head pointer; turn pages of a book with head pointer; operate T.V., VCR and microwave with head pointer. I have also learned how to operate and program a Minspeak Light Talker. The Light Talker works by pointing a light beam at certain symbols on the keyboard. All of this can be interfaced with either an Apple or an I.B.M. computer. My Light Talker also has a printer so I am able to print out anything I have said.

I have a Fortress power chair which I operate with my chin and mouth. With this chair I am a lot more mobile. I can't transfer without assistance. If I worked all day, I would need a P.C.A. for approximately 1 hour.

Using my head without a head pointer, I can open doors, bowl, turn on/off lights, turn on/off T.V. if remote is on flat surface.

My vocational abilities include reading, basic math, time management, money management, operating a computer, word processing, keen observation skills, rapid learning, good memory. I have no limitations vocationally.

I am a member of the Alabama Handicapped Association, and I am sometimes involved with the A.C.C.D. For recreation, I bowl, paint, watch T.V., play cards, play checkers, watch sports, go to shopping centers and parks, go to movies, and go to football and basketball games. I have the use of all five senses.

I worked at the workshop at U.C.P. in 1980 for about three months. I was a card counter in the silk screen shop. I made $.90 a week. The type of work I would really like to do is work with computers (data entry). I think it would be too much stress to watch an E.K.G. monitor, but I could watch a security monitor all day. I can work a forty hour week.

My family is supportive of me financially and emotionally. I have a lot of friends.

Mike Holsomebeck lives in Birmingham, AL and is employed as a data entry clerk with the Jefferson County Personnel Board.

SPECIAL RECOGNITION FOR A REAL HERO: MIKE HOLSOMBECK

Reprinted from *The Sounding Board: An Informational Newsletter*, a publication of the Employee Relations & Development Program, Jefferson County Personnel Board

"Mike" Holsombeck is a full-time employee on the Personnel Board Staff. His coworkers describe him as a very hard worker: he's fast and he's accurate with any data entry assignment he is given. Mike is fiercely independent yet very outgoing; he's a "people-oriented" person. He is also very active in many after hours activities, such as bowling (he has won trophies) and landscape painting (he has sold some of his creations). So what makes Mike a "hero"? Mike has cerebral palsy; he has very little mobility in his extremities; and he can only speak with the assistance of some impressive electronic devices.

Mike's single-minded and relentless dedication, along with the willing assistance of others, has enabled him to overcome incredible obstacles presented both by his physical limitations and the common misconceptions generally held by the public concerning his medical condition. He has recently moved out of the transitional home and into his own apartment, where he enjoys his hard-earned independence—made possible by a new chair that enables him to turn lights off and on, operate common household items such as a TV, and even open the door for himself. Mike's accomplishments go well beyond helping himself, however. He is also a very active advocate for the handicapped, having recently served at the Southeast Augmentative Communication Conference on a three-member panel composed entirely of "non-speakers" who communicate through light or touch talker devices.

In recognition of the impressive achievements he has made in overcoming multiple physical impairments, securing gainful employment, and attaining an amazing degree of independence, Mike recently was awarded a "Certificate of Achievement" from the Governor's Committee on Employment of People with Disabilities. The Personnel Board was also recognized at the Tenth Annual Awards Luncheon for its support of Mr. Holsombeck when it was awarded a "Citation for Meritorious Service" for contributing to his success in achieving the Committee's goals of "DIGNITY, EQUALITY, AND INDEPENDENCE THROUGH EMPLOYMENT."

We feel fortunate to have an individual like Mike Holsombeck on our team. He is truly a "hero" by overcoming the odds and teaching all of us that physical limitations are not necessarily handicaps.

MY NEW LIFE

by Don White as told to Brent Johnson
Reprinted from the Winter 1989 *AVANT GARDE*, the National Newsletter on Integrated Services, a publication of the Rocky Mountain Resource and Training Institute

My name is Don. I live on a tree-lined street in Greeley, Colorado. I enjoy walking home on sunny days after work, going out for coffee with my roommate Art, and working in my yard. Most people may find such everyday things boring. I look forward to my daily routine because life for me did not exist until 1986. That is the year which meant my getting out of the institution. I spent most of my 49 years surviving the nightmare of existing in institutions, mostly because no one took the time to understand me better. Institutions are horrible places. I kept telling the staff that I did not belong there and resisted in a variety of ways in order to survive. I have cerebral palsy and a developmental disability, but my emotions and needs are no different than those of anyone else. I have a great deal of difficulty in speaking due to the cerebral palsy, but as most people who now know me realize, I may be understood with a little extra time and effort.

I have lived in a number of institutions over the years. I was able to live with my family in Kansas until adolescence, but was put in an institution at that point in my life. There were a few breaks in routine over the years. I was able to go back to living with my mother from 1974 through 1977. Although mom meant a great deal to me, she was getting old and could no longer help. She had to go live with my sister's family in Washington state. This meant my being sent to an institution in Colorado near the homes of my two brothers.

It didn't matter whether the institution was in Kansas or Colorado, if I posed a problem for the staff, being physically restrained and sedated with heavy medication was their way to achieve desired behavior from me. Since I have trouble talking, I had to do whatever I could do to tell them I did not belong in such a place. I wanted out badly. The staff realized that a smaller place would be better for me, so I was moved to a group home in Denver where I lived for a few years until it closed. I had to move again; this time to a private home. I lived in the basement, which was a dark, dungeon-like place where people discarded things they did not need. It does not take much imagination to realize how I was feeling. Later I found that the couple who operated this home were not giving me letters sent by my family and of course there was no way for me to get a word to them. The State Department of Health forced the couple who owned this home to close its doors for good.

I often have feelings of self-doubt, helplessness and depression. All of this is related to a lifetime of negative experiences, and this one really took the cake. Surely life had to get better and would improve. It is with some irony that I tell you of the next institution to which I was sent. It turned out my hopes would again be false. As with the staff in other institutions, their way of dealing with me was through physical restraint and medication to subdue me. This sometimes involved aggressive manhandling of me on the part of the staff. I knew I did not belong at this place either and resisting way my only way of communicating; eventually this was necessary in retaining my sanity.

I find it a draining experience to relate all of what was a living nightmare for me. I still have trouble comprehending it all. I just wanted to live a normal life. While living at this institution, I told a friend how bad things had been going for me since I moved there. My friend suggested that I ought to write to the Governor of Colorado to explain my plight. That is just what I decided to do. With some help from my friend, I wrote that letter.

People were listening to me for a change; I prayed that the Governor would too. He did; a state official traveled from Denver to start the ball rolling. My prayers were answered when funding was made available through the Personal Care Alternative program. I could live in my own home. A support person, who is made available through this program, lives in the basement apartment of my house. This person helps my roommate and me in meeting many of our personal needs. It is nice to have someone around who cares about the quality of our lives. The program also ensures that several other people are available in helping make life a little easier. I enjoy being able to have the freedom of choice in my life. ***Life . . .*** *continued on page 17*

ALDER STREET CLOSED

by Sally Weiss

In 1979 UCP of Northwest Oregon received a great deal of press coverage heralding the establishment of the first group home in the state of Oregon to serve people with cerebral palsy and other physical disabilities. The opening of the 12-bed facility on Alder Street was attended by the governor and other state dignitaries who commended UCP staff and Board of Directors for their forward thinking and commitment to providing "state of the art" services for persons with disabilities.

Ten years later the Alder Street facility has been closed—and the UCP board and staff are again to be commended for their forward thinking and commitment to state of the art programs and policies.

What happened in between is a result of the openness and flexibility of UCP of Northwest Oregon's Board Members. As Executive Director Bud Thoune explains, "Every time we think there is something new and better coming up, we try to get into it. The Board is willing to risk as long as the payoff is high enough on the service side."



In 1979 the development of a group home specifically for persons with physical disabilities was a new direction for Oregon. By 1983, however, the Board had trained its sights on developing options other than traditional facility-based programs. At that time the Board was focussing on employment and not on residential programs, but they did decide to get out of the "large group home business" by eventually phasing out the Alder Street facility.

A few years later, Executive Director Bud Thoune and members of the Board attended the 1987 UCPA Conference in St. Louis, MO. There they heard Allan Bergman, Deputy Director, UCPA Governmental Activities Office and Jay Klein from Centennial Development Services (Greeley, CO) share their vision of community integration for persons with disabilities. The Board was intrigued. This Conference marked the beginning of an understanding that there was something other than group homes for people with disabilities. It was also the first time that they understood the critical need for an intense individualized planning mechanism we have come to call "futures planning."

This understanding was further increased by a Community Development Conference sponsored by the Oregon DD Council which again featured Jay Klein. Allan Bergman also spent a great deal of time in Oregon, working with this affiliate on a one-to-one basis and attending Board retreats and also spending time with ARC and with state agencies, sharing his vision and gaining credibility.

Armed with examples of successful community integration such as COIL in San Antonio, TX and Options in Madison, WI and also faced with a large balloon payment in 1988, the Board decided to close down the Alder Street facility by June of 1989. They had made a commitment in 1983 that they were going to get out, and they did not want to invest any more money in a facility like this one. They informed the county and state agencies that Alder Street would be closed and embarked on a host of information meetings with staff, residents and their families at the Alder Street facility. County and state agencies asked the Board to reconsider their decision, stating that they had no alternative settings for Alder Street residents if that facility were to close. The Board persisted with plans for closing Alder Street, however, again enlisting Allan Bergman's assistance in helping state and county agencies understand the nature, importance and potential of what they were setting out to do. The idea caught on, and the county and state got behind them one hundred percent. The 12-bed group home which promoted independent living for people who are physically disabled that was new in 1979 has been replaced by a commitment to the belief that people with severe physical disabilities can—and should—live in their own homes in the community. As of November 1989, each of the eleven persons living in the Alder Street facility had made the transition into his or her own home. Some elected to rent a house; others chose to live in apartments. Decisions about where to live (in a house? in an apartment? in which neighborhood?) and who to live with (nondisabled roommates? personal care attendant? combination of both?) were left to the discretion of each individual.

One person who made the transition from Alder Street into his own apartment is John Calhoun. His journey from institutions out into the community is chronicled in the article from the August 10, 1989 *Oregonian* reprinted on page 7.

Sally Weiss is UCPA Information/Publications Coordinator.

THE NETWORKER, a quarterly publication of the UCPA Program Services Department, is designed to provide UCP affiliate staff and volunteers with a vehicle for exchanging best practice information and program resources. ***THE NETWORKER*** is available free to all UCP affiliate staff and volunteers. Persons or organizations not affiliated with United Cerebral Palsy Associations are invited to subscribe to ***THE NETWORKER*** for an annual subscription rate of $12.00.

_____ I am a UCP affiliate staff/volunteer.
_____ I am not affiliated with United Cerebral Palsy. Enclosed is a check for $12.00.

NAME: _____

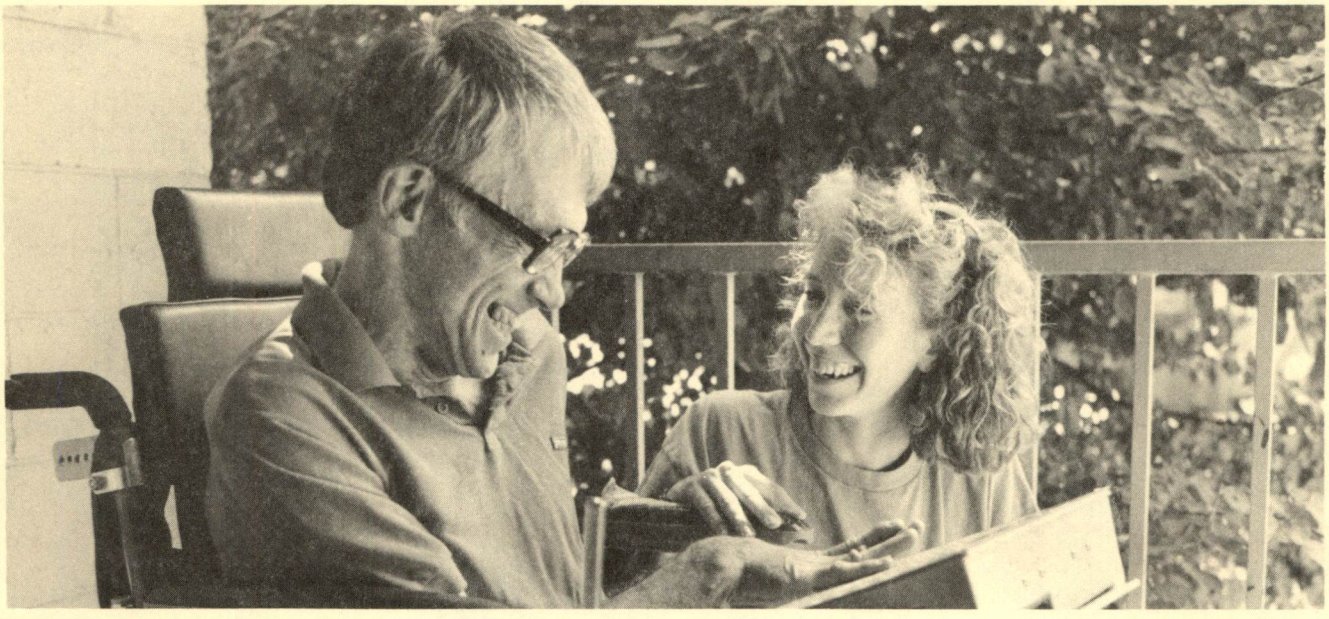
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ADDRESS: _____

CITY/STATE/ZIP: _____

Mail to: Jim Hollahan, Director
UCPA Program Services Department
1522 K Street, N.W., Suite 1112
Washington, D.C. 20005



John Calhoun and Ariel Tindolph enjoy time together on the balcony of John's new home. Steve Nehl, *The Oregonian*

INDEPENDENT LIVING LIBERATES CALHOUN

A disabled Portlander celebrates the new technology and attitudes that make renting his own apartment a reality

Excerpts reprinted from *The Oregonian*, August 10, 1989
by Ann Sullivan, of *The Oregonian* staff

John Calhoun, severely disabled by cerebral palsy, is finally a happy man, on his own.

He has his own place after a lifetime of dependency on other people, dependency on a series of institutions and agencies, including 34 years alone in Fairview Training Center.

He truly was "put away" there at the age of 5, a bewildered and terrified little boy who could not walk, could not feed himself and could not talk, a difficult and impossible burden to a poor family with several younger siblings.

He was a sad little boy who suddenly no longer was carried around by a cheerful father to "see" things. That is one of his happy memories.

John Calhoun is 54 years old and gray-haired. After some 15 years of transition and changing public attitudes, he is overjoyed to be on his own. He has his own apartment with two balconies, a job at a sheltered workshop, a bus pass, an electric wheelchair, a television set, a music system and a voice synthesizer that allows him to communicate.

He has new friends and he lives alone with help from trained assistants a few hours a day.

Most important, he is his own boss....

Calhoun has been collecting new friends, activities and experiences since he moved into his own apartment in Southwest Portland last May.

He travels to work and throughout the city on the bus, exploring his new world. He loves going out in rain by himself.

He has collected friends rapidly at work, on the bus, in his apartment house and, between bus transfers, among the workers constructing the new Pioneer Place building downtown. He also meets people at professional wrestling matches, which he adores.

Calhoun's new electronic voice is a pleasant, male baritone that speaks succinct answers on a small loudspeaker, activated when he punches buttons on the voice synthesizer.

Throughout his own effort to speak, which has improved slowly, his brown eyes are bright and direct. He misses nothing that goes on around him, and his gaze appears amused and disarming because he is so eager.

The observer realizes that he is a bright man imprisoned behind a physical disability.

Calhoun was not suddenly "rescued" from his restricted life. Rather, during the last 15 years he slowly has been liberated by a succession of attendants, advisers and helpers who realized that he was not retarded. Technology, new hardware and caring people with new ideas liberated him.

His life after Fairview included a care center, a training center near Florence, and a foster home in Eugene, where he attended night classes in psychology and English at Lane Community College.

Today, although freed from institutional or group living, Calhoun requires the support of attendants.

His current personal assistant is Nick Cramer, a young man who arrives daily at 5:30 a.m. to help him with breakfast, dressing and picking up, and then again at 5 p.m. for the dinner hour.

Calhoun chooses his own menus and has become a vegetarian because he thinks it is more healthy. Two or three times a week, he has a visit from another assistant, Ariel Tindolph, a community specialist for United Cerebral Palsy who helps him with decisions, budgeting and other problems. Laboriously, through the years, Calhoun has written an autobiography.

It isn't long; its sentences are short, and he had help. But throughout the autobiography is the poignant revelation of how a little boy who was put into an institution felt; how much he understood; how he helped other younger and more handicapped children and played with them; and how he sometimes teased nurses.

The memoir reveals his sense of humor, and his belief that he knew what other,

more handicapped children wanted to say by simply looking into their eyes.

He recounts his appreciation of kindnesses shown him; his ill-concealed sorrow that he was largely abandoned by his family; his pain that his family neglected to tell him about their various moves.

He writes of a sister who won a pie-baking contest and promised him a piece that never was delivered.

He remembers the Christmas he didn't get any presents and other children did; and a sister who promised to take him home for a visit but didn't when her husband apparently objected.

In an interview, Calhoun reaffirmed the feelings expressed in his writings. Using his voice synthesizer, he revealed that he was born at home in an extremely prolonged 30-hour delivery, a 10-pound baby. Both he and his mother almost died, he said. He blames the doctor for failing to initiate an early Caesarean, which he says was necessary because of the baby's size and the difficulty of the delivery.

He expressed extreme hurt that his mother, a teacher, hired a lawyer to put him in Fairview, although his father, a carpenter, did not agree. He does admit that he must have been a terrible burden to a woman with three younger children.

He complains bitterly that the occasional visits from parents and sisters dropped off completely, and he lost track of where anyone was living. His parents divorced and his father remarried.

His mother is ill in a nursing home, and Calhoun asked that she not be bothered by questions. He thinks at least one sister may live in the Portland area.

PROJECT SPICE*: COMMUNITY INTEGRATION

by Brenda Yarnell

One of the more debilitating effects of living most of your life in an institution is the lack of experiences that shape intellectual and personal growth. While most people routinely make choices about events affecting their lives from infancy onward, people who reside in institutional environments have not had the opportunity to make decisions for themselves about the most simple things in their lives: what they eat, when they bathe, who they spend time with, or when they sleep.

As part of Project SPICE, UCP of Land of Lincoln staff are challenged with teaching adults choice- and decision-making skills that most of us take for granted. Since the current eight SPICE participants have a combined 152 years in institutions, the task facing us is formidable. However, one of the most significant and unique aspects of Project SPICE is the role of community integration. Adults with disabilities who have been "warehoused" in nursing homes and state institutions need to learn about their community and its resources. UCP staff accomplish this by providing SPICE participants with opportunities to take part in everyday activities such as grocery shopping, dining out, or going to the movies. Project participants also give back to the community through their volunteer efforts in the Jaycees, at a local day care center and historical research center, and with their respective churches.

It is important to note that of the eight people now living in the community, five attend the church of their choice rather than a "generic" church that is "convenient." Furthermore, church members provide transportation and assume responsibility for helping the SPICE participants with their needs during church services. In two instances, SPICE participants attend a mid-week Bible study class, again with transportation and other assistance provided by members of their congregations.

Another notable outcome of the SPICE Project is a subtle but significant change in staff attitudes. UCP of Land of Lincoln has operated residential programs since 1984. During that time, staff referred to the various residential sites by program name or street address, e.g., the Buckner House. As Project SPICE participants moved into their own homes and began to participate in regular community activities, however, we noticed that instead of saying, "I'm going over to Buckner" or "we'll be at Dirksen House," staff now say, "I'll be at Anna and Mary's house." Mary, by the way, is also no longer "Mary-the-client" but Mary who lives on Schrader Street, has a dog named Cubby, is a devout Catholic and recently joined the Jaycees.

Friendships between UCP staff and SPICE participants are another positive spinoff from the Project. Two of the men from the Adult Day Program are frequent social and dinner guests in several homes, and another staff member takes Mary to religious services on her lunch hour during certain holy days.

Changes in the way that services are provided have also accompanied Project SPICE. From the very inception of the Project, Land of Lincoln staff began to build an "ideal" program of **consumer-controlled**, integrated services. When people residing in a nursing home choose to participate in the program, they are **the** decision maker in choices that affect their lives. They choose where they will live, their furnishings, who the staff will be who work for them, and what they want to do in their leisure time.

As Project SPICE participants moved into their own homes and began to take part in mainstream society activities, it became clear that we had enabled them to control their own lives and that our role was simply to provide support in those areas where they needed assistance. In response to this changed role, Land of Lincoln has replaced individually assigned staff with teams that respond flexibly to the level and types of support each person needs and wants. The team approach has been so successful in meeting individual needs that it is now being used in all of Land of Lincoln's residential programs.

Project SPICE has not only made dramatic changes in the lives of persons formerly living in nursing homes but it has permitted us at UCP of Land of Lincoln to practice fully the "ideal" in terms of how we provide programs and services. In Project SPICE, integration begins the moment a person decides to participate: goals, decisions and choices are all made **with**—not **for**—each individual, and Land of Lincoln staff work in partnership with each person as he or she moves out of the nursing home and into the community.

Brenda Yarnell is Program Director for UCP of Land of Lincoln in Springfield, IL.

*The Supported Placements in Integrated Community Environments (SPICE) is a residential program through which persons are moving out of nursing facilities and into their own homes. It was designed as a pilot project to demonstrate that persons with multiple and severe disabilities can live outside congregate settings when provided with appropriate services and support.

A LIFE OF FREEDOM

Two women with disabilities move into a home of their own

Excerpts from the *Illinois State-Journal Register*, September 10, 1989
by Mary Nolan. Photographs by Rich Saal.



Mary Moskal and Anna Clark in the yard of their new home in Springfield, IL.

When Anna Clark was 9 years old, she took a ride with her dad. He dropped her off at a large brick building and said he'd pick her up later.

He never did.

The little girl never again saw family or home life.

For almost 65 years, Anna lived in a state institution or nursing homes.

She was shut off from the world for no other reason than her disabilities. She never received an education. She never had a place to call her own—until this summer.

Anna, who was born with cerebral palsy, now lives in her own house equipped with wheelchair ramps and extra-wide doorways.

She's wasting no time making up for lost years. Her attendant describes Anna, 72, as a "socialite."

Anna keeps a busy schedule of ice cream socials, baseball games, church meetings and Bible study classes. She goes grocery shopping once a week and for the first time in her life she makes the decisions about what she's going to eat.

Anna grimaces when she recalls her former life. Before, she says, she usually had a dry cheese sandwich for lunch.

Deep dimples show in her face as she opens a shiny red tin canister to remove the lunch she has packed. She needs help opening a can of sausages but she's able to feed herself. She also has a banana, cheese crackers and peanut butter, and brownies sprinkled with nuts.

Anna shares her house with Mary Markal, who had been her roommate at Dirksen House. For Mary and Anna, the house is not just a home—it represents a new life free from the regimen, intrusions and limitations of nursing homes and institutions.

A statewide study identified Mary and Anna as among the thousands of developmentally disabled adults who were shut up in nursing homes when they could actually live a normal life in a regular house with some support from a trained staff.

Through a state grant, United Cerebral Palsy of Land of Lincoln rented a house for Mary and Anna and hired a skills trainer who assists them in learning to live independently.

They are enjoying a routine that includes things most people take for granted. They go to the public library to select books, shop at White Oaks Mall, listen to Municipal Band concerts at Douglas Park and worship at the church of their choice.

Shortly after the pair moved into their house on the north side, they hosted a party for Mary's birthday.

Mary is unable to speak but she communicates by pointing to pictures on a lap board that attaches to her wheelchair. She squeals, claps her hands and spells out D-O-G—the birthday present she cherishes the most.

Having a pet was something that Mary could only dream about when she was in a nursing home. The pup, who has yet to be house-trained, is spending the evening in the garage.

Mary, who is in her 30s, is as exuberant as a child at Christmas. She looks like she wants to spin around from all the excitement.

Cerebral palsy has limited her movement to her head and hands, which bob and shake as each guest arrives.

Most of her friends are from the United Cerebral Palsy training program that she attends with Anna. A bus picks them up every day. Mary learns simple tasks like sorting cards and stacking paper. Once she masters these skills, she may move on to a vocational workshop to prepare for a job or a volunteer position.

Mary and Anna are among eight persons with developmental disablities in Springfield who are benefiting from a pilot state program called SPICE—supported placements in integrated community environments. About 100 persons with cerebral palsy statewide will be moved from nursing homes into one- or two-person homes.

"People were living in nursing homes where they were inappropriately placed. They didn't need nursing care. They needed attendant care," says Barbara Sideman of United Cerebral Palsy.

Most of these patients in nursing homes came out of institutions, Sideman said. The move into the community fulfills the long-awaited promise to deinstitutionalize those who are physically or mentally disabled.



Angie Drennan, a skills trainer, prepares dinner from a menu the women planned themselves.

Sideman said there's been no opposition locally to moving persons who have developmental disabilities into city neighborhoods. Larger group homes with eight to 15 residents have often met zoning obstacles and neighborhood resistance.

"We haven't had a problem because we are doing it quietly. We go in and meet the landlord, pay the rent and once we are there, we meet the neighbors. In some neighborhoods, neighbors extend a hand and say call us if you need anything. Our houses don't look like an agency program. There's no van with a label sitting in the driveway. The only thing that would possibly look different from the rest of the neighborhood is a wheelchair ramp and that's not uncommon today," she said.

Anna and Mary's north side neighbors made curtains for the house and children from nearby St. Agnes grade school planted flowers before Mary and Anna moved in.

Sideman said reaching out into the community is difficult for nursing homes because the staff is so busy making sure that residents get the physical and medical care they require.

"They are worried about whether everyone is showered and fed and gets their medication. They don't have time to say 'Anna, would you like to volunteer at the hospital?' Our staff works on getting people involved in the community."

The staff helps participants find ways to develop their own interests and skills.

"One of our participants, who is blind and uses a cane or a walker to walk, now volunteers at a day-care center one hour a day and tells stories to the kids," Sideman said.

Mary, an avid baseball fan, hopes someday to work at a ballpark concession stand. From the back porch of her house, she can see games from a neighborhood baseball diamond.

Anna has her own interests. Arrangements are being made for Anna to work in a hospital mailroom.

"She just loves being around people," Sideman said.

Anna's new battery-powered wheelchair lets her be even more independent. The new wheelchair made it possible for an attendant to take Mary and Anna on excursions into the city together. Between them this summer they hit the city's main events—LincolnFest, the Carillon Festival, the Illinois State Fair, along with blockbuster movies and church picnics.

"I assist them with whatever they want to do. These guys can communicate a lot," says Kendra Guernsey, a skills trainer for Mary and Anna, who previously worked in a group home for delinquent kids.

"Mary and Anna don't argue with me. They want to sit down to their meal, take a bath and go to bed," Guernsey said. "Doing normal things in life is just thrilling to them."

Anna adds, "I had to fight with them to give me a bath in the nursing home."

"To go to the bathroom you'd have to wait an hour for them to help you," she says. Mary points in agreement with Anna.

Guernsey reads to Mary and Anna in the evening. This week's selection from the library includes "His Gentle Voice," a Christian romance, and the autobiography of Amy Grant, the Christian pop singer. Anna and Mary share favorite music—rock n'roll—and soap operas.

The only conflict they have is over what baseball game to watch.

Anna likes the Cardinals and Mary likes the Cubs.



UCP skills trainer Kendra Gurnsey accompanies Mary and Anna on a shopping trip for a stereo.

JESSE DAVIS' ROAD TO INDEPENDENCE

by Mary Boaz

In the 40 years that make up his life, Jesse Davis has become an expert at overcoming the hurdles he has encountered on the road to independence. Jesse has spastic quadriplegia cerebral palsy. At the age of 18, when his parents became too frail to care for him at home, he was placed in a state institution. Soon after their deaths, Jesse fought his first battle toward becoming his own person when family members tried to declare him incompetent. Exercising his rights, Jesse went to court and convinced the judge that he was not only competent but more than capable of making his own decisions. The judge awarded guardianship to the rightful owner—Jesse Davis.

During subsequent counseling sessions at a development center, Jesse made it clear to his social worker that he was unhappy living in an institutional environment. Thus began a journey that led Jesse to UCP of Central Arkansas in Little Rock. On New Year's Eve 1986, Jesse and another person with disabilities celebrated a new way of life by becoming residents of the first UCP Group Home.

During the past three years, Jesse has become more and more skilled in the ways of independence. He has also spent much of his time serving as an advocate for others determined to live on their own. As president of United Together, a national advocacy group for persons with disabilities, he has had the opportunity to meet and influence politicians who play an integral part in appropriating funds and devising new programs to aid persons with disabilities.

Throughout this time, independence continued to be Jesse's personal goal. While the group home was a step in the right direction, it was just that . . . a step. On August 18, 1989, Jesse moved again. He became the first person in the state of Arkansas to take advantage of the Medicaid Home and Community-Based Services program, which gave him the means to move into his own home. He now resides in an adapted apartment, and with the help of friend, personal care attendant, and live-in companion Dwight Smith, Jesse is ready to take on the world. Jesse says it best: "I had never been able to live independently all my life, and I said that was something I wanted to do. I told myself if the Good Lord gives me the encouragement, I'll go ahead." And "go ahead" he has . . . to a life filled with possibilities instead of limitations.

Mary Boaz is a Community Development Specialist for UCP of Central Arkansas.

MAKING HOMES BARRIER-FREE

by Susie M. Reid

Often one of the obstacles that prevents people with disabilities from living in the community instead of an institution is the lack of home accessibility. With a $112,000 grant from the New Jersey Division of Developmental Disabilities, UCP of Mercer County's **Housing Rehabilitation Program** provides modifications to private homes of persons with disabilities to ensure full accessibility, safety and mobile independence. Modifications include ramp construction, stair glide installation, door widening, bathroom modifications, and installation of safety railings.

Participants may own or rent the home that they wish to have renovated. In order to be eligible for full services which include financial assistance and the needed renovations, individuals must be both developmentally and physically disabled and reside in Mercer County. When a request for services is received, the Program Director visits the home and conducts an "accessibility assessment survey." Various modifications are suggested, and the Program Director and the family determine which modifications would be most appropriate.

For example, Scott Ellis, a 21-year-old Hightstown resident disabled after a diving accident nearly three years ago, has been sleeping in the dining room of his parents' house. While meeting with our staff to discuss possible modifications, Scott stated firmly, "No more curtains! I want doors!" Plans for Scott's new first-floor bedroom and bath call for a 41-inch wide hallway and 40-inch wide doorways; retractable doors eliminate the need for Scott to maneuver around an open door. Scott was equally adamant that there was no need to extensively modify the family kitchen: "I didn't cook before. No reason to start now." However, his parents' views prevailed in this case, and the kitchen will be adapted as well.

Once eligibility has been determined, the needed renovations are completed using contractors experienced in accessibility and local medical equipment suppliers. For those individuals who are not eligible, technical assistance and suggestions regarding modifications are provided.

Started in July 1987, the Housing Rehabilitation Program was UCP of Mercer County's first funded program. It was modeled after "Project Open House" in New York City, but was designed as a scaled-down version of New York's more comprehensive program. Fifty-two referrals were received in the first year alone. Thirty of the families received only technical assistance and 17 received full program services including financial assistance for needed modifications. To date, 85 families have requested assistance from the "Housing Rehabilitation Program."

As these numbers suggest, only minimal outreach was required to find program participants. After a few families received services, they spread the word, and so did other service providers. If your affiliate is considering creating a similar service, you may find, like we did, that your program is the "only game in town." When other social service providers learn of your program's existence, they will happily refer families to you for assistance. Believe me, the calls will pour in!

Furthermore, it is not difficult to integrate a housing rehabilitation program into an existing array of services, since a program can range from simply offering technical assistance and financial referrals, to doing accessibility assessments, to providing financial support, to arranging for renovations--or any combination of the above. Our staff is not large: it consists of a full-time Program Director, a part-time Assistant Program Director, and two independent contractors. Yet even with this small a staff, families, who

Homes . . . *continued on page 17*

SUPPORTING ADULTS WITH DISABILITIES IN THE COMMUNITY

by Julie Ann Racino

This article is based on work on individualized supports conducted by Steve Taylor, Julie Racino, Bonnie Shoultz, Pam Walker, Zana Lutfiyya and Jim Knoll and is a reprint of a January 1988 article by this author.

During the past few years, the Center on Human Policy has studied a growing number of places throughout the country where adults with disabilities are being supported in individualized ways in the community. When we first begin our national search for exemplary practices in community living in 1985, we expected to identify many good examples of group home and apartment living for adults with severe disabilities. Instead, we found that the most exemplary practices represented a new way of thinking about providing supports to people with disabilities. Unlike the traditional approach of establishing residential programs, fitting people into the program, and then individualizing within the context of the program, these agencies were starting with the person first and developing the supports and housing around the person. This article will describe some of the key elements in this new way of thinking about and developing supports for adults.

Key Elements in Individualized Supports

- ***Separation of Housing and Support Components***

Probably the most critical element in thinking about and implementing individualized supports for adults is the separation of the components of housing and support services. Typically, we have bundled both together, requiring a person to live in a certain place (*e.g.*, a group home) in order to receive a given intensity and type of support (*e.g.*, 24 hour support). By separating the components of housing and support services, it becomes possible for a person, including someone with severe disabilities, to receive supports wherever they may live.

This separation of housing and support services can lead to greater control by the consumer.

(a) CHOICE IN HOUSING – The person can live in a variety of kinds of housing, dependent on their particular circumstances, from a duplex to an apartment to a condominium to a flat to a trailer to a house. The person is not required to live in a certain type of housing in order to receive supports. For example, under the supported independence program in Michigan, a variety of types of housing (excluding trailers) are options.

(b) CHOICE OF LOCATION OF HOME – The person can choose where she wants to live, including the specific neighborhood. Because the housing and supports are not tied together, the person can have greater choice in the home's location. Thus, the location of the home can build on and strengthen natural supports as opposed to severing those ties. For example, as one staff member in Minnesota said, "we help people to decide what neighborhood they will live in and look for a place that seems right for the people."

(c) CHOICE OF LIVING ALONE OR WITH OTHERS – Because the location and number of people is not predetermined, there is greater flexibility in how many people will live together. The option of living alone, at least for a period of time, is an important one for some people. Individualized, however, does not mean that a person will always live alone or with one other person. People may also choose to live with a number of other people.

(d) CHOICE OF ROOMMATES – The person can have greater choice in their roommate(s), if having a roommate or roommates makes sense in their life. By separating the aspects of housing and support services, it becomes easier for a person to choose with whom they would like to live. Because supports are not tied to a certain setting, one can live with a variety of people, including "typical" people, family, people with other labels or alone AND still receive the needed intensity of supports. This approach recognizes the critical importance of the people we live with and the impact they may have on our lives.

- **Housing and Home Ownership**

While there are many critical aspects to the issue of housing, a central one is that of leasing and home ownership. People with disabilities are typically required to move to agency-owned housing to receive intense support services. One of the key elements in an individualized approach for adults is an emphasis on a person living in a place that she owns or leases either alone or in conjunction with other people. Only under certain limited circumstances should an adult live in the home of another or in agency-owned housing.

Ownership and leasing have both legal and personal ramifications. Ownership means that it is the person's home first and foremost. It is a place that staff, not the person, can be asked to leave. People with disabilities have seldom had the opportunity for their home to be "their castle." This approach underscores the importance of MY home and the feeling of ownership.

- **Individualized and Flexible Supports**

One of the most critical elements in this type of approach to supporting adults is the individualized and flexible nature of the supports.

(a) INDIVIDUALIZED SUPPORTS – Unlike the typical approach of fitting a person into existing programs, individualization in this situation means tailoring to or developing the supports that will best match the person and her current life circumstances. As stated in the Wisconsin Community Integration Program Medicaid Waiver, "services must be designed or modified to fit the person and meet that person's unique needs." The individualized nature of the supports is typically accomplished through the establishment of an array of possible supports/services that can be accessed by the person, in any combination. For example, individualized supports can include: dental and medical care not otherwise covered, respite, recreation, homemaker services, transportation, attendant care/home health care, therapeutic and nursing services, home and vehicle modifications, home and community training and support, equipment/supplies, legal services, crisis intervention and counseling services, and employment services. Since it is impossible to anticipate every type of support that may be needed, it is very important that the array of services includes "another category" (or some mechanism to insure that unanticipated items can be included).

Individualized supports have been provided, to some extent, under the home and community-based care Medicaid waivers in a few states. For example, under one state's Medicaid wavier, the following supports can be matched to the individual persons and can vary in amount, frequency and duration based on

individual needs: respite, homemaker, habilitation (including therapeutic activities, monitoring, supervision, training or assistance in self-care, sensory/motor development, communication, behavioral supports, community living and mobility, health care, leisure and recreation, money management and household chores), adaptive aids, and supported employment/day habilitation services. This approach can be more flexibly accomplished through the use of state general funds such as Michigan's supported independence program. Some states combine funding sources (Medicaid, state dollars, county dollars, and others) to provide individualized supports.

(b) FLEXIBLE SUPPORTS – Flexibility means the supports must be able to be adjusted in a timely way both in kind and in intensity. Thus, supports can be changed over time without the person needing to move from one place to another because "she no longer needs that level of support." When supports and housing are separated, the staff can "withdraw" or "fade" instead of the person needing to move to a new location. This results in continuity for the person, and again builds on existing supports. Also, when a person needs more or different supports, she can continue living in the same place, but the supports can be changed.

In many ways, this flexibility is much more difficult for service systems to achieve than individualization. We may "individualize" once, but our systems are not often designed to adapt and change at the pace that people change. Flexibility has been built into this approach by keeping decisions as close as possible to the people being supported.

The Development of Supports

An individualized approach to supports typically involves a change in our way of thinking about "assessment" and "service development."

(a) COMMUNITY ASSESSMENTS – Unlike the typical "deficit-based" assessment, a community assessment typically involves a less formal process of getting to know the person in a variety of community environments. The emphasis is not on screening in or out of services, but on using the assessment process to determine the supports that will be initially needed. For a good discussion of this type of assessment, see "Getting to Know You: One Approach to Service Assessment and Planning for Individuals with Disabilities" (Brost and Johnson, 1984). More structured ecological strategies (Ford et al, 1984) can also be used.

Under the Wisconsin Community Integration Program Medicaid Waiver, all assessments must include social relationships, meaningful education or vocational programs, recreation and leisure activities, health and wellness monitoring, social and physical integration in the community, involvement of family and friends, home, and protection of individual legal rights.

(b) BUILDING ON NATURAL COMMUNITY SUPPORTS – An individualized approach to supporting adults in the community builds on the existing community ties and relationships that each person already has in their life. Instead of supplanting these ties, this approach looks at how these natural supports can be both maintained and strengthened, if that makes sense in the life of the person. Just as Ed Skarnulis, then in Nebraska and now Minnesota state director, said "support, don't supplant the family," it is also important to support neighbors, friends, acquaintances, and other relationships in the person's life.

Many of the supports that people with disabilities need are already available through "generic" or community services available to the general public. An individualized approach includes an emphasis on using these existing supports as opposed to the creation of segregated supports and services.

(c) CHANGING OUR THINKING ABOUT SUPPORTS – This approach requires a shift in how we think about the development of supports and services. In order to facilitate a change in our thinking, a technique called personal futures or lifestyle planning (O'Brien, 1987) has been used to help groups of people create a positive future vision for the life of a specific person with a disability. This approach is one useful way of beginning to break away from "fitting people into services" to developing the supports that enable the person to lead a meaningful life. It also asks key questions about what we can do to make this vision occur as opposed to our current focus on what the person herself must change.

The way in which we think about supporting people seems to be one of the main impediments to changing to a more individualized approach. While funding mechanisms, regulations and other structures are not always designed to support individualization, often simply shifting our thinking can assist us to recognize options even within current constraints. As one staff member said "It can be done. It is a problem in thinking."

(d) CHOICE OF SUPPORT PROVIDERS – The best examples of supporting individuals included consumer control over the hiring and firing of their staff. In these situations, the staff worked for the person with a disability, not for the agency. The role of the agency was to support the person in managing their staff, including the aspects of hiring and firing. As agencies move out of the housing business, their role in the area of support services can also be expected to change. In this area, developmental disabilities services have a tremendous amount to learn from the independent living movement in this country.

Even when a person with a disability does not directly hire or fire their own staff, it is critical that mechanisms be established for changes to another provider during the contract period. There are times when a person and their support providers will not be a good match and mechanisms to facilitate a change in providers must be in place.

(e) AVAILABILITY OF SUPPORTS FOR PEOPLE WITH SEVERE DISABILITIES – Another element that differentiates this approach is the availability of the supports to people with severe disabilities. Unlike "supportive apartments" or semi-independent living which typically support people with mild disabilities, this approach enables people with severe disabilities to live in an apartment or home with the supports that they need. It is critical to include up to 24-hour support. Thus, instead of being uprooted from their homes continually, several agencies we have visited support people with severe disabilities in moving directly into their own places with the supports that they need.

(f) INCREASED USE OF PHYSICAL ADAPTIONS – This type of approach also appears to increase the physical adaptations that are made for individuals. When living in your own place comes first, doing it all on your own (i.e., process) may become secondary to getting it done (i.e., outcome). Thus, a person can be supported in living a meaningful life, before they are able to do it "all on their own." We have been continually impressed with the inexpensive innovations that staff, family and people themselves have developed (e.g., cassette tapes of morning routines, strings on cupboard doors) to support people in living in their own homes.

Supporting . . . *continued on page 21*

CAMIA

Camia has recently had her third birthday. Her diagnosis reads: "cerebral palsy with spastic quadriparesis, microcephaly, and strabismus." When she was 15 months old, her mother enrolled her in the UCP of Western New York's early intervention program, located in Cheektowaga, New York. When she first joined the program, she smiled a lot. She tried with all of her might to make toys work, usually by batting at them with either arm. The staff started to work on her use of eye gaze to make visual choices between toys. At the same time, they recognized that Camia's use of even easy-to-operate toys was almost impossible.

Camia quickly showed everyone what technology could do for her. Once the best switch was identified (a highly sensitive plate switch), along with her optimal positioning and the best set-up of materials, Camia set about stretching everyone's expectations. Her favorite switch-activated devices became the Fisher Price TV, a mooing, moving cow, and tape-recorded music—all of which she operates with a plate switch. The same plate switch helped her use switch software on the computer. But she has also shown everyone that the Power Pad, Touch Window, Unicorn Board, and a partially masked Muppet Learning Keys work, as long as her position and the equipment set-up allow her to touch the right spots at the right times to make things happen on the screen. Her versatility across peripherals occurs despite the fact that the physical movement she uses most consistently is a swipe of either splinted arm. She taught staff from the beginning, however, that other children bring out her best. Whether playing with switch-activated toys or on the computer, she is most consistently attentive and happy when another child is playing with her or beside her—even when it means she has to take turns!



About the same time that Camia was showing both staff and her mom her technology prowess, her mother requested some help. It seems that screaming was Camia's way of keeping mom's attention at home. Staff introduced Camia to the use of a tape-recorded message, played on an audio loop tape, and activated by the same switch that she used for playing with toys and operating the computer. When she touched her switch, the tape recorder would call mom, teacher, friends, or teacher's aide to her side. Camia quickly learned the power of the "spoken word," and now at school uses her voice to call—not scream—for help or attention. At home, she still uses the tape recorder signalling strategy at times when her mother is busy or not nearby.

Camia's quick adaptation to and use of switch-activated messages in different activities across the day showed staff that she would simply not wait for a more effective and efficient communication system. During group learning times in her classroom, she is now using the Power Pad to convey messages related to the lessons at hand. Staff have recently been experimenting with her on the use of a Light Talker.

THE TLC PROJECT:
Helping To Stretch Expectations About Technology In The Lives Of Youngsters

by Kathleen Gradel, Ed.D., and Janet Sloand-Armstrong, M.S.

AMANDA

Amanda is 2 1/2 years old. Today, she is busy playing with her mom with a five-plate busybox. Activating each of the five switches produces a different consequence, including vibration, a radio tuned to her favorite station, or a light blinking on. Amanda and her mom both make choices about what to activate on the adapted busybox. Besides making choices among the switches, Amanda shows that she is actively engaged by attending to the toy, by initiating, and by just having a good time.

Amanda was born with multiple congenital anomalies. Her current diagnosis reads "cerebral atrophy, seizure disorders, central blindness with left glaucoma, and hydronephrosis." Before her first birthday, Amanda underwent numerous surgeries. Today, she takes phenobarbital and dilantin to control seizures.

A little more than a year ago, when she was 13 months old, Amanda was first enrolled in the early intervention program run by UCP of the Capital Area, in Camp Hill, Pennsylvania. She was a real "doll"—not demanding, and pleasant to be with. But she paid little attention to anything. She did not seem to do anything intentionally to control people or events—what little she initiated seemed to be unrelated to things going on around her. Last year, Amanda's parents and the staff did not see any evidence that she had learned that what she did would produce consequences (i.e., "cause-effect"), or that something "out of sight" had any meaning (i.e., "object permanence"). Further, she did not appear to have any consistent preferences or be motivated to play or do anything. Then and today, she is a child who shows very little progress when measured by traditional developmental checklists.

The interdisciplinary staff and Amanda's parents were unsure about Amanda's future, but they were in agreement on at least three things: They all wanted her to be able to be productive, to control her world, and to be happy. They agreed that technology could help. Initially, they introduced the vibrating plate switch in playtimes with Amanda. It was used without a toy at first, since Amanda had difficulty attending to a switch and a toy at the same time. Further, the vibration that occurred when she even accidentally touched the switch appeared to be motivating. This was one of the first clues to figuring out what motivated Amanda. She also showed her parents and the staff a few other key things. First, she seemed to want the switch "on" more than "off," as indicated by her increasingly frequent activation of it. Second, she increased her "attending" behaviors when playing with it—by looking at the switch, and by smiling when the switch was on. Third, her activation of the switch appeared to become less "accidental" and more "intentional" over time.

Since those first few times playing with the vibrating plate switch, Amanda has changed a lot, although she still scores in the range of 4 to 8 months on developmental checklists. She uses various switches to play with lots of different toys. She prefers music over other things, so a switch-activated tape recorder or the adapted Fisher Price TV/music box are constant companions. She locates the switch she is using and, when she activates it, easily shifts her attention to the toy that is connected to it. She shows that she does and doesn't want to play with certain things at certain times, too. For Christmas, her parents and extended family filled her toy box with new already-adapted toys and others (like Teddy Ruxpin) that they temporarily adapt using a battery interrupter.

How Amanda and Camia Help Us Stretch the Expectations and Practices of Early Intervention Practitioners

Amanda and Camia are just two of the youngsters who serve as continuing "success stories" in our experiences in the UCP affiliates of the Capital Area and of Western New York. They have taught and continue to teach us some invaluable lessons about expectations and what is possible given the potential role of technology in their and our lives. We have summarized three of these "lessons" briefly in the following paragraphs.

Lesson 1: Don't make children wait.

Children and their families have repeatedly shown us that, if we wait to introduce technology in one form or another, we are probably doing it more for *us* than for the child. In other words, Amanda and Camia have taught us that there are no good guidelines or rules that dictate when something should be tried or when it might work—whether it be a switch, a computer peripheral, some new software, a toy, a signalling device, or a communication device. The only "golden rule" that has been reasonably successful is to not make children wait to try out a form of technology that may help them play better, learn better, better show what they know, communicate with important folks in their lives, or otherwise control their worlds. Our underlying assumption is that, if the adaptation we have built, bought, or borrowed results in people responding, toys working, and kids acting like kids, then we *haven't* kept children waiting. If, on the other hand, we see youngsters exerting little or no control over people, places, and things with the technology we have chosen, we can be certain that we have more work to do . . . so that children are not kept waiting to be active participants in their own lives.

Lesson 2: Rules about sequencing technology use haven't been much help.

No rules about lock-step introduction to or instruction on switch or computer use have lasted long enough for us to record them. We have found anecdotally that children's use of various forms of technology are highly idiosyncratic to the child and his/her opportunities for using them. Thus, we have little confidence in describing a child as a "switch" child versus a "computer" child, or in assuming that switch use must precede computer use. In fact, we have found that children "do the darndest things," surprising us at every turn about what is motivating or meaningful to them. Hand-in-hand with our lack of confidence in the ability of typical "readiness" skills to predict what technology will work for which child is a healthy fear we have acquired. Specifically, if we were to take seriously the notion that mastery of typical developmental milestones is needed to use technology for learning and living, we are fearful that many of the youngest children and those with the most significant disabilities would be "wait-listed" for technology services. The potential dangers of doing "other things" until a child is "ready" or has mastered presumably prerequisite skills that will enhance technology use stand in marked contrast to the potential of technology to make more equal the learning and interaction potential of babies, toddlers, and preschoolers who possess disabilities.

Lesson 3: Real-life is best.

It may not be the easiest, but using technology in real activities, with sisters and brothers, in real kitchens and family rooms, and in real childcare settings is the true test in early intervention programs. What this may mean to the early intervention practitioner is that the technology we and parents select for their children must work in real living and learning situations—NOT be confined to one-to-one instructional periods that occur in clinics, classrooms, and even in the home. Instead, we have to be willing for our toys to get fondled, thrown, bumped, bruised, and used. Computers need to be on the floor, on low tables and carts, and be able to move. And—most important—we as interventionists must be willing to help youngsters, and their peers, siblings, and families use technology devices at times and in contexts which make the most sense in their day-to-day lives.

The TLC Project

Amanda, Camia, and their peers are becoming familiar faces to early intervention practitioners across Pennsylvania and New York, through the training activities of the TLC Project. TLC is a national outreach project funded through the federal Handicapped Children's Early Education Program (HCEEP) to UCPA, Inc., UCP of Western New York, and UCP of the Capital Area. The project's primary function is to train and deliver follow-up technical assistance to cross-discipline practitioner teams as they use technology with children aged three and younger. A three-part training sequence introduces teachers, therapists, and paraprofessionals to the how's and why's of making "low-tech" adaptations, using adaptive switches for play and to control children's worlds, and integrating computer use into the lives of young children. The training emphasizes making informed decisions with families about using technology to the child's and family's best advantage, in "real life" play, learning, and living contexts.

To date, three teams in Pennsylvania and three in New York have participated in TLC's training. Participants have just been selected for the project's second year—six teams, including three to four UCP affiliates in each state. An additional six teams will be selected in each state in the project's third year. A new component will be initiated this year, involving a separate but complimentary training of pairs of program representatives—one early intervention practitioner and one agency supervisor or administrator. This component will focus on practices to facilitate within-program changes to systemically support technology use in the context of good early intervention service delivery practices.

For more information about the TLC Project, please contact one of the following staff members:

Ms. Janet Sloand-Armstrong
Lead Trainer, TLC Project
UCP of the Capital Area
1-717-737-3477

Ms. Pauline Digati-James
Lead Trainer, TLC Project
UCP of Western New York Children's Center
1-716-633-4440

Dr. Kathleen Gradel
Project Director, TLC Project
1-716-886-0562

Kathleen Gradel, Ed.D., is TLC Project Director for UCPA. Janet Sloand-Armstrong is Lead Trainer for the TLC Project site in Camp Hill, PA.

AGING WITH A DISABILITY: ANOTHER ADVOCACY PRIORITY

by June Isaacson Kailes

People with disabilities are now experiencing problems that combine the problems of aging with the problems unique to a life spent living with a specific disability.

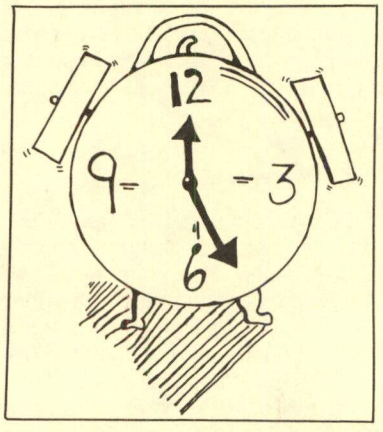
We have all been told that, "when you get older, you slow down physically, and you can't do as many things as you could when you were younger." For most of us who grew up with a disability and who already couldn't do as much as our peers without disabilities, this warning was rather meaningless. Others with disabilities who did listen to this warning certainly did not expect that the aging process would be exaggerated. In fact, however, people with disabilities are experiencing unexpected declines in their energy and activity levels as they age. We are exhibiting signs of aging much earlier than the rest of the population our age, yet existing public policy and health and human services are not dealing with this issue.

When I, a person with cerebral palsy, began to articulate my own concerns to friends who were medical professionals, I thought I sounded vague and slightly crazy. When I explained, "I'm not walking as fast as I used to, my balance is not as good as it used to be, and I have more spasticity as well as aches and pain," I did get quite a few blank looks. So I decided to check out just how weird I was by conducting my own very scientific (i.e., informal and undocumented) survey of friends and colleagues with disabilities. My survey results confirmed I was not alone.

After mulling the question over a bit, I chose not to accept my self diagnosis: increasing brain damage secondary to (1) spending too much time on airplanes breathing inadequate, smoke-filled, recirculated air or (2) poor sleeping positions resulting in blood draining from my brain. Given the uniqueness and ambiguousness of these conclusions, I decided to seek some additional professional opinions.

Because I had some background in rehabilitation and neurology, I felt confident that I could make the proper connections. I was wrong! The process was disconcerting, especially given that I live in Los Angeles, not exactly a medically resource-poor area! I found doctors who specialized in children with CP, but I was not able to identify anyone who specializes in adults with CP. After a costly and probably unnecessary MRI of the brain, the most common advice I received was to concentrate on strengthening specific muscles. Other than that, no one had anything very definite to say.

I then sought the help of my out-of-town network and obtained some names. A name listed frequently among the few I received was Dr. Barry Bouser in Houston, so the next time I was there on business, I looked him up. Not only was he very helpful, but he had some very different but specific advice regarding energy conservation, exercise and mobility aids. He felt muscles strengthening would *not* be that helpful because the unevenness in cerebral palsy comes from imbalance in the degree of damage in the motor cortex. That is, the firing pattern is asymmetrical and it is not going to change. Therefore I could strengthen muscles as I wanted but eventually they would return to being unequal in strength. The time and energy were not worth the very temporary, if any, results.



At this point, I felt I had found some answers for myself. But if I had to go through this rather exhausting search for advice and information, I wondered what was happening with others who were asking similar questions. I also wondered what would happen to the upper extremities of others with cerebral palsy who I saw walking so slowly and laboriously on crutches. Was walking so supremely valued by the medical community, parents and society that the long-term effects of wear and tear were better off ignored until they could be ignored no longer?

The publication of Roberta Trieschmann's important book, **Aging with Disability** (available from Demos Publications, 156 Fifth Ave., New York, NY 10010, 1987), confirmed for me and many others that we were not losing our minds. Roberta substantiated the issue that many of us have creeping into our reality: people with disabilities are now experiencing problems that combine the problems of aging with the problems unique to a life spent living with a specific disability.

The combination of aging and disability is an unexplored, undiscussed and unacknowledged area. Why is this such a new and unanticipated issue? I am told that in the past people with disabilities just never lived that long and thus little is known about aging and disability. My peers and I are the first generation of people with disabilities who are approaching middle age, retirement and beyond in great numbers. People with disabilities have been taught how to *live* with a disability but *not* how to plan to *age* with a disability nor how to prevent a disability from increasing via the aging process.

Prior to the distribution of Roberta's book, peer input was the only validation and support people with disabilities had to assure each other that what we were experiencing was something real. Her book also alerted disability advocates that we must make room for yet another issue on our already overfilled advocacy plate. We have to insist that health and social services concentrate a substantial portion of their efforts on the issues of aging with a disability.

Confirmation and Validation

Roberta correctly points out that many of us considered our disabilities to be static (spinal cord injury, polio, cerebral palsy, spina bifida). A progressive component to our disability was not anticipated. Now, however, we are experiencing the natural process of aging superimposed on other impairments that have themselves imposed a range of physical, emotional and financial penalties on our daily lives.

Roberta explains that aging not only relates to chronological age but also correlates with the time since the onset of disability. Living twenty or thirty years with a disability, depending on one's lifestyle, genetic heritage and type of disability, produces wear and tear on the muscles, skeletal system and other body systems. Most people with major physical disabilities of at least thirty years' duration note some tenderness and soreness in joints, muscles, and tendons which have been carrying the extra load of impaired physical function from other parts of the body. Heavy use or overuse of parts of the body to compensate for lost motor ability in other body parts can lead to problems over time. As people with disabilities age, the physical penalty increases—and with that goes an often inevitable financial penalty as well.

Why Has This Issue Been Ignored?

Roberta explains that rehabilitation is commonly viewed as not a high prestige specialty because it does not focus on dramatic new discoveries leading to "cures." Nor does it focus on the development of new procedures that "solve" problems as do specialties like surgery, cardiology, radiology, and oncology. In the medical world, research that's focused on practical issues such as helping people with disabilities lead more satisfactory lives is considered a "weak" science. More prestige is attached to cellular, molecular and biological research, i.e. the "hard" sciences.

Furthermore, rehabilitation medicine continues to focus on acute management of newly acquired disabilities. This focus becomes increasingly weaker when looking at the person who lives with a long-term disability. The gap between the needs of people with disabilities who are aging and the programs in existence to help minimize the impact of the aging process is immense. The research area of "living and aging with a disability" is either not on the list or is a very low priority. The only groups given the slightest attention in the area of aging with a disability are people with spinal cord injuries or survivors of polio. What about people with other types of disabilities? The scope of the research must be broadened.

Obtaining serious input from "users", people with disabilities, is also not on any list. The pattern of professionals determining what services will be given, what research will be conducted, and what type of training will be offered is something that we must impact! We cannot be quiet and invisible any longer! We must convince people that we are a large and growing market and that there is a great need for answers to questions about aging with a disability.

In addition to demanding attention from the research community, we must also muster our advocacy battalions to address the following issues:

- Integrating an aging and disability focus into the practice of allied health professions;
- Reworking and coordinating fragmented social legislation which, although not intended to, keeps people poor and requires that they remain so if they expect any assistance; and
- Demanding an array of community-based long term services that embrace the values of empowerment and self-determination and assist us to stay in our homes. Community-based long term services, although frequently viewed as just a "seniors issue," is our issue also. If our function declines, we still want to remain independent, free to manage our own lives in our own homes.

In summary, our new awareness of the effects of aging with a disability is accompanied by a growing urgency for information, answers and services. We must be heard and must forcefully demand that the medical, health and social service providers, as well as public policy makers, spend time and dollars on fill the many gaps in knowledge and services surrounding the issues of aging with a disability.

June Isaccson Kailes, MSW, lives in Los Angeles and is a private policy and independent living consultant. She is working with the UCPA Community Services Division on developing a consumer leadership development program. In addition, she provides consultation to UCP affiliates in the areas of organization analysis and development, barrier-free design, peer counseling and consumer advocacy.

Life . . . *continued from page 5*

I still pray for renewed contact with my family. They last visited me at the institution and saw me when I was not at my best. I still cannot help but worry over their thoughts of me on that day. My sister has always kept in touch by writing to me; although I treasure her letters, she lives a long way from me. This summer my twin brother came up for a surprise visit. Our relationship has a good chance for growth, but it is hard to remain patient. In the meantime, I had a great birthday party where friends gathered with me at a restaurant for pizza and birthday cake. I also regularly attend meetings held by the American Indian Club of which I am a member. I almost forgot to tell you that I was born in Oklahoma and am very proud to have a great deal of Indian blood in me. I rarely miss a Sunday at the neighborhood Catholic church; Jesus has always meant a great deal to me. The members of the parish are going to help me become a Catholic. They would like to see me as a member of the Knights of Columbus, and I'm not about to miss a chance at that. I recently met Bill; he has become my friend for which I give thanks.

People tell me it was a good thing that I decided to live in my own home; my life has been improving steadily. All I have to say about that decision is "me too!!!!!!"

Brent Johnson is a Community Support Specialist in the Residential Division of Centennial Developmental Services, Inc. (CDSI). Don White lives in his own home which he shares with another person with physical disabilities; Don and his housemate receive support services from CDSI.

Homes . . . *continued from page 11*

have tolerated inaccessible conditions for years and years, usually have needed modificiations completed within three months.

The program started with an initial grant of $40,000 from the New Jersey Department of Developmental Disabilities. We presently receive $112,000 from the Department, $30,000 of which is earmarked specifically for modifications. Under the terms of the grant, these funds may only be used by persons who have developmental as well as physical disabilities. Other funding sources that we have used include civic organizations, such as the Elks Clubs, and private foundations. Housing modification programs can also be funded by Community Development Block Grant monies from the federal government.

Even when a family does not qualify for full program services, technical assistance alone can have an incredible impact on the life of someone with a physical disability. Suggesting possible modifications to increase independence and referring families to qualified contractors experienced in accessibility renovations can make the difference between living life fully and just merely existing. As UCP of Mercer County Executive Director Wendy Crook points out, "Making the home barrier-free increases safety, independence and feelings of self-worth. It provides relief for the caregiver, and it keeps families together. Accessibility prevents institutionalization."

Susie M. Reid is Director of the Housing Rehabilitation Program for UCP of Mercer County (NJ), Inc.

HOUSING, INDIVIDUAL AND FAMILY SUPPORTS:
RESOURCES FROM THE *CENTER ON HUMAN POLICY* (December 1989)

by Bonnie Shoultz, Pam Walker, Susan O'Connor, Steven Taylor and Julie Racino

Introduction

In 1985, the Center on Human Policy conducted a national search for "model programs" supporting people with severe disabilities in the community. Through this study, we learned that (1) children with severe disabilities belong and can be supported in families, and (2) adults with disabilities can live in their own homes, if given the supports that they need. Since that time, we have moved away from the term "model program." We discovered that each organization has its unique strengths and weaknesses, and organizations seem to learn through borrowing ideas from other organizations as opposed to replicating programs.

The following are a sample of organizations nominated for some of their practices in one of three major areas:

(1) Organizations providing supports for children and their families, including family supports, adoption and permanency planning;
(2) Organizations providing supports for adults with disabilities to live in homes in the community; and
(3) Organizations exploring ways to use regular integrated housing options (as opposed to agency-owned facilities) for people with developmental disabilities.

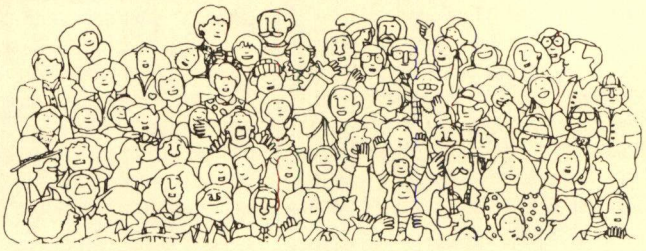
Children with Developmental Disabilities: Family Support and Permanency Planning

Over the past ten years, many states have developed programs which provide supportive services and/or cash subsidies to families of children with severe disabilities. Families are clearly saying that some ways of providing support are more effective than others in enhancing the family's quality of life and in preventing placement of children outside the home.

The most promising approach to family support involves a commitment to enabling all children to live with families, and a commitment to do "whatever it takes" to support families. It includes the following components: a family-centered approach, individualized and flexible supports, family empowerment, use of natural community supports, and a wide array of available services from which families can choose. It means planning with, not for, the whole family.

Permanency planning provides protection for children at risk of out-of-home placement; it is based on the belief that all children deserve and need permanent homes and enduring relationships with adults. In 1980, Congress (P.L 96-272) mandated that states receiving federal funds for child welfare services comply with permanency planning for each child in foster care and other out-of-home settings. These protections have not been routinely applied for children served by developmental disabilities agencies, however.

As applied in the field of developmental disabilities, permanency planning includes support to birth families. When out-of-home placement becomes necessary, the first efforts should be directed toward reunifying the family; if that is not possible, efforts should be redirected toward finding a permanent home in a family for the child with the disability. Permanent homes should be found with adoptive or foster families, depending on the circumstances, with arrangements for ongoing involvement by the birth family when possible.



Networking Resources

A number of places in the United States provide services or supports which reflect aspects of the family support/permanency planning approach. These include:

Family Support and Resource Center
521 North Sherman Avenue
Madison, WI 53704
Phone: 608-256-0400
Contact: Terri Johnson, Director

This program is a private, non-profit agency providing family support services in Dane County, funded largely by the state family support program. The Center offers a variety of types of support, including information and referral, financial assistance (cash subsidy), respite care, and other supports a family identifies as needed.

Community Services
Michigan Department of Mental Health
Lewis Cass Building
Lansing, MI 48926
Phone: 517-373-2900
Contact: Sherida Falvay, Coordinator

Four noteworthy initiatives in Michigan contribute to the state's leadership in deinstitutionalization: (1) its innovative family subsidy program which provides direct cash subsidies to families of children with severe disabilities; (2) a developing regionalized service system which provides for local accountability, independent case management, innovative programming, and flexible funding; (3) an array of family support services which offer families real choices and control; (4) a statewide policy of permanency planning for children with developmental disabilities. Policy and practice is therefore directed to family preservation, family reunification, and adoption for children no longer able to live with their families.

Department for Family Support Services
Office for Community Program Development
The Kennedy Institute
2911 East Biddle Street
Baltimore, MD 21213
Phone: 301-522-7500
Contact: Cynthia Kaufmann, Director

The mission of this department is to provide a wide array of supports to enable families to meet their children's needs. These include: coordination of services, training, counseling, support groups, and assistance with purchase of needed services and equipment. Supports are individually tailored with emphasis placed on a "family-centered" approach.

Family Support Services Department
Calvert County ARC
Calvert Executive Plaza
P.O. Box 1860
Prince Frederick, MD 20648
Phone: 301-535-2413
Contact: Kimberly Gscheidle, Director

This program provides respite, specialized family support, and integrated day care to children with developmental disabilities and their families. Their "specialized family support" assists families to obtain any service, piece of equipment, or adaptation needed in order to maintain a family member with a disability at home. The program uses "parent counselors"—people who themselves have a child with disabilities—as the primary contact person for the families and emphasizes that services are "family-driven."

Project S.T.A.R.
Rehabilitation Institute of Pittsburgh
6301 Northumberland Street
Pittsburgh, PA 15217
Phone: 412-521-9009
Contact: Susan Maczka, Director

Project S.T.A.R. (Specialized Training for Adoption Readiness) finds adoptive homes for children with developmental disabilities, many of whom have severe and multiple disabilities. The project recruits, screens, and trains prospective parents for children who have been released for adoption due, in many cases, to difficult personal histories (many were abused, neglected, or institutionalized). Parents, who may come from any socioeconomic or racial group and who may be couples or single parents, receive a monthly subsidy and coverage for medical expenses for the child. They cover some of the adoption expenses and are encouraged and trained to use community resources to meet the needs of the child.

Agencies Providing Support for Adults with Developmental Disabilities

Enabling adults with developmental disabilities to live successfully in their own homes (apartments, condominiums, or houses rented in their own names or owned by the people living there), with people with whom they choose to live, often means providing individualized, flexible supports. It may mean ensuring that people have live-in roommates or attendants or that someone is available (e.g. by phone or living nearby) to assist. It usually means ensuring that necessary medical and other therapeutic services are provided to each person, in as unobtrusive a fashion as possible, and that other needed adaptations are made to the environment.

Agencies that take this approach begin with the person first and develop the supports and the housing needed and wanted by that person, rather than developing the program and fitting the individual into what has already been developed. They ensure that the people they support, including those with the most severe disabilities, have choices regarding where and with whom they will live. They develop the supports a person needs to be successful in the home of his/her choice, based on careful and positive assessments of the person's strengths and areas needing support. They build on natural community supports (families, neighbors, community resources, friends) rather than just professional, human service ones. In many cases, they encourage and enable the people they support to choose the individuals who work with them. The goal of these agencies is interdependence rather than independence. These agencies include:

Options in Community Living
22 North Second Street
Madison, WI 53704
Phone: 608-249-1585
Gail Jacob, Executive Director
Contact: Kim Turner, Acting Director

This agency provides support to approximately 100 adults, including people who need 24-hour/day support, who live in their own apartments and homes. These apartments and homes are dispersed throughout the Madison area, and people live alone or with one or two roommates. Approximately 25 of these people live with paid roommates/attendants who see to their extensive needs. The people supported by the agency hire and manage their own attendants with agency assistance. A range of specialized supports are also provided by agency staff.

Residential Support Program
Centennial Developmental Services, Inc.
3819 St. Vrain
Evans, CO 80620
Phone: 303-339-5360
Contacts: DeLayne Hinton, Janelle Enns, and Richard Pantaleo, Co-directors

The Residential Support Program of this agency supports 56 people, some of whom have extensive needs, in individualized ways. Most of the people supported live in their own homes or apartments with a variety of supports, and a few share the home of a typical community resident. Support can be reduced or intensified as needed at any point in time. The program uses a team approach for providing support, whereby each member knows well very person supported by the team. Team members can help with problem-solving, provide backup and relief to each other, and give each other emotional support as well.

Residential, Inc.
Box 101
New Lexington, OH 43764
Phone: 614-342-4158
Contact: Joel Yeager, Executive Director

This agency supports 22 people in a small town in southern Ohio. Fourteen of the people they support now live alone or with roommates in their own homes and apartments. One, a high school student, lives with his birth family three days a week and with the family of an agency employee four days a week. The agency is planning, as quickly as it can within stringent state regulations, to move the other seven people (who now live in two purpose-built houses constructed in 1982) into homes of their own. Each person supported by the agency has one staff member who has made a personal commitment to plan with him or her and to help the person make or re-establish connections with family, neighbors, and other community members.

Housing Associations, Cooperatives, Trusts and Subsidies

Today, new efforts are being made to support adults with disabilities to live in homes of their own. To make this possible, organizations and families are examining a variety of housing strategies that can promote home ownership by people with disabilities and access to decent, affordable and accessible housing options used by the community at large.

People with developmental disabilities are often required to live in agency facilities—places owned or leased by an

agency—in order to obtain support services. Agency facilities are typically licensed or certified; the same agency is both landlord and service provider; funding is available only long as the individual resides in the agency's facility; and staffing is based on the needs of the group, not individuals.

In contrast, housing trusts, cooperatives and associations are being developed which can (1) promote home ownership by people with disabilities and (2) lead to a separation between the roles of landlord and service provider. Thus, people can continue to live in their own home, no matter how their relationship to the service-providing agency changes. Housing subsidies, developed through Offices of Developmental Disabilities, are an immediate strategy that can be used to make housing affordable to people with disabilities, until larger scale housing reforms can occur.

The following are some examples of developing organizations promoting strategies that can benefit people with disabilities:

The Reservoir Cooperative
Madison Mutual Housing Association
200 North Blount Street
Madison, WI 53703
Phone: 608-255-6642

(Excerpted from ARC-US, Housing and Technical Assistance Project) This non-profit venture was developed by groups representing people with disabilities and a housing developer. The cooperative apartment complex was designed to meet the needs of different types of people and the concept was conceived with the goal of creating an integrated and multi-generational living environment. Since residents are members of the cooperative but do not solely own the units, they can still use housing assistance payments such as Section 8 certificates.

Area Agency for Development Services, Region VI
Suite 22, Harris Pond
32 Daniel Webster Highway
Merrimack, NH 03054
Phone: 603-882-6333
Contact: Beth Raymond, Community Resource Developer

This area agency in New Hampshire is pursuing integrated cooperatives (and is planning to develop home ownership and family-intiated housing) as housing options for people with developmental disabilities. Support services are provided through the area agency to people living in a variety of housing options.

State of Connnecticut
Department of Mental Retardation
Housing Subsidy Program
90 Pitkin Street
East Hartford, CT 06108
Phone: 203-528-7141
Contact: Terry Cole, Director of Program Management

This housing subsidy program assists people with mental retardation to meet housing costs, such as rent (including payments for mutual housing and limited equity cooperatives), security deposits, utility costs, personal property insurance and costs related to routine maintenance. This subsidy is available to any person who is eligible for residential services provided by DMR, meets the income guidelines and has pursued all other funding sources, including Housing and Urban Development Section 8 subsidies.

North Dakota Department of Developmental Disabilities
State Capitol
Bismarck, ND 58505
Phone: 701-224-2768
Contact: Russ Pittsley

As part of their home and community-based Medicaid waiver planning process, this Department will subsidize housing costs, when necessary, for a person with developmental disabilities to live in a home or apartment, either alone or with one or two other people with developmental disabilities. This state supplement is determined by a individual review that takes into account the person's financial status, the specific home, shared expenses of roommates (if any), and the programmatic determination of whether the state will supplement the costs of an individual to reside alone.

Housing Trust Fund Project
580 Shepard Street
San Pedro, CA 90731
Phone: 213-833-4249
Contact: Mary E. Brooks

This project was an effort sponsored by the Center for Community Change in Washington, DC to put together information about the development of housing trust funds throughout the country. It also focused on the promotion of neighborhood organizations in creating trust funds that benefit those most in need of housing.

This article was prepared by the Center on Human Policy, Division of Special Education and Rehabilitation, Syracuse University with funding provided by the National Institute on Disability Research and Rehabilitation through a subcontract with the University of Minnesota's Research and Training Center on Community Living (Cooperative Agreement No. H133B80048) and Syracuse University's Research and Training Center on Community Integration (Cooperative Agreement No. G0085C03503). Members of the Center are encouraged to express their opinions; these do not necessarily reflect the position of NIDRR. For more detailed information on supports for people with severe disabilities, contact the Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340.

ASSISTANCE WANTED

Are any UCP affiliates actively involved in doing research and establishing ethical guidelines for developmentally disabled individuals participating in biomedical or behavioral research? If so, Mary Ann Carroll, Director of Special Projects for UCP of New York City, would like to network with you. Please contact her at UCP of New York City, 120 East 23rd Street, New York, NY 10010; 212-677-7400.

HELP WITH KEYBOARD MANIPULATION AND TYPING SPEED NOW AVAILABLE

How much would it help you to type two or three characters in your word processor and have the computer automatically insert whole words or phrases? Or be able to press one key at a time in a multi-key combination without having to hold them all down at once?

Such help is now available in a product called *Productivity Plus* (PRD+). PRD+ works by assigning a short form to common words or phrases. When you type the short form, followed by a space or other normal punctuation, it expands into its full form. For example, when you type "j," it comes out as "Gentlemen:" or when you type "asap," it expands to "as soon as possible."

PRD+ is a RAM resident program that can be used to advantage with almost any program you use. You can create your own macro library (word list) to supplement or replace the more than 3,500 macros that come with the program. Macros are often useful in many spreadsheet, word processing or other programs. Eleven or more supplemental specialty word lists, such as Gregg Computer Shorthand or legal word lists, are also available for purchase. Many users claim double or more increase in speed of entering data.

Included with PRD+ is a utility program called PECK. PECK permits sequential pressing of keys in multi-key combinations without having to hold them all down together (*e.g.*, Ctrl-Alt-Delete). This feature is particularly useful to persons with physical disabilities who are using a computer. PECK is also available separately at a very nominal cost to those not purchasing PRD+.

Productivity Plus (PRD+) runs on all IBM personal computers and 100% compatibles. It requires at least 256K RAM, DOS 2.0 or later, and one disk drive. PRD+ is presently priced at $89.95 and may be purchased from

Productivity Software International, Inc.
1220 Broadway
New York, NY 10001
1-800-566-PLUS
1-212-967-8666 in NY

Supporting . . . *continued from page 13*

(g) SUPPORTING PEOPLE vs INDEPENDENCE – A critical issue raised by this approach is the differentiation between helping people to become independent and supporting people in the community. As a reaction to the custodial care of the past, in this decade there has been an increased emphasis on the potential for growth, development and independence of people with mental retardation. While this has been a positive step forward, the interdependence of people has often been overlooked for people with disabilities. A more individualized approach tends to build on existing natural networks of family, friends, and associations, provides training and support within the context of home and community, and does not require that a person attain certain skills in order to have the right to live in the community and in a home.

Conclusion

This article primarily examined some of the key elements in individualized supports based on learnings from existing programs. Future articles will provide more information on other key elements such as enabling structures (i.e., funding, training, individual services coordination and other administrative issues), and future directions and issues.

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This article was prepared by the Community Integration Project and by the Research and Training Center on Community Integration, Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University, with support from the U.S. Department of Education, Office of Special Education and Rehabilitation Services, National Institute on Disability Research and Rehabilitation. No endorsement by the U.S. Department of Education of the opinions expressed herein should be inferred.

UPDATE ON THE AMERICANS WITH DISABILITIES ACT

by Patty Brady and Bob Williams

Status

On September 7, 1989, S. 933, the Americans with Disabilities Act (ADA) introduced by Senator Tom Harkin (IA), passed the Senate by a vote of 76-8. On August 2, President Bush strongly endorsed passage of this landmark legislation. Representative Steny Hoyer (MD) leads the effort to pass H.R. 2273, the House version of the ADA which currently has 239 cosponsors. On November 14, 1989, the House Education and Labor Committee voted 35 to 0 in favor of a modified substitute. Hearings must still be held by three other House Committees which have jurisdiction over ADA—Judiciary, Public Works and Transportation, and Energy and Commerce.

Although it is expected that the ADA will be brought to a House floor vote early this session, continued opposition from the business sector (particularly small business and private transit companies) is delaying its passage in the House. Education about the ADA is key to getting this essential legislation passed.

Synopsis

The ADA is legislation to provide a clear and comprehensive national mandate to end discrimination against individuals with disabilities; provide protection against discrimination; bring persons with disabilities into the economic and social mainstream of American life; provide enforceable standards; and ensure that the Federal government plays a role in enforcing these standards.

The ADA prohibits discrimination on the basis of disability in the areas of employment, public accommodations, transportation, telecommunications and the activities of State and local governments.

Answers to Some Frequently Asked Questions About ADA

1. Aren't individuals with disabilities protected under existing civil rights laws?

Currently, Federal law, Section 504 of the Rehabilitation Act of 1973 (as clarified by the Civil Rights Restoration Act), only prohibits recipients of Federal funds from discriminating against individuals with disabilities. This Act would extend protection to people with disabilities in the public and private sector even when they are not recipients of federal funds.

2. Does ADA have bipartisan support? What is the position of the President?

The ADA has wide bipartisan support which is growing daily in Congress. ADA has the support of President Bush. As of January 20, 1990, the ADA has 239 cosponsors in the House. An agreement reached between the White House and key Senate leaders resulted in a statement from the White House on August 2nd endorsing the ADA.

3. Who will be protected by the ADA?

Approximately forty-three million persons with disabilities will be entitled to the protections of ADA as employees, job applicants, clients and customers of places of public accommodation and users of telephone services. There are approximately 24 million persons with hearing impairments and 2.75 million individuals with speech impairments who will benefit from the telecommunication provision of the ADA.

4. How much will ADA cost?

Savings to the public and private sectors in the form of increased earnings for people with disabilities and decreased government benefit and private insurance and benefit payments are estimated to be in the billions of dollars per year.

Costs to businesses for reasonable accommodations are expected to be less than $100.00 per worker for 30% of all workers needing an accommodation, with 51% of those needing an accommodation requiring no expenses at all. A Louis Harris national survey of people with disabilities found that among those employed, accommodations were provided in only 35% of the cases.

For renovation and new construction, costs of accessibility are generally between zero and one percent of the construction budget. For new buses, lifts are available for approximately $11,000 per bus, with a Federal subsidy of 80% of the capital costs of municipal buses. AT&T has informally estimated the costs of providing telecommunication relay services to be around $300 million, while the Federal Communications Commission's estimate is $250 million. This translates to about $1.20 per customer per year.

5. Does the ADA take into consideration the cost to small business?

Yes. In employment, the bill totally exempts all employers with fewer than 15 employees, and exempts those with fewer than 25 employees for the first two years. The bill provides an exemption from making accommodations for employees with disabilities if it poses an "undue hardship."

The provisions regarding employment are not new; employers doing business with the federal government or receiving federal funding have been complying with these provisions for 15 years. With respect to the provision of auxiliary aids and services, establishments need not provide them if they can demonstrate that doing so would result in an "undue burden."

In public accommodations, every standard in the bill recognizes the legitimate cost concerns of small businesses.

With respect to making buildings accessible, the bill focuses on new construction, where access has been found to add only 1/2 to 1% to the cost of the building. The bill exempts buildings under 3 stories or under 3000 square feet per story from elevator requirements unless the facility is a shopping center or health care facility.

In the case of an existing facility, changes are required only if they are easily accomplished and able to be carried out without much expense. When facilities are altered, only the altered area must be made accessible. In major structural alterations, a path of travel to the altered area and the facilities serving the area such as restrooms must be made accessible as well.

It should be noted that there are existing tax deductions available to businesses which remove architectural barriers to provide access to people with disabilities.

6. Does the ADA consider the cost of implementation to the private intercity bus industry?

Yes. The private transit industry only has to make brand new vehicles accessible, and the ADA allows 5 years for large carriers and 6 years for small providers before new vehicles must be accessible. No bus has to be retrofitted to comply with the ADA.

Despite claims by the private intercity bus industry that making buses accessible is very expensive and requires sacrificing many passenger seats and luggage space, existing accessible bus services in many cities use a moderately priced lift which requires no loss of baggage space and the loss of only one seat. It is generally expected that technological development will quickly bring down price and provide an even better design for making vehicles accessible.

Action Needed

Calls and letters to your member of Congress are important *right now*. All members of Congress can be reached by calling the Capitol Switchboard at (202) 224-3121. Correspondence to your legislators should be addressed as follows:

The Honorable _____
U.S. House of Representatives
Washington D.C. 20515

The Honorable _____
U.S. Senate
Washington D.C. 20510

For effective communication, please keep in mind:

- Keep letter one page.
- Write about one issue.
- Personal (vs. form) letters have greater impact.
- Ask for specific action:
  1) Support the Senate ADA Bill negotiated with and supported by the Bush Administration.
  2) Encourage your member of Congress to support ADA as it is now. Oppose all weakening amendments.
  3) Pass the ADA as soon as possible.
  4) Tell why this legislation is important to you.
- Use specific case examples from your local area/programs.
- Ask to have letters inserted in the *Congressional Record*.
- Follow-up.

If you have any questions about the Americans With Disabilities Act, please contact Bob Williams at the UCPA Governmental Activities Office, 1-800-USA-5UCP. Also, more detailed information on the Americans with Disabilities Act will appear in the December-January 1990 issue of *Word from Washington*.

Patty Brady is a Research Associate and Bob Williams is a Policy Associate with the UCPA Governmental Activities Office.

FOR THE NEXT DECADE

BUILDING A HERITAGE OF EXCELLENCE

United Cerebral Palsy Associations, Inc.
Annual Conference and Corporation Meeting
May 17-19, 1990
Sheraton Harbor Island Hotel
San Diego, CA

Mark your calendars now with the dates for the UCPA Annual Conference—May 17 through 19—in San Diego, CA. Four plenary sessions plus 20 concurrent sessions on the topics of management, consumer involvement, community living, early intervention/family support, and assistive technology will challenge our thinking, renew our sense of mission and inspire us to build a heritage of excellence for the next generation.

In addition to the Annual Conference, two "Conferences within the Conference" will also be held:

Supported Employment: Findings and Recommendations of the National Seven-Site Demonstration Project—9:00 A.M. Wednesday, May 16 to 5:00 P.M. Thursday, May 17

Early Intervention: Technology That Delivers Its Promise, a montage of successful approaches by UCPA, UCLA and Apple Computer for program staff and parents—9:00 A.M. Thursday, May 17 to 5:00 P.M. Friday, May 18.

Contact the UCPA Community Services Division, 1-800-USA-5UCP, for further information.

TELECONFERENCE SCHEDULE 1989-1990

February 28, 1990	**Seating and Positioning: How Important Is It?**
March 7, 1990	**Seating and Positioning: Strategies for Success**
March 28, 1990	**User-Directed Personal Assistant Services**
April 25, 1990	**The Personal Side of Supported Employment**
June 27, 1990	**Early Intervention: Successful Examples of Integrated Services**
July 25, 1990	**Augmentative Communication**
September 26, 1990	**National Demonstration Project on Supported Employment: Final Report**

For more information, call Jim Hollahan 1-800-USA-5UCP

TRAINING INSTITUTES SCHEDULE 1989-1990

April 26-28,1990 Northglenn, CO	**Technology Institute From the Man on the Moon to ____, The Future Is Today**
March 18-20 Washington, DC	**Governmental Activities Leadership Institute**
May 16-17, 1990 San Diego, CA	**Special Conference: Supported Employment—Findings and Recommendations of the National Demonstration Project**
May 17-18, 1990 San Diego, CA	**Special Conference: Early Intervention—Technology Delivers Its Promise**
May 17-19, 1990 San Diego, CA	**UCPA Annual Conference (including four training workshops in *each* of the following areas: Affiliate Management, Consumer Involvement, Community Living, Early Intervention/ Family Support, and Assistive Technology)**
July 27-28, 1990 Washington, DC	**Executive Directors Leadership Institute**
September 1990 Tennessee	**Family Support Institute**

For more information, call Fran Smith 1-800-USA-5UCP

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THE NETWORKER

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Policy Research Brief

A summary of research on policy issues affecting persons with developmental disabilities.

March 1989 Vol. 1, No. 1

Deinstitutionalization of Persons with Mental Retardation: The Impact on Daily Living Skills

Nationally, the policy of deinstitutionalization of persons with mental retardation has been pursued for 20 years. In fiscal year 1967, state institutions for persons with mental retardation had an average daily population of 194,650; by fiscal year 1987, the average daily populations of the same institutions had decreased by 100,000 persons to 94,696 (White, Lakin, Hill, Wright & Bruininks, 1988). Much of the early momentum for deinstitutionalization was drawn from recurring evidence of very poor, often deplorable, conditions in state institutions, including unsafe and unsanitary conditions, overcrowding, regimentation, and progressive debilitation of residents. Since then, much has been done to improve these conditions. Perhaps the most important effort toward improvement was the enactment of the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program in 1971, which established specific standards for institutional care in return for federal participation in at least half the costs of care. Today the ICF-MR program certifies 93% of all state institution "beds" (Lakin, Hill, White & Wright, in press). Court cases in the majority of states also have required significant improvements in the conditions of one or more state institutions. Related to the above, as well as to the general commitment on the part of states to improve institutional care, per resident expenditures in 1987 ($54,500) were 5 times greater in real dollars than per resident expenditures in 1967 (White et al., 1988).

In response to policy deliberations at the federal and state levels that would continue the depopulation of state institutions, including in many instances closure of entire institutions, advocates of maintaining institutional services are suggesting that today's institutional care may be as effective or more effective than community-based care. This review of literature responds to that issue with respect to a single, but important, area: the changes in adaptive behavior (the basic skills of daily living) of individuals moving from state institutions to community living arrangements. It does so by reviewing all published and unpublished literature meeting standards for quality and identifiability.

Research Selection

Research screened for inclusion in this summary was identified from the following sources: 1) a computer search of the Psychological Abstracts from 1976 to 1988; 2) computer search of the ERIC research data base from 1976 to 1988; 3) manual review of major journals in mental retardation from 1980 to 1988; 4) review of Dissertation Abstracts from 1980 to 1988; and 5) requests to all state mental retardation agencies for studies of behavioral change for persons living in different kinds of residential facilities. Over 50 studies were identified and screened according to the following criteria for inclusion in this review: 1) followed 6 or more individuals from public institution placements through at least six months of living in a community facility, with community facility defined as having 15 or fewer residents and located off the grounds of a large facility; 2) collected baseline data while persons were still in the institutions; 3) measured overall adaptive behavior and /or specific types of adaptive behavior (e.g., self-care/domestic skills, communication skills, social skills) in the same manner and with the same instruments in both settings; 4) reported basic demographic and diagnostic information on institution and community facility subjects; and 5) discharged community-based facility subjects from institutions in or after 1975. The 17 studies meeting these criteria were included in this review of adaptive behavior outcomes. In addition, where any of the studies of changes in adaptive behavior also examined changes in problem behavior, those results were also summarized.

Published by the Research and Training Center on Community Living in the Institute on Community Integration, University of Minnesota. Issue authors are Sherri Larson and Charlie Lakin. Additional copies are available through the Center at 110 Pattee Hall, University of Minnesota, 150 Pillsbury Drive SE, Minneapolis, MN 55455 - (612)625-3396.

Results

Tables 1 and 2 (see pages 3-4) show the changes in three categories of behavior of individuals with mental retardation as they moved from large state institutions to small community living arrangements. The first category was change in overall adaptive behavior score. The second category was change in one or more of seven specific types of adaptive behavior. These results were summarized according to the types that most closely matched the categories reported in each study. The third category was change in problem behavior associated with a move to a community living arrangement.

Outcomes were reported in terms of the direction of change with the public institution as the point of reference. That is, a positive outcome (+) means adaptive behavior was greater in the community, or that problem behavior was less evident. A negative outcome (-) means the adaptive behavior was lower in the community, or that problem behavior was more evident. Two pluses (++) or minuses (--) are used when the magnitude of difference indicates a probability of less than 5% that the result occurred because of random error (statistically significant). One plus (+) or minus (-) indicates that a difference was found between the groups, but that there was more than a 5% chance that the result was due to random error, or that the differences were not tested for statistical significance. A zero (0) indicates that no difference was found or that statistically insignificant findings were reported in a manner not permitting evaluation of the general tendency. Blanks indicate the topic was not studied or that no data were reported.

Table 1 shows the outcomes reported for studies that used an experimental/contrast group format. Those studies compared the changes in adaptive behavior (and in some instances, problem behavior) for persons who moved to the community with changes for persons of similar characteristics who remained in state institutions. Some of the studies involved random selection of subjects for either the experimental (community living) or the contrast (continued institutionalization) group. Other studies matched individuals who moved and individuals who stayed on characteristics such as sex, age, measured intellectual level, and initial level of adaptive behavior. The adaptive and problem behaviors of each group were measured both before and after the move. Table 1 summarizes the differences between groups in changes in adaptive and problem behavior after the experimental group moved to community settings.

Table 2 shows the outcomes reported in studies utilizing a longitudinal approach to measuring changes in adaptive behavior (and, in some instances problem behavior). These studies measured behavior before or at the time of deinstitutionalization and then at various times after the move. Some studies measured change once after the move while others measured change repeatedly. The results summarized on Table 2 reflect overall changes in adaptive behavior after movement to community settings.

Discussion

Six of the seven experimental/contrast group studies reported statistically significant greater achievement in either overall adaptive behavior or in the basic self-care/domestic skill domain for those who moved to community living arrangements relative to those who remained in state institutions. In the seventh study, the community sample had greater achievement in the self-care and domestic skills area, but the difference was not statistically significant. There were statistically significant changes favoring community over institutional settings in numerous other adaptive behavior areas as well. None of the experimental/contrast group studies, however, reported statistically significant differences between groups for changes in problem behaviors.

Among the longitudinal studies, 7 of the 10 reported statistically significant increases in overall adaptive behavior or in the basic self-care/domestic skill area after movement to the community. An eighth study would have most probably shown statistically significant changes, but no statistical tests were employed and the reported data did not permit such testing at this point. The other two studies in this area showed positive behavior changes after movement to a community residence, but the magnitude of the changes was not statistically significant. A number of statistically significant improvements were noted in specific types of adaptive behavior. There was considerable variation in the reported changes in problem behavior in this set of studies.

Overall, 13 of the 17 studies summarized for this report noted statistically significant improvements in either overall adaptive behavior or in the basic self-care/domestic skill area. All studies showed at least a tendency toward improved adaptive behavior associated with movement to the community. Conversely, in only one was any negative change in any area of adaptive behavior associated with community placement. In that study (Kleinburg & Galligan, 1983) a small (statistically insignificant) decrease was noted in the domain of "vocational behavior." Therefore, one must conclude that available research provides considerable support for the assertion that people who move from state institutions to small community living arrangements can be expected to experience increases in adaptive behavior skills. On the other hand,

for the seven studies that reported changes in problem behavior, no consistent pattern of change was demonstrated related to movement from institutional to community settings. While again it is noted that this summary only examined changes in problem behavior that were included in studies focusing on adaptive behavior, these studies do not support the assertion that people who move from state institutions to small community living arrangements can be expected to experience reductions in problem behaviors solely as a function of moving. ■

Table 1
Experimental/Contrast Group Studies
Behavioral Outcomes Associated with Movement from State Institutions to Small (15 or Fewer Persons) Community Living Arrangements

Author (date)	State	# Subjects Exp.	# Subjects Cont.	Age	Time (months)	Level of MR Bord/Mild	Level of MR Mod	Level of MR Sev	Level of MR Prof	BEHAVIORAL OUTCOMES Adaptive Behavior General/Overall	Adaptive Behavior Specific Domains	Problem Behavior
Bradley et al. (1986)	NH	80	80	AC	72	X	X	X	X	++	+ d	o
Close (1977)	OR	6	6	A	12			X	X		++ a	
Conroy et al. (1982)	PA	70	70	A	24	X	X	X	X	++		+[1]
D'Amico et al. (1978)	WV	6	7	AC	6,12[2]	X	X	X	X	++[3] ++[4]	++ a,b,c,f o d,e	
Eastwood et al. (1988)	N.E. USA	49	49	A	24-48	X	X	X	X		++ c + a	
Rosen (1985)	AR	58	58	A	24	X	X	X	X	++	++ a,d,e,f	
Schroeder et al. (1978)	NC	19	19	A	12			X		++		

[1]The movers stayed the same while the contrast group got worse.
[2]After measuring behavior at 6 months, 2 of the control subjects were randomly assigned to move to the community.
[3]Time 1 (4 exp., 9 cont.)
[4]Time 2 (6 exp., 7 cont.)

Outcomes
++ = statistically significant improvement relative to the contrast group
+ = improvement relative to the contrast group but not statistically significant
o = no change relative to the contrast group
- = decline relative to the contrast group but not statistically significant
-- = statistically significant decline relative to the contrast group

Adaptive Behavior Domains
a = self-care, domestic
b = communication/language
c = social skills
d = vocational
e = academic
f = community living
g = recreation/leisure

Age
A = adult
C = children
AC = adults and children

Table 2
Longitudinal Studies
Behavioral Outcomes Associated with Movement from State Institutions to Small (15 or Fewer Persons) Community Living Arrangements

Author (date)	State	# Subjects	Age	Time (months)	Level of MR				BEHAVIORAL OUTCOMES		
					Bord/ Mild	Mod	Sev	Prof	Adaptive Behavior General/ Overall	Adaptive Behavior Specific Domains	Problem Behavior
Aanes et al. (1976)	MN	46	A	12	X	X	X	X		++ a,b,c o e,d,f	
Bell et al. (1984)	TX	66	AC	10	X	X	X	X		+ a,e	
Colorado Div. of DD (1982)	CO	115	AC	12	X	X	X	X	+		
Conroy et al. (1985)	PA	383[1]	AC	72[1]	X	X	X	X	++		+
Conroy et al. (1988)	CT	207	A	24	X	X	X	X	++	++ d	--
Feinstein et al. (1986)	LA	103	AC	9,18	X	X	X	X	++		++
Horner et al. (1988)	OR	23	AC	60	X	X	X	X		++ a,c,f	+
Kleinburg et al. (1983)	NY	20	A	4,8,12		X	X	X		++ a[2],b,c o e,g - d	++[3] --[4]
O'Neil et al. (1985)	NY	27	A	3,9	X	X	X	X		++ a,b[5]	
Thompson et al. (1980)	MN	8	A	24			X	X	+[6]	+ a,b,f[6]	

[1]This study included 6 groups, all of which showed significant gains, the largest group measured over the longest time is reported here
[2]Domestic skills increased significantly, but grooming skills showed no overall change
[3]IQ above 20
[4]IQ below 20
[5]Significant increases were found in 4 of 16 subcategories in these skill areas
[6]Mean differences were not tested for statistical significance

Outcomes
++ = statistically significant improvement after move to the community
+ = improvement after move but not statistically significant
o = no change after move
- = decline after move but not statistically significant
-- = statistically significant decline after the move to the community

Adaptive Behavior Domains
a = self-care, domestic
b = communication/language
c = social skills
d = vocational
e = academic
f = community living
g = recreation/leisure

Age
A = adult
C = children
AC = adults and children

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Summary of Major Specifications: S.384

"Medicaid Home and Community Quality Services Act of 1989"

by Allan I. Bergman

Purpose

- To amend Title XIX (Medicaid) of the Social Security Act.
- To assist individuals with a severe disability in attaining or maintaining their maximum potential for independence and capacity to participate in community and family life.

Eligibility

- In order to be eligible for services, people with severe disabilities **must** meet the **Federal SSI** test and become disabled before age 22.
- The legislation allows the age of onset for eligibility to increase by one year each fiscal year until it reaches age 50. This will gradually allow coverage of persons who become disabled in adulthood.
- States **will be allowed** to deem children under 18 years of age living at home as eligible for services, regardless of the income of their families.
- There are **provisions to equalize** the income and resources standards which States use in determining eligibility for institutional and community services.

Services

- Services will be available to persons living in family homes, foster family homes, and community living facilities, as these terms are defined in the bill.
- Services **must** be based on an Individualized Habilitation Plan (IHP) developed by an interdisciplinary team and coordinated by a case management system which is **independent** of the local providers of direct services.
- **States must provide**, at a minimum, the following services:
  - —Independent case management
  - —Individual and family support services (including respite and attendant care)
  - —Specialized vocational services including prevocational services and supported employment services)
  - —Protection and advocacy services
  - —Protective intervention services.

- **States may offer** any of the following services under their State Medicaid plans:
  - —Habilitation services
  - —Case coordination services
  - —Educationally-related services
  - —Physical therapy
  - —Speech and language pathology and audiology
  - —Nonaversive behavior intervention therapy
  - —Diagnostic assessment services
  - —Personal assistance and attendant care services
  - —Domestic assistance and home health services
  - —Chore services
  - —Prostheses, orthoses, supplies, appliances, adaptive equipment, communication aids, and other functional assistive technology and devices (including sensory aids) and rehabilitation technology services to evaluate, design, assemble, repair and maintain such equipment, aids, assistive devices, and systems to train the individual, family and provider agency staff in their use
  - —Design, and as necessary and reasonable, adaptations or modifications of equipment and vehicles, and of housing and other space, to be used by an individual with a severe disability
  - —Purchase and maintenance of guide dogs and similar trained animals
  - —Dental services, preventive and therapeutic
  - —Comprehensive outpatient rehabilitation facility services
  - —Crisis intervention
  - —Specialized transportation services
  - —Personal guidance, supervision, representation and advocacy
  - —Preventive services to decrease the needs of individuals for future services
  - —Such other services proposed by the State and approved by the Secretary.

- **Community living facilities are limited to a maximum of three times the average family household size in the areas** as determined by the census. There are provisions for "grandfathering" existing facilities serving 15 or fewer persons and existing "cluster" facilities defined as two or three co-located facilities, each of which has 8 or fewer residents.
- The following services **are not allowed** under a State's Medicaid plan as community and family support services:
  - —Room and board other than room and board provided for less than 6 consecutive weeks and less than 12 weeks in a year as an integral but subordinate part of another community and family support service. Auxiliary payments to cover extraordinary food and housing costs attributable to a person's disability, however, may be treated as Medicaid-reimbursable
  - —Any service reimbursable under AFDC programs
  - —Cash payments
  - —Aversive behavior intervention, management or therapies
  - —Any Medicare reimbursable services
  - —Any educational service which the State makes available to its residents without cost and without regard to income, except for educationally-related services as defined
  - —Any services to an individual in a hospital, skilled nursing or intermediate care facility (including an ICF/MR(DD) or mental hospital).
- An individual's receiving community and family support services **does not affect** the individual's entitlement to other Medicaid reimbursable services (e.g., physician services, prescription drugs, therapies) which are covered in a State's Medicaid plan and needed by the individual.

Service Principles

- **State standards must assure services.**

- Are based on timely assessment and designed to assure optimal individual development, **independent functioning, productivity and community integration**.
- Are furnished in accordance with the written Individualized Habilitation Plan.
- Reflect the **strengths** of the individual and the services needed to assist the individual to achieve more independent functioning with respect to health and physical development, receptive and expressive communication, cognitive learning, mobility, self-direction, socialization, leisure time, and vocational activities.
- Are provided in a manner that maximizes opportunities for and fosters development of **social integration** in the community.
- Are provided in settings where existing or new skills can be put to practical use.
- Are designed to assist the individual to acquire **functional life skills** necessary to enhance his/her capacity to achieve independent living, to be integrated into the community, and to interact socially with persons who do not have disabilities.

State Assurances

In order to receive Medicaid funding for community and family support services **the State must make certain assurances** to the Secretary of Health and Human Services regarding:

- The disbursement of community living facilities throughout residential neighborhoods.
- Filing reports and otherwise cooperating with the Secretary.
- Developing standards for each element of community and family support services consistent with the service principles outlined above.
- Monitoring annually all providers of such services.
- Developing steps to assure that standards are promptly and effectively enforced.
- Developing a State implementation strategy (plan) for community and family support services.
- Maintaining the prior level of State expenditures.
- Safeguarding the rights of eligible individuals.
- Equality of access to services regardless of severity of disability or place of residence.
- Providing of residential services near the individual's family home.
- Ensuring that priority is given to providing vocational services in integrated work environments.

State Planning

- The **State must develop a five-year implementation strategy** which is updated annually to address specific requirements in the bill. There must be **public hearings**, including input from the State Developmental Disabilities Council, and the State's Protection and Advocacy System on the contents of the State's implementation strategy.
- In the state implementation strategy, the State **must outline its plans as they relate to:**
  —**A multi-year strategy** for systematically expanding community services and identifying the Federal and State Medicaid dollars which will be obligated for community and family support services
  —Detailed methods for administering community services for eligible persons living at home or in other non-institutional settings
  —Methods to be used to **protect the interests of employees** affected by the movement of persons from institutions
  —Appropriate relocation of persons who inappropriately live in nursing homes
  —Policies and procedures to **assure** that all provider agency personnel have received pre-service education and/or training
  —Methods to **assure** that every service agency maintains written personnel policies and provides in-service training and continuing education to service personnel
  —An **assurance** that all provider agencies have access to needed **technical assistance** services
  —The methods to **assure** that every person receiving these services has access to inter-organizational case management services which are **independent** of any agency or program providing day and/or residential treatment services to the individual
  —The methods to implement an appropriate **management information system** to track the outcomes of all persons in Medicaid-funded services/facilities, the service needs of underserved and inappropriately served persons, and the flaws or gaps in existing services statewide
  —The policies and procedures the State will adopt to offer eligible persons and their families **due process safeguards** and notification of rights, including a **hearing** by an **impartial** hearing officer
  —Methods to coordinate planning with the State's education and rehabilitation agencies.

Financing

- The State must **limit the amount of federal funds** claimed for services provided to eligible persons in Medicaid-certified facilities (ICFs, SNFs) with 16 beds or more. The limit is the level of funding for those services during the year of enactment with some provisions for inflation. (The bills reflect emerging trends in many States that institutional placements are decreasing, but it does not represent a time schedule for closing or phasing down of institutional facilities.) **The limit is on Medicaid funds coming into the State for large facilities but is not on the rates paid to any facility.**
- All community and family support services in the State implementation strategy will be funded at the State's Federal Medicaid matching ratio with **no limits** on the availability of Federal matching funds.

Quality Assurance

The State **must** set forth in its implementation plan, subject to the review process, the **component parts of a comprehensive, integrated quality assurance system.** The State must include at least the following:

- Standards governing each element of community and family support services.
- Methods and procedures for monitoring, and licensing and/or certifying eligible providers.
- Procedures for an annual **independent third party evaluation** of a cross section of services which must include:

—an analysis and validation of the individualized data base;
—periodic visits to a representative sample of agencies providing for individuals receiving such services;
—an assessment (of a statistically valid sample of eligible individuals receiving services, using reliable and valid instruments) to determine the extent to which services contributed to reduced dependency, enhanced opportunities to make choices, the acquisition of positive social behaviors, improved social integration and participation in community life, increased productivity, consumer satisfaction, the physical comfort of the individual, the attractiveness/appropriateness of his/her living environment and achievement of the goals/objectives in the individual's written habilitation plan; and
—a summary of findings and recommendations with regard to needed changes in State laws and administrative practices.

- An annual assessment of **consumer satisfaction.**
- A residential **services environment assessment** by a local review body with a majority of its members being parents, guardians, or relatives of individuals with severe disabilities.
- Methods of assuring prompt correction of deficiencies.
- **Provision of training and technical assistance.**
- A system of penalties for non-compliance with standards.
- Procedures for **continuity of service** when a provider fails to continue service provisions.
- The **criteria** governing use of psychotropic and anticonvulsant medications as well as behavior management techniques and the methods to ensure compliance with the criteria.
- For persons moving to the community from large facilities, the State **must** develop a community transfer plan, which involves the individual, family and interdisciplinary team in planning for the services the individual will require. The State **must** ensure that such services are available to the individual prior to transfer and provide 60 days written notice of same.
- The bill provides for the **right** of any party adversely affected by a violation of the Act to seek **injunctive relief** in Federal court including the recovery of attorney's fees, under specified circumstances.
- The Secretary is responsible for conducting an **annual assessment** of each State's progress in carrying out its implementation **strategy** as well as its compliance with the statutory **assurances** outlined above.

Administration

- The Secretary of Health and Human Services **would be required to establish** a separate Bureau of Developmental Disabilities within the Health Care Financing Administration. The Bureau would be responsible for planning, policymaking, and operational responsibility for overseeing all Medicaid programs for persons with developmental disabilities including the ICF/MR (DD) program and Medicaid waiver.
- The Governor **may assign** responsibilities for administering services under the Act, including the delegation of responsibilities to agencies other than the State Medicaid agency.
- For a complete copy of S.384 (70 pages) call or write your United States Senator.

Definitions of Key Terms in the Medicaid Home and Community Quality Services Act of 1989 - S.384

Note: The term medical assistance as used below means Medicaid funded services.

"*Community and Family Support Services* — The term 'community and family support services' means supportive services made available to an individual with a severe disability (or to such individual's natural, adoptive, or foster family or spouse) to enable such an individual to begin, resume, or continue living in a family home, foster family home, or community living facility. Such supportive services shall include both in-home and out-of-home services (as needed) from among those enumerated in section 1921 (a)(2).

"*Family Home* — The term 'family home' means a residence maintained by an individual (whether or not disabled) or a couple, or by a natural or adoptive family in which one or more individuals with a severe disability are living who receive medical assistance which include payment for some services enumerated in section 1921(a)(2).

"*Foster Family Home* — The term 'foster family home' means

a residence maintained by an individual or couple —

"(1) in which no more than three individuals with a severe disability are living, are provided surrogate family services, and receive medical assistance which includes payment for one or more services enumerated in section 1921(a)(2); and

"(2) that is under contract with an agency licensed or designated to place individuals with a severe disability in such residence.

"*Written Habilitation Plan*"— The term 'written habilitation plan' means a plan for medical assistance and other services for an individual with a severe disability which

"(1) is developed by an interdisciplinary team consisting of—

"(A) such individual, persons requested to participate by the individual, and, when appropriate, the spouse, parent, guardian, other family member or advocate of such individual, and

"(B) individuals who are representative of professional and other disciplines which are relevant to the habilitation of such individual, and have been involved in providing services to the individual or are likely to be involved in providing services to the individual including the individuals responsible for providing case management services and case coordination services to the individual);

"(2) is based upon a comprehensive assessment of the strengths of the individual and the services and support necessary to —

"(A) enable such individual to attain or retain capabilities for independence or self-care,

"(B) promote and increase interaction between disabled and non-disabled individuals within the community, and

"(C) in the case of any such individual who has attained the age of 18 and who is not engaged in supported employment (or other employment in an integrated employment environment), assess the services and support needed by the individual to engage in such forms of paid employment;

"(3) specifies —

"(A) the individuals responsible for providing services under the plan and the frequency and duration with respect to which such services are provided,

"(B) the particular objectives to be achieved with respect to an individual described in behavioral terms that provide measurable indices of performance,

"(C) the dates by which the particular objectives are to be achieved,

"(D) the services and program strategies for achieving the specific objectives, and

"(E) the priority with which the specific objectives are to be achieved; and

"(4) is reevaluated by such team at least once each year.

"*Case Management Services* — the term 'case management services' means, with respect to any individual with a severe disability, services rendered to such individual by a designated qualified individual who —

"(1) has a continuing relationship with such individual but who is neither associated with nor employed by (nor has any other conflict of interest with respect to) the community living facility, foster family home, or any other provider of ongoing direct services to such individual;

"(2) coordinates and monitors the development and implementation of the written habilitation plan for such individual;

"(3) provides such individual (or such individual's spouse, parent, guardian other family member, or advocate, as appropriate) with information about, and referral to, appropriate social, educational, vocational, medical, advocacy, or other services which are among or in addition to those for which payment may be made under this title;

"(4) provides assistance and service as an advocate in procuring such services as necessary;

"(5) periodically reviews the changing needs of such individual and the appropriateness of the medical assistance and other services provided to such individual;

"(6) cooperates with personnel in school, employment related, habilitation, or treatment settings who have specific responsibilities for developing or implementing any individual education plan, plan of vocational services, plan of habilitation, or plan of treatment designed for such individual, so that all such plans are coordinated and complementary; and

"(7) is available to such individual or such individual's family for consultation or crisis intervention when required.

Additional requirements for case management are contained in the state plan section which mandates the state set forth the steps by which "the State ensures that each individual with a severe disability receiving community and family support services under the State plan has access to case management services which are provided —

"(i) by an entity that is organizationally independent of (and free of any conflict of interest with respect to) any entity furnishing ongoing direct services to individuals with a severe disability,

"(ii) with sufficient frequency and intensity to ensure that the objectives in an individual's written habilitation plan are achieved within the period of time specified in such plan, and

"(iii) by a trained individual with a caseload capability to visit each individual under such individual's responsibility not less than once a month;

"*Individual and Family Support Services* — The term 'individual and family support services' means —

"(1) those services provided to an individual with a severe disability which the individual's interdisciplinary team determines are appropriate for carrying out those activities of daily living which the individual cannot perform for himself, including nonmedical personal assistance, attendant services, assistance in ambulating or transferring, limited domestic services, and assistance with assistive devices and communicative devices and aids; and

"(2) services provided to the family of an individual with a severe disability which the individual's interdisciplinary team determines are appropriate for assisting the family in providing services described in paragraph (1) to the individual, including respite care.

"*Specialized Vocational Services* —

"(1) The term 'specialized vocational services' means services designed to enhance the independence, productivity, and integration of an individual with a severe disability, including —

"(A) prevocational services for such an individual whose earning capacity (as determined on the basis of a current vocational assessment or other objective measure of work performance) is less than 50 percent of the minimum wage established under section 14(c) of the Fair Labor Standards Act of 1983, and

"(B) supported employment services for such individuals for whom competitive employment—

"(i) has not traditionally occurred, or

"(ii) has been interrupted or intermittent as a result of such disability (and for whom ongoing support services are needed to perform such employment).

"(2) For purposes of paragraph (1) —

"(A) the term '*prevocational services*' means services that are designed to assist an individual in acquiring and maintaining basic work and work-related skills necessary to acquire and retain work in an integrated work setting, which services shall include —

"(i) training the individual to follow directions, adapt to work routines, and carry out assigned duties in an effective and efficient manner,

"(ii) helping the individual to acquire appropriate attitudes and work habits, including instruction in socially-appropriate behaviors on and off the job site,

"(iii) assisting the individual to adjust to the productive and social demands of the work place,

"(iv) familiarizing the individual with job production and performance requirements,

"(vi) providing mobility training, including the utilization of public and paratransit systems,

"(vii) instructing individuals in appropriate use of job-related facilities (e.g., break areas, lunch rooms, cafeterias and rest rooms); and

"(B) the term '*supported employment services*' means services designed to assist an individual in procuring and maintaining integrated, paid employment, which services shall include —

"(i) individualized assessment,

"(ii) individualized and group counseling,

"(iii) individualized job development and placement services that produce an appropriate job match for the individual and such individual's employer,

"(iv) on-the-job training in work and work-related skills required to perform the job,

"(v) ongoing supervision and monitoring of the individual's performance on the job,

"(vi) ongoing support services necessary to ensure job retention,

"(vii) training in related skills essential to obtaining and retaining employment, such as the effective use of community resources and transportation,

"(viii) transportation between the individual's place of residence and the work place when other forms of transportation are unavailable or inaccessible, and

"(ix) adaptive equipment necessary to obtain and retain employment.

"*Assistive Technology* — The term 'assistive technology means the systematic application of technology, engineering methodologies, or scientific principles to meet the needs and address the barriers confronted by an individual with a severe **disability** (including physical, sensory, and cognitive **functional limitations**) in such areas as employment, recreation, **independent** living and other home and community **living arrangements**.

"*Independence, Productivity and Integration* — The terms, 'independence', 'productivity', and 'integration' when used in reference to the provision of community and family support services under this title have the same meaning with respect to individuals with a severe disability as the meaning given to such terms with respect to persons with developmental disabilities in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act . . . which are:

The term '*independence*' means the extent to which persons with developmental disabilities exert control and choice over their own lives.

The term '*productivity*' means —

"(A) engagement in income producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or

"(B) engagement by a person with developmental disabilities in work which contributes to a household or a community.

The term '*integration*' means —

"(A) the

"(i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and

"(ii) participation by persons with developmental disabilities in the same community activities in which non-handicapped citizens participate together with regular contact with non-handicapped citizens, and

"(B) the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity of community resources, together with regular contact with non-handicapped citizens in their communities."

Representatives Florio, Waxman and Dingell Introduce Medicaid Long-term Care Legislation: H.R.854

By Allan I. Bergman

On Monday February 6th, Representative James Florio (NJ) was joined by Representatives Henry Waxman (CA) and Ron Wyden (OR) at a press conference to introduce the Medicaid Community and Facility Habilitation Amendments of 1989. This legislation would **allow States, at their option,** to amend their State Medicaid plans in order to receive federal Medicaid matching funds for "community habilitation and supportive services" for individuals with mental retardation or related conditions.

Representative Florio, in introducing the bill, emphasized that current Medicaid law forces parents to make difficult choices . . . "they can put their children in institutions and get Federal help in paying the high cost of care, or they can opt for the often more positive settings of other forms of care and have to pay for it on their own." He further stated that the bill was designed to be . . . "an affirmation of the right of people with disabilities to live in the community. They deserve that chance and this bill would provide it."

Representative Waxman introduced the bill as . . . "the result of many long hours of discussion and compromise." He emphasized that the bill . . . "in no way caps federal payments to institutions. That approach would be dangerous and harmful to clients and workers." Rather, he said, the bill would "level the playing field" by

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Action Alert

TO: UCP Executive Directors and Other Interested Persons

FROM: Christopher Button, Senior Policy Associate CB

DATE: March 2, 1990

RE: **SUPPORTED EMPLOYMENT REGULATIONS**
Re-opened by Office of Special Education and Rehabilitation Services (Attached)

The Office of Special Education and Rehabilitation Services (OSERS) has published their intent to revise regulations governing the State Supported Employment Services Program authorized under the Rehabilitation Act.

The Rehabilitation Act Amendments of 1986 authorized supported employment services for people with severe disabilities who, because of their disability, need ongoing support services to enter and maintain competitive employment. This clearly includes people with cerebral palsy and others with severe physical disabilities. Yet recent data indicates that, while overall the number of people in supported employment has increased dramatically since enactment of the 1986 amendments, currently only 0.6 percent of those people have cerebral palsy.

The expression by OSERS of their intent to reconsider and revise the regulations, which were promulgated on August 14, 1987, presents a **critical opportunity for individuals and organizations to influence public policy and remedy existing regulatory problems which limit participation in supported employment by people with cerebral palsy and other physical disabilities.**

We urge you to send your written comments on or before April 16, 1990 to:

Nell C. Carney, Commissioner
Rehabilitation Services Administration
Mary E. Switzer Building
330 C. Street, SW, Room 3325
Washington, DC 20202-2899

Comments should be focused on the following issues, and should include individual examples of how current regulations exclude persons with cerebral palsy:

(1) **Exemption from the requirement for job skill training at least twice monthly.**

The need for on-going support services is required for supported employment eligibility and refers to job skill training and other supports that are needed on a regular basis by persons in supported employment. Current regulations specify that all individuals must require job skill training at least twice monthly at the job site, and may require other supports at or away from the job site. People who are mentally ill are exempt from the job skill training requirement.

People with cerebral palsy and other physical disabilities require numerous supports both at and away from the job site. For many individuals, however, these supports may not include the need for job skill training. The effect of this regulatory provision is that many people with cerebral palsy or other severe physical disabilities are excluded from eligibility for supported employment.

The current requirement for on-site job skill training at least twice monthly included in the definition of ongoing support services discriminates against people who, solely because of their severe physical disability, require support, but do not require traditional job skill training. The regulations should clarify that people with severe physical disability but no intellectual disability are also exempt from the requirement for job skill training.

(2) **Definition of job skill training.**

Current regulations require that all people with severe disabilities in supported employment require job skill training but do not provide a definition for this term. It is critical for people with severe physical disabilities that the term be broadly defined to include not only training in specific job functions, but support in areas which affect job performance, such as communication, transportation, environmental adaptations, job redesign, use of assistive technology or personal assistance at the job site.

(3) **The 20 hour work week.**

Requiring that in all cases people with severe disabilities work at least 20 hours per week from time of placement in supported employment is based on a traditional "readiness" model of rehabilitation which is inconsistent with the philosophy of supported employment. In addition, there is nothing in the legislative history of this program which mandates a minimum number of work-hours for participation.

The effect of this regulatory provision is that people who are unable to work the minimum number of hours are excluded from employment opportunities altogether. This regulatory provision should be modified to allow greater flexibility based on individual circumstances.

(4) **The availability of post-transition or post-closure services from the Vocational Rehabilitation State Agency.**

Individuals in supported employment programs should be entitled to the same services available to all people who have completed rehabilitation programs. However, current regulations for supported employment have been interpreted to mean that the Vocational Rehabilitation agency may no longer provide even limited services to people in supported employment once they have moved into extended support (the costs of which are borne by some agency other than Vocational Rehabilitation). Such a provision discriminates against people with the most severe disabilities who participate in supported employment, denying them services provided to all other recipients of services from the rehabilitation system. The regulations should be changed to allow provision of post-transition or post-closure services to people in supported employment.

(5) **Requirement for identifying sources of extended support.**

Current regulations require that sources of extended support from other agencies or organizations be identified and included in the individualized written rehabilitation program. The need to identify extended support prior to placement severely limits access to supported employment for people with cerebral palsy and other physical disabilities for whom there is no state agency to pick up the cost. The UCPA Governmental Activities staff is currently trying to identify remedies for this significant problem. However, we request that anyone who has knowledge or information about people with cerebral palsy who have been denied access to supported employment because of the lack of availability of extended support funding include this in their comments, and describe the efforts undertaken to identify sources of support, so that OSERS will be aware of the extent and impact of this problem.

The supported employment program was designed to ensure opportunities for increased independence, productivity and integration into the workforce for people with severe disabilities who had previously been denied such opportunity. It was enacted due to the actions of people with disabilities, and their families and advocates, who demanded the opportunity to move from spectator to participant in the world of work. We urge you to use the power

of your knowledge and experience to help make important changes in regulations governing this program and thus ensure greater participation and access for people with cerebral palsy and other severe disabilities.

Thank you in advance for you efforts.

If you need any additional information, please contact me at 1-800-USA-5UCP.

******SPECIAL REQUEST******

PLEASE SEND COPIES OF THE COMMENTS YOU SEND TO NELL CARNEY, AND ANY REPLIES YOU MAY RECEIVE, TO UNITED CEREBRAL PALSY ASSOCIATIONS, 1522 K STREET N.W., WASHINGTON, D.C., 20005 TO THE ATTENTION OF CHRISTOPHER BUTTON, SENIOR POLICY ASSOCIATE.

THANK YOU.

CB:js

Attachment: Federal Register section re: Supported Employment

rehabilitation agencies to conduct public meetings throughout the State to allow the public an opportunity to comment on the Title I State vocational rehabilitation plan. Commenters noted that the supported employment State plan is a supplement to the Title I State plan and that, therefore, the regulations should require public participation in the development of the supported employment plan supplement.

Discussion: The Secretary agrees that the public participation requirements of section 101(a)(23) of the Act apply also to the supported employment supplement to the Title I plan.

Changes: The Secretary has modified § 363.11 to add a new § 363.11(e)(7) State plan assurance that requires the State vocational rehabilitation agency to comply with the provisions of section 101(a)(23) of the Act in developing its supported employment plan.

Collection and Reporting Requirements. Section 363.52

Comments. Some commenters indicated that § 363.52(a) does not comply with section 636 of the Act because it does not specifically cite the information collection and reporting requirements contained in section 13 of the Act.

Discussion: The Secretary agrees that § 363.52(a) should track more closely the statute by referencing the requirements of section 13.

Changes: The Secretary has revised the language in § 363.52(a) to remove the reference to 34 CFR 361.23 (general reporting requirements) and substitute a more specific reference to the collection and reporting requirements of section 13.

Note: Because this is a new kind of rehabilitation program with which neither the Department nor States have much experience, the Department will consider in the next two years whether to solicit additional public comment on the need for further regulatory revision.

Executive Order 12291

These regulations have been reviewed in accordance with Executive Order 12291. They are not classified as major because they do not meet the criteria for major regulations established in the order.

List of Subjects in 34 CFR Part 363

Education, Grant Programs—education, Grant Programs—social programs, Reporting and recordkeeping requirements, Supported employment, Vocational rehabilitation.

(Catalog of Federal Domestic Assistance Number: 84.187 State Supported Employment Services Program)

Dated: July 23, 1987.

William J. Bennett,

Secretary of Education.

The Secretary amends Chapter III of Title 34 of the Code of Federal Regulations by adding a new Part 363 to read as follows:

PART 363—THE STATE SUPPORTED EMPLOYMENT SERVICES PROGRAM

Subpart A—General

Sec

363.1 What is the State Supported Employment Services Program?
363.2 Who is eligible for an award?
363.3 Who is eligible for services?
363.4 What are the authorized activities under a State Supported Employment Services grant?
363.5 What kinds of activities may the Secretary fund under a planning grant?
363.6 What regulations apply?
363.7 What definitions apply to the State Supported Employment Services Program?

Subpart B—How Does a State Apply for a Grant?

363.10 What documents must a State submit to receive a grant?
363.11 What information and assurances must be included in the State plan supplement?

Subpart C—How Does the Secretary Make a Grant?

363.20 How does the Secretary allocate funds?
363.21 How does the Secretary reallocate funds?

Subparts D-E [Reserved]

Subpart F—What Post-Award Conditions Must Be Met by a State?

363.50 What collaborative agreements must the State develop?
363.51 What are the allowable administrative costs?
363.52 What are the information collection and reporting requirements?
363.53 What special conditions apply to services and activities under this program?

Authority: 29 U.S.C. 795j–q, unless otherwise noted.

Subpart A—General

§ 363.1 What is the State Supported Employment Services Program?

(a) Under the State Supported Employment Services Program, the Secretary provides grants to assist States in developing and implementing programs of supported employment for individuals with severe handicaps.

(b) Grants under this program are intended to provide training and traditionally time-limited post-employment services to individuals with severe handicaps.

(Authority: 29 U.S.C. 795j)

§ 363.2 Who is eligible for an award?

Any State is eligible for an award under this program.

(Authority: 29 U.S.C. 795m(a))

§ 363.3 Who is eligible for services?

A State may provide services under this program to any individual who—

(a) Has severe handicaps, and for whom competitive employment has not traditionally occurred or has been interrupted or intermittent as a result of those handicaps; and

(b) Has been determined by an evaluation of rehabilitation potential, as defined in section 7(5) of the Act, to have—

(1) The ability or potential to engage in a training program leading to supported employment;

(2) A need for on-going support services in order to perform competitive work; and

(3) The ability to work in a supported employment setting.

(Authority: 29 U.S.C. 795k)

§ 363.4 What are the authorized activities under a State Supported Employment Service grant?

Under this program, the following activities are authorized:

(a) Evaluation of the rehabilitation potential for supported employment of individuals with severe handicaps. Any evaluation must be supplementary to an evaluation of rehabilitation potential done under 34 CFR Part 361.

(b) Development of and placement in jobs for individuals with severe handicaps.

(c) Provisions of traditionally time-limited post-employment services that are needed to support the trainees in employment, such as—

(1) Intensive on-the-job training and other training provided by skilled job trainers for workers with severe handicaps;

(2) Provision of follow-up services, including regular contact with employers, trainees with severe handicaps, parents, guardians or other representatives of trainees, and other suitable professional and informed advisors in order to reinforce and stabilize the job placement; and

(3) Regular observations or supervision of individuals with severe handicaps at the work site.

(Authority: 29 U.S.C. 795n)

§ 363.5 What kinds of activities may the Secretary support under a planning grant?

(a) For fiscal year 1987 only a State may request a planning grant in place of its allotment under this program.

(b) The State shall conduct activities under a planning grant that include the following, unless those activities have already been completed:

(1) Developing the Statewide needs assessment for supported employment services, as specified in § 363.11.

(2) Developing and evaluating collaborative agreements with State agencies and private nonprofit organizations.

(3) Developing goals, priorities, policies, and procedures for the provision of supported employment services to individuals with severe handicaps.

(4) Seeking participation in the development of a State plan supplement for supported employment services by individuals with severe handicaps, their parents or guardians, and providers of supported employment services.

(c) The State may also conduct the following activities under a planning grant:

(1) Developing sites to test and evaluate the provision of supported employment services.

(2) Other activities necessary to prepare for the implementation of a system of supported employment services.

(d) The requirements of §§ 363.11, 363.20, 363.21, and 363.50–363.53 do not apply to planning grants.

(e) The Secretary awards a planning grant of no more than $250,000 for up to 18 months.

(Authority: 29 U.S.C. 795i(c))

§ 363.6 What regulations apply?

The following regulations apply to the State Supported Employment Services Program:

(a) The Education Department General Administrative Regulations (EDGAR) in 34 CFR Part 74 (Administration of Grants), Part 76 (State Administered Programs), Part 77 (Definitions that Apply to Department Regulations), Part 78 (Education Appeals Board) except for hearings under Subpart G of Part 361, and Part 79 (Intergovernmental Review of Department of Education Programs and Activities).

(b) The regulations in this Part 363.

(c) The following regulations in 34 CFR Part 361 (The State Vocational Rehabilitation Services Program):

§ 361.32; § 361.33; § 361.34; § 361.40; § 361.41; § 361.46; and § 361.49.

(Authority: 29 U.S.C. 795j and 711(c))

§ 363.7 What definitions apply to the State Supported Employment Services Program?

(a) As used in this part—

(1) "Supported employment" means—

(i) Competitive work in an integrated work setting with on-going support services for individuals with severe handicaps for whom competitive employment—

(A) Has not traditionally occurred; or

(B) Has been interrupted or intermittent as a result of severe handicaps; or

(ii) Transitional employment for individuals with chronic mental illness; and

(2) As used in the definition of "supported employment"—

(i) "Competitive work" means work that is performed on a full-time basis or on a part-time basis, averaging at least 20 hours per week for each pay period, and for which an individual is compensated in accordance with the Fair Labor Standards Act;

(ii) "Integrated work setting" means job sites where—

(A)(*1*) Most co-workers are not handicapped; and

(*2*) Individuals with handicaps are not part of a work group of other individuals with handicaps; or

(B)(*1*) Most co-workers are not handicapped; and

(*2*) If a job site described in paragraph (A)(*2*) of this definition is not possible, individuals with handicaps are part of a small work group of not more than eight individuals with handicaps; or

(C) If there are no co-workers or the only co-workers are members of a small work group of not more than eight individuals, all of whom have handicaps, individuals with handicaps have regular contact with non-handicapped individuals, other than personnel providing support services, in the immediate work setting;

(iii) "On-going support services" means continuous or periodic job skill training services provided at least twice monthly at the work site throughout the term of employment to enable the individual to perform the work. The term also includes other support services provided at or away from the work site, such as transportation, personal care services, and counseling to family members, if skill training services are also needed by, and provided to, that individual at the work site;

(iv) "Transitional employment for individuals with chronic mental illness" means competitive work in an integrated work setting for individuals with chronic mental illness who may need support services (but not necessarily job skill training services) provided either at the work site or away from the work site to perform the work. The job placement may not necessarily be a permanent employment outcome for the individual; and

(v) "Traditionally time-limited post-employment services" means services that are—

(A) Needed to support and maintain an individual with severe handicaps in employment;

(B) Based on an assessment by the State of the individual's needs as specified in an individualized written rehabilitation program; and

(C) Provided for a period not to exceed 18 months before transition is made to extended services provided under a cooperative agreement pursuant to § 363.50.

(b) The following terms used in this part are defined in 34 CFR 77.1:

Fiscal Year; Nonprofit; Private; Secretary; and State.

(c) The following terms used in this part are defined in 34 CFR Part 361:

Act; Designated state unit; Individual with handicaps; Individual with severe handicaps; and State plan.

(Authority: 29 U.S.C. 706(18), 711(c), and 795i)

Subpart B—How Does a State Apply for a Grant?

§ 363.10 What documents must a State submit to receive a grant?

To receive a grant under this part, a State must—

(a) Submit to the Secretary, as part of the State plan under 34 CFR Part 361, a State plan supplement that meets the requirements of § 363.11; or

(b) For fiscal year 1987 only, submit an application for a planning grant in place of its allotment under this program.

(Authority: 29 U.S.C. 795l(c) and 795m(a))

(Approved by the Office of Management and Budget under control number 1820–0551)

§ 363.11 What information and assurances must be included in the State plan supplement?

Each State plan supplement must—

(a) *Designated State agency.* Designate the State unit or units for vocational rehabilitation services identified in the State plan submitted under 34 CFR Part 361 as the State agency or agencies to administer this program;

(b) *Results of needs assessment.* Summarize the results of the needs assessment of individuals with severe handicaps conducted under Title I of the Act when that assessment identifies the need for supported employment services. The results of the needs assessment must address the coordination and use of information within the State relating to section

618(b)(3) of the Education of the Handicapped Act:

(c) *Quality, scope, and extent of services.* Describe the quality, scope, and extent of supported employment services to be provided to individuals with severe handicaps under this program. The description must address the timing of the transition to extended services referred to in § 363.50(b)(2);

(d) *Distribution of funds.* Describe the State's goals and plans with respect to the distribution of funds received under § 363.20;

(e) *Assurances.* Provide assurances that—

(1) An evaluation of rehabilitation potential, as defined in section 7(5) of the Act, is provided under 34 CFR Part 361, and if necessary a supplementary evaluation under this part, for each individual with severe handicaps who receives services under this program;

(2) An individualized written rehabilitation program as specified in 34 CFR 361.40 and 361.41 will be developed—either under this part or under 34 CFR Part 361—outlining the services to be provided to each individual served under this program, including a description of the extended services needed, the identification of the State, Federal, or private programs that will provide the continuing support, and a description of the basis for determining that continuing support is available;

(3) Services provided to individuals under this program will be coordinated with the individualized written rehabilitation program or education plan as required under section 102 of the Act, section 123 of the Developmental Disabilities Act of 1984, and sections 612(4) and 614(5) of the Education of the Handicapped Act;

(4) The State will conduct periodic reviews of the progress of individuals assisted under this program to determine whether services provided to those individuals should be continued, modified, or discontinued;

(5) The designated State agency or agencies will expend no more than five percent of the State's allotment for administrative costs of carrying out this program;

(6) The State will make maximum use of services from public agencies, private nonprofit organizations, and other appropriate resources in the community to carry out this program;

(7) The public participation requirements of section 101(a)(23) of the Act are met;

(f) *Collaboration.* Demonstrate evidence of collaboration by and funding from relevant State agencies and private nonprofit organizations to assist in the provision of on-going supported employment services following the termination of time-limited services under this part; and

(g) *Other information.* Contain such other information and be submitted in the form and in accordance with the procedures that the Secretary may require.

(Authority: 29 U.S.C. 795m)

(Approved by the Office of Management and Budget under control number 1820-0551)

Subpart C—How Does the Secretary Make a Grant?

§ 363.20 How does the Secretary allocate funds?

The Secretary allocates funds under this program in accordance with section 633(a) of the Act.

(Authority: 29 U.S.C. 795l(c))

§ 363.21 How does the Secretary reallocate funds?

The Secretary reallocates funds in accordance with section 633(b) of the Act.

(Authority: 29 U.S.C. 795l(b))

Subpart D-E [Reserved]

Subpart F—What Post-Award Conditions Must Be Met by a State?

§ 363.50 What collaborative agreements must the State develop?

(a) A designated State unit must enter into one or more written cooperative agreements or memoranda of understanding with other appropriate State agencies and private nonprofit organizations to ensure collaboration in a plan to provide supported employment services to individuals with severe handicaps.

(b) A cooperative agreement or memorandum of understanding must, at a minimum, specify the following:

(1) The training and traditionally time-limited post-employment services to be provided by the designated State unit with funds received under this part.

(2) The extended services to be provided by the other State agencies and private nonprofit organizations, following the termination of time-limited services under this part.

(3) The estimated funds to be expended by the participating party or parties in implementing the agreement or memorandum.

(4) The projected number of individuals with severe handicaps who will receive supported employment services under the agreement or memorandum:

(Authority: 29 U.S.C. 795m(b)(4) and 795n(b))

§ 363.51 What are the allowable administrative costs?

(a) *Administrative costs-general.* Expenditures are allowable for the following administrative costs:

(1) Administration of the State plan supplement for this program.

(2) Planning, program development, and personnel development to implement a system of supported employment services.

(3) Monitoring, supervision, and evaluation of this program.

(4) Technical assistance to other State agencies, private nonprofit organizations, and businesses and industries.

(b) *Limitation on administrative costs.* Except for planning grants which the Secretary may award in fiscal year 1987, not more than five percent of a State's allotment may be expended for administrative costs for carrying out this program.

(Authority: 29 U.S.C. 795l(c) and 795m(b)(5))

§ 363.52 What are the information collection and reporting requirements?

(a) A State shall collect and report information as required under section 13 of the Act for each individual with severe handicaps served under this program.

(b) The State shall collect and report separately information for—

(1) Supported employment clients served under this program; and

(2) Supported employment clients served under 34 CFR Part 361.

(Authority: 29 U.S.C. 712 and 795o)

(Approved by the Office of Management and Budget under control number 1820-0551)

§ 363.53 What special conditions apply to services and activities under this program?

Each grantee shall coordinate the services provided to an individual under this part and under 34 CFR Part 361 to ensure that the services are complementary and not duplicative.

(Authority: 29 U.S.C. 795 n and q)

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